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Exploring Care

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Introduction

The availability of Catholic social care in its previous guise of older people's homes, where care was predominately led and delivered by religious sisters, has diminished. It is essential to understand if there is something particular about 'Catholic care' and if it can be disseminated in future models of support, both in Catholic and secular provision. Many of us will experience the challenges of older age and/or caring for others. It is critical to understand how Catholics hope to experience care in the future and to explore their role in creating the environment of support they may want or need in their later years.

This research is based on interviews and focus groups in the first half of 2019, with 50 people in England who either receive, provide or may need care in the future. Participants were either resident in Catholic care homes, providing professional or pastoral care in a Catholic care home, or working age Catholic parishioners.

Summary of findings

- It was striking that when asked about what they understood care to be, or what they thought it looked like, all of the three working-age adult focus groups moved directly to a conversation about the cost of care and care as a business, and what they saw as value for money in terms of the care they had witnessed. There seemed little awareness or discussion about how little local authorities paid for those needing residential or nursing care, the actual cost, or the difficulty of providing care at that level. Whereas those providing care set out the stark realities of funding, the implications for care, and some of the current commissioning practices where homes are left bidding against others to provide individuals with care.
- Those receiving care noticed how staff paid attention to the detail, describing what they experienced as caring as being kind and pleasant, putting people at ease and not talking down to people. Both recipients and providers of care emphasised the importance of sustained relationships in caring, and the environment that enables carers to take time and be present with residents.
- Observing the care others received had an impact on individuals' understanding of the care they were receiving, and how they might be treated if their circumstances changed. The most powerful experience of observing care was seeing how other residents were cared for at the end of their lives.
- All groups of participants involved in the study mentioned end of life care. There were concerns amongst working age adults that the process of dying may involve being dependent on the care of others whilst in much pain. Religious sisters talked about the power of being present with a person at the end of their life, as something they felt was an important part of their work. This delicate act of being present, providing support for residents and their family, clearly comes from extensive experience, which is in part embedded in their faith. Residents

observed this end of life care as they understood how they would be cared for, and it had an impact on their confidence about how they might experience dying,

- Care home residents often talked about the on-site chapel and how they were able to attend Mass every day. For many this provides the opportunity to continue practising their faith as they have done throughout their life, as an essential part of their identity.
- Faith underpins the care provided by religious sisters. Values of the orders were shared with staff at care homes with a view to ensure the way they offered care reflected these values as the number of sisters providing direct care diminishes. Arguably this is more effective where there is a stable and consistent staff team.
- Caring for others can be enjoyable and rewarding, however for those who had experience of caring for relatives it was often described as tough, frightening and horrible.
- For those providing care, there is a significant challenge in finding staff that care and will stay with the organisation longer than six months. This was frequently attributed to the low wages available, with staff moving once they had gained experience to other providers, such as hospitals, which offered better rates of pay and benefits.
- There is frequently a failure in wider society to recognise and value the work of paid carers. Supporting staff development, and empowering care staff to challenge and take action, were seen as essential in affecting how care is delivered and received.
- It is crucial that organisations care for their carers - among whom many will have complex challenges in their own lives, which will also be present with them at work. Providing effective support and a listening ear helps create a stable staff team, enabling an environment where relational care can be delivered.
- Participants in the research recalled poor care they had experienced during the course of their lives, not necessarily relating to their current circumstances. These ranged from a failure of carers to pay attention to the detail of the individual’s preferences and needs, to reports of previous care homes where one participant was assaulted, and another was unable to leave the confines of a bedroom. In all these examples it seemed that concerns, needs and preferences had not been heard or responded to.
- Participants talked about coming into residential care after a particular event or crisis. When talking about this time, it was notable that there was little discussion about exercising choice, planning their care, or autonomy in decision-making.
- Those working age adults who had cared for relatives were deeply affected by this experience, and they were clear that they did not want their children to go through a similar experience so would plan future care to avoid this. Whereas those who had not had this experience assumed that they would stay in their own homes, and/or their children would care for them. For many, this was the first time they had been asked to think about how they might manage any future care needs and they were unsure how to answer.

- Discussions around the delivery and funding of care were focused on the need for government to take action, but also individuals questioning their own role, and that of the (institutional) Church in challenging current provision. There were concerns that the complexity of needing and receiving care is not considered until too late.
- Participants of focus groups explored their role as a ‘church family’ going beyond the walls of the church and creating some kind of support for older adults and their carers. In other groups participants felt ‘paralysed’: they wanted to do something but did not know where to start.
- There are silences in the research process, and it is essential to pay attention to the things that are not said or discussed as they also have meaning and value. There are times when participants struggled to put things into words, where they were unable to answer, or glossed over subjects. There were also ‘silences’ on particular topics, or the things that are not talked about. In the focus groups this related to gender and caring, the expectation of family to care in the future, and for those who had not been exposed to the realities of caring for others in later years, their understanding of what this might look like for themselves.

Key messages

- The distinctive Catholic care that is offered at end of life is at risk of being lost with diminishing numbers of priests and religious in England and Wales, and their availability to be present with individuals in their last days and hours. Consideration and action are needed to ensure this powerful act of presence continues, and is encompassed in wider care standards.
- Supporting paid carers to provide relational care requires organisations to commit to providing an enabling environment and effective support. Catholic care providers should bring together their expertise and values to develop care practice that prioritises relational care. This will require a focus on how organisations care and value those they employ to care, and how this focus can be sustained among a shrinking group of small, independent Catholic care providers, by co-operation or more radical partnering.
- Caring for others can be rewarding and joyful. It is also a huge responsibility and a stressful emotional labour. Given the steep increase in ageing in the Catholic population of England and Wales, many parishioners and priests will be involved in caring for others, and there needs to be action taken both at a national and local level to value and support them in this role
- In conjunction with Catholic charities involved in care (where these exist), parishes need to find the support and confidence to self-organise and extend Catholic care to older adults in the community and their carers - additionally creating and providing reliable networks of pastoral care for those receiving residential and nursing care. The Church is well placed to provide this, but it is a significant undertaking requiring long-term resourced networks of support.
- Receiving care, providing care, and planning for future care, will affect all members of the Catholic community at different points in their lives, and in

fulfilling their distinct vocational responsibilities. Additionally, Catholics have made a lot of investment in care, as individual donors of land and buildings, and by enabling Catholic charities to build expertise as care providers. Therefore, it is essential that the Catholic Church hears the experiences of care and brings its voice to the wider policy debate to champion care.

Acknowledgements

I am very grateful to all those who participated in the research. Particular thanks are extended to Clive Chapman for his extensive work organising the interviews and focus groups, and his helpful and thoughtful comments on earlier drafts of this report. Many thanks to Dr Sarah Burch for the expertise and guidance she offered during this project.

Context

Caritas Social Action Network (CSAN) commissioned this research; it commenced in January 2019 and was completed in June 2019. CSAN has previously commissioned three research projects that have reported on the services provided to older people by the Catholic community in England and Wales (Ryan et al., 2009; Philpot, 2007, 2002). These studies have mapped Catholic social care provision, explored the impact of diminishing vocations on residential care, and explored the support available via parish communities. These reports made recommendations on how the Catholic Church in England and Wales could respond to the challenges of home closures and associated impact of social policy and related market, fewer vocations to priesthood and religious life, and the increasing population of older people needing help and support.

Additionally, throughout the research, there were recommendations to connect local churches with the older people in their community. In particular Philpot (2007) noted how well churches and Catholic schools had maintained close links and partnerships, and how this could be replicated for social care provision. In his forward to the report by Ryan et al. (2009), Rt Rev Terence Brain commented that it was hoped that those who read the report "begin to see how you and others can engage in the mission of the Church to enable older people to continue their journey in the things of God, and for us also to provide opportunities for older people to teach us from their journey in the things of God".

Much of the research identifies gaps in and the nature of provision and brings attention to the future social care of older people. The previous CSAN reports comment on the value of 'Catholic care'. Whilst there is discussion about the nature of faith and spirituality in care (especially health care), it is clearly difficult to define what 'Catholic care' looks and feels like, for those receiving and providing it, beyond sacramental participation. However, there is also a view that there is something particular about 'Catholic care', although descriptions on what this looks like, how it is delivered, and how it is experienced are limited. There is also much commentary on the need to engage the Church (at various levels) with provision of care for those in need of support in the local community.

If we are losing Catholic social care in its previous guise of older people's homes, where care was predominately led and delivered by religious sisters, then it essential to understand if there is something particular about 'Catholic care' and if it can be disseminated in future support, in provision managed by both Catholic and non-Catholic organisations. In addition, since anyone may need care, and most older people do not need care of the most complex kinds, it is critical to understand how members of the church community hope to experience care in the future, and to explore their role in creating the environment of support that they may want or need in their later years.

To explore these two broad areas, this research addressed the following questions:

- What are the different understandings of ‘care’?
- What do older people consider to be important aspects of the care they have received?
- How do working age adults/church congregations think about the ways they want to be cared for?
- What are the narratives of religious sisters/other carers involved in the care for older people?
- Is there a model of ‘care’ that can be developed and understood?

Care: A relationship, a crisis, and future plans

Care: a relationship

The concept of 'care' is a "complex and evolving social phenomenon and has an enduring moral value" (Rummery and Fine, 2012, p.323). There are broadly three distinct facets of care. The first attends to the feelings and emotions involved in care, often appearing as empathy, concern and a degree of responsibility for another's wellbeing. The second facet, where care is a form of labour, has a focus on competency and the impact of caring on the workforce, such as workload, financial recompense, physical and mental wellbeing. The third explores the social relationships of care, where it is not just caregivers who can dominate or exert power, but that the caregiver can be dominated in these relationships through the sacrifices made to provide care (Rummery and Fine, 2012).

In her work exploring kindness and its role in social policy, Unwin (2018) observes that care has always been provided and seen as something done by one part of society to another. She brings attention to the two lexicons that are used in public policy:

> …there is the language of metrics, and value added, of growth and resource allocation, of regulation and of impact. And there is the language of kindness and grief, of loneliness, love and friendship, of the ties that bind, our sense of identify and of belonging (Unwin, 2018, p.9).

Both languages have their strengths, but on their own are 'dangerous', and there has been pressure on the value of kindness in public policy in part due to reductions in public expenditure, digital analytic capability, and digital communication (Unwin, 2018). Changes which have provided a higher level of predictability and an associated focus on impact, have played a key role in developing a transactional, rather than relational approach, eroding the ability to "respond to individuals, to recognise their differences and to engage with the complexity of individuals and their community" (Unwin, 2018, p.11).

Elsewhere in the literature and policy, attention has returned to relationship-based practice (Munro, 2011; Folgheraiter, 2007; Ruch, 2005; Trevithick, 2003). All social care is undertaken within and through relationships, and the medium of relationships is the "primary means of intervention" (Ruch, 2005, p.113). Relationship-based practice, "explores not only the 'how and what', but also the 'why' of practice", with practitioners developing a holistic understanding engaging with all aspects of an individual's behaviours, recognising that "individuals are complex, multifaceted and more than the sum of their parts" (Ruch, 2005, p.113).

The concept of being 'met as a person' develops and progresses relational models from general guidance for service approach and delivery, into the details of one-to-one interactions between care-seekers and professional caregivers; "a framework for thinking about the way we interact with one another" (McCluskey, 2005, p.3). This framework also demonstrates the relational complexity of giving and receiving care. Ultimately a failure to be met as a person occurs when professional caregivers do not consider the individuals' needs when seeking help and support, a large part of which includes previous experiences of seeking support and receiving care.

Care: a crisis

There are significant challenges continuing to affect overall provision of social care for older people in this country, including the potential of Brexit to affect the availability of care assistants, (Department of Health, 2017) alongside the on-going austerity conditions in which care is being delivered (ADASS, 2019). The nature of the ageing population and increasingly complex support needs, mainly of those over 85, has been reported extensively (RSA Action and Reserach Centre, 2012; CSJ, 2011). Alongside these challenges are the intersecting and complicating experiences of older age, family support, isolation and loneliness, grief and loss, pensions and housing, and physical and mental wellbeing.

The proportion of the population who are retired will rise to about 24% in 2050 from the 12% recorded in 2012, and there will be around eight million adults aged over eighty years old, three times more than there are currently (RSA Action and Research Centre, 2012; CSJ, 2011). Forecasts suggest that by 2040 there will be double the number of older people needing social care support, of whom 1.4 million would be diagnosed with dementia (RSA Action and Research Centre, 2012; CSJ, 2011).

Social care throughout the life course is "widely recognised to be in crisis" (Land and Quilter, 2018, p.1). Additionally, since 2009/10, it is estimated that there has been a "25% reduction in the number of older people accessing publicly funded care" as a result of tightening in eligibility criteria during this time (Age UK, 2018). According to Age UK (2018), there are more than 1.2 million adults in England aged over 65 years who do not receive the comprehensive care and support they need to support them with essential aspects of daily living, an increase of 48% since 2010 (Land and Quilter, 2018).

It is thought that there are six million informal carers in the UK providing unpaid care and support to older people. Age UK (2018) estimate that 2 million informal carers are aged over 65 years, with more than 400,000 of this number over 80 years old. The majority of paid and unpaid carers are women, and women are most likely to need support in their older age (Land and Quilter, 2018). Previous research has found that spouses are likely to care for each other. However, outside of this relationship, female relatives are more likely to provide necessary unpaid care and support (Arber and Ginn, 1990). Further information about the cost of caring to the individual and to the state can be found at the Carers UK website[1].

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[1] https://www.carersuk.org/

The paid care sector is facing a “recruitment and retention crisis due to poor pay and working conditions” (Land and Quilter, 2018, p.1). Brexit poses additional challenges that are likely to affect recruitment and retention, with European Economic Area (EEA) staff making up approximately 7% of the adult social care workforce in England, the majority of which (around 69,000) are employed in relatively low-paid direct care roles (Department of Health (DoH), 2017). If demand for social care staff is not met, and “if we fail to meet social care needs adequately we are likely to see a decrease in labour market participation levels, especially among women, as greater numbers undertake informal care’ (DoH, 2017, p.3).

Care: to plan for (or not)

In their comprehensive scoping review of literature around how we plan for later life, Preston et al write (2018) that “there is a widespread and common-sense-based perception, backed to some extent by evidence, that planning and preparing for later life is associated with increased wellbeing in older age”. However, their review found that many in mid-life have not yet planned for their later years (Preston et al., 2018). Whilst there is a much greater evidence base which considered pension planning and the timing of retirement, there was less literature which explored some of the other key decisions, such as potential home moves or developing support networks (Preston et al., 2018). They found characteristics shared amongst those less likely to plan for the future, including, “having a lower income or fewer assets, living in rented accommodation, having lower educational attainment, being in poor health and working part-time or in the private sector” (Centre for Ageing Better, 2018, p.3). Elsewhere, women were more likely to have considered and participated in preventative health care, and have thought about end of life care, whereas men were more likely to have focused on particular tasks such as making a will or putting in place power of attorney (Preston et al., 2018).

Below is a table from the review illustrating the range of barriers and enablers to adults planning and preparing for their later life.

	Enablers	Barriers
Awareness/salience	Wanting to attain something in future	Issue seems a long way off
	Wanting to avoid a perceived risk	
	Wanting to escape a current aspect of life	
	Wanting to preserve an aspect of life	
Choice and control	Feel that they can exercise choice and control over future	Experience of life as unpredictable
	Positive life-course experience of planning	Fatalistic attitude about survival into old age
	Sufficient financial resources to plan	Socio-economic constraints
Knowledge and skills	Sufficient knowledge and skills	Inadequate understanding of and familiarity with planning products and services
		Difficulty in predicting probable future timeline and understanding risk
Instrumental and informational support	Sufficient support from employers	Inadequate support from employers, industry, regulators and landlords
		Inadequate infrastructure
Social influence	Social networks promote planning	Peers' views undermine planning behaviour
		Gendered role beliefs undermine planning
	Positive age stereotypes	Negative perceptions and terminology of ageing

Table 1: Enablers and Barriers to planning (Preston et al., 2018, p.5)

Methods

Research Strategy

Data was generated from semi-structured interviews and focus groups involving Catholic care home residents, religious sisters providing care and support at these care homes, care home staff, and working age adults from parishes local to the care homes.

Three Catholic residential care homes were visited, with residents from each of these homes involved in the study. These residential homes were in three different geographical locations across England. In two of the homes religious sisters lived nearby or on site, providing either direct care, management of care, or pastoral support. A number of the sisters at these two sites were involved in the study. Focus groups of working age adults were organised at parish churches in the vicinity of the residential homes. Those who attended the focus groups were Catholic parishioners.

It was intended that hearing from individuals at three different geographically located sites would offer some diversity of experience. However, chosen locations were also chosen by those available and willing to be involved in the study. The three locations included a city in the south of England, a city in the Midlands, and a town in the Midlands. CSAN's national team identified and engaged with the organisations (including some not in the Caritas network) and parishes in this study.

The details of those involved in this study are set out below;

Those receiving care

- This study heard from 3 men and 10 women who were in receipt of residential care.
- 2 of the male participants were priests and 5 of the female participants were religious sisters.

Those providing care

- In total 9 women who provided care in various capacities to older people agreed to be involved in the study, 8 of whom were religious sisters.
- The care they provided was in the capacity of a pastoral volunteer, or as a paid care assistant, or nurse. 2 held senior management positions in the care organisation.

Working-age adults

At three churches local to the residential homes in the study, working age parishioners were invited to attend a focus group on a weekday evening. One of the groups attracted a high number of attendees, and in 2 groups a couple of people attended who were a little over working age.

- City in the South of England: 7 adults in total, of which 5 were female and 2 were male.
- City in the midlands: 15 adults in total, of which 10 were female and 5 were male.
- Town in the midlands: 6 adults in total, of which 2 female and 4 male.

The interviews explored residents' experiences of needing care, and thoughts about the care they receive. Additionally, those providing care talked about what led to and informed the care they provide, their understanding of how care should be delivered, and the challenges that impede this. In the focus groups there were discussions about what ‘care’ was, observations of care being provided, and what receiving care in the future might be like.

Ethical considerations

This study has been designed and undertaken in line with the British Sociological Association Statement of Ethical Practice (2017). The nature of this research, and associated questions asked during interviews, may have been on sensitive topics for some people, or provided the opportunity to reflect and talk about things that may have caused upset. Steps were taken to ensure the safety and wellbeing of those involved. Information sheets were produced and shared with those who said they were willing to be involved before the interview or focus group, so they could understand what the research was about. Individuals’ understanding of the contents of the information sheets was checked out before interviews and written consent obtained. The interviewer reminded participants that they may choose not to talk about things that will cause upset, and where necessary this was checked throughout the interviews for any potential negative impact.

Participants’ views may not be representative of all those receiving care, providing care or working age adults. This study specifically focused on adults involved in Catholic care and/or practice. Many of those involved were religious sisters or priests, providing different experiences and opinions about care, particularly when considering the charisms of religious orders. The voices heard in this study enabled an exploration of the research questions, and participants came from different parts of England to provide diversity of voice and experience.

Analysing the data

All interviews and focus groups were transcribed, and a thematic approach taken to analyse the data generated, using the six-phased approach set out by Braun and Clarke (2006). Additionally, Bacchi’s (1999) What’s the Problem? Approach (WTPA) was used to consider the themes that arose from the data and to interrogate the data itself. The WTPA designed by Carol Bacchi (1999) is used here to enhance a thematic analysis, bringing attention to what the problem is represented to be rather than relying on the usual policy derived frameworks.

Diagram I: Illustrates the themes emerging as part of the WTPA analysis. Solid lines indicate clear connections and dashed lines to bring attention to the interconnections. The darker colour palette indicates the main themes in line with the WTPA, with a lighter palette indicating sub-themes.

Diagram II: Illustrates how this analysis has been developed into themes.

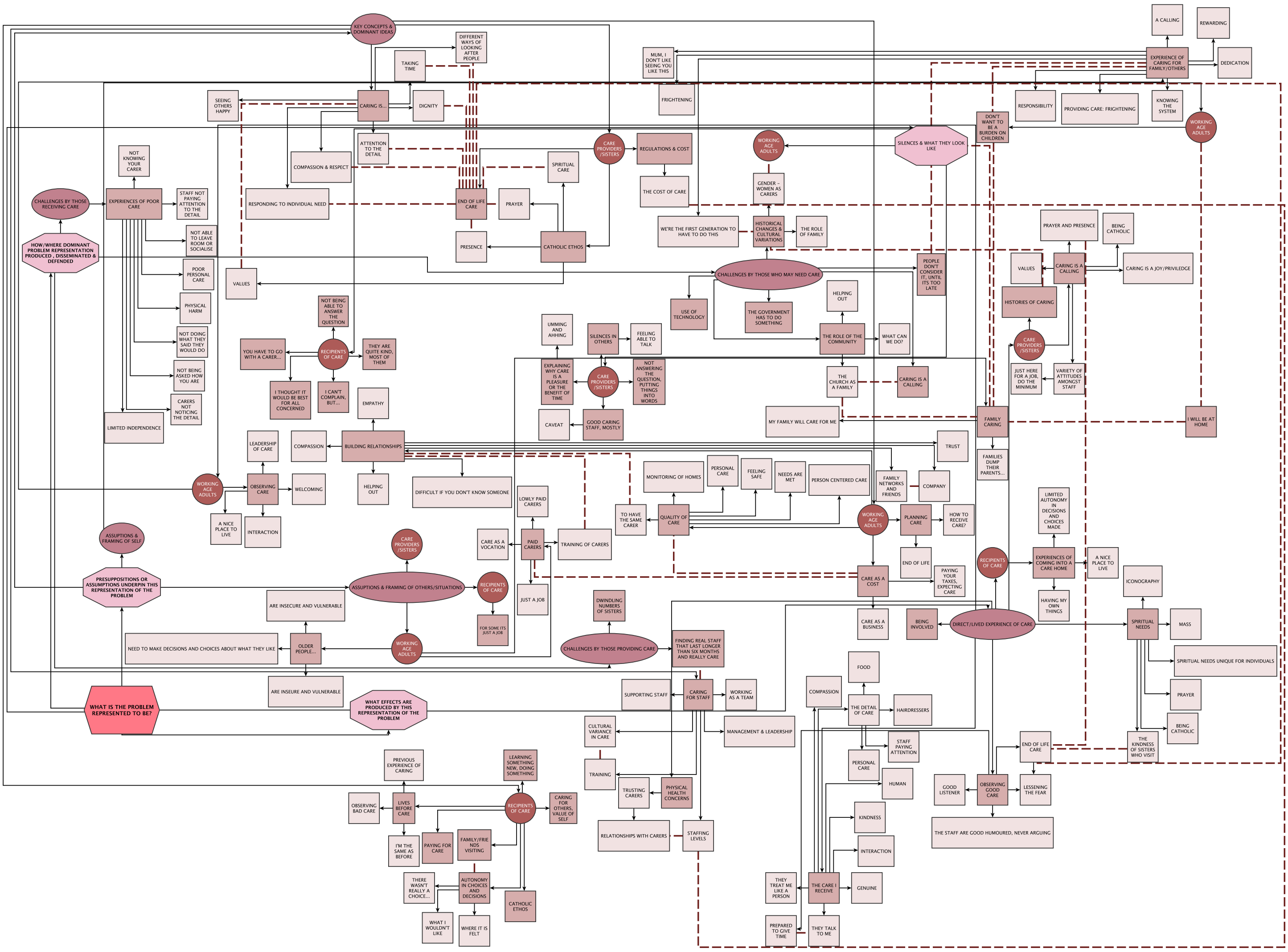

Diagram 1: WTPA analysis

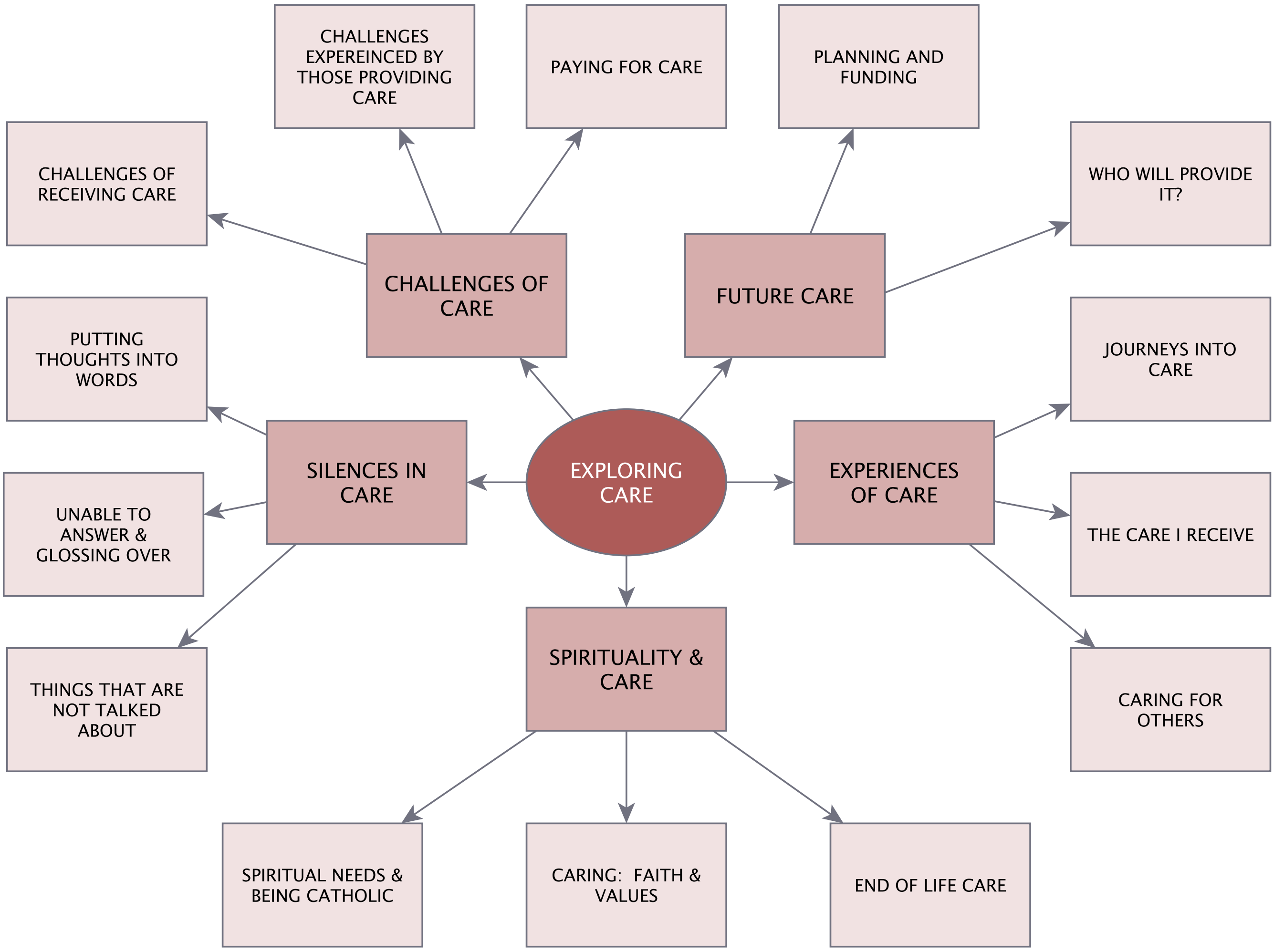

Diagram 2: Key themes

Findings: Experiences of care

A note on names and initials

Participants involved in the one-to-one semi-structured interviews chose other names for themselves, creating anonymity but enabling participants to recognise themselves in the study. Focus group members are not individually identifiable in the transcripts and chapters on findings, and letters have been used to indicate their gender and the focus group they were involved in.

Focus group and gender	Group identifier
Female participant in city in the South of England focus group	FCS
Male participant in city in the South of England focus group	MCS
Female participant in city in the Midlands	FCM
Male participant in city in the Midlands	MCM
Female participant in town in the Midlands	FTM
Male participant in town in the Midlands	MTM

Table 2: Focus group identites

Journeys into care

Those receiving care were asked about a time when they thought they needed some help and support. Some of the religious sisters and priests recalled their move into residential care as one directed by a senior priest/sister.

> John: The Archbishop wanted me to get out of the parish because he was afraid that I would hurt myself going up and down the steps...I didn't want to do that, but I did it, being the servant that I am.

> Sarah: I was down at the convent you see…It wasn't fair to them. So when there was a vacancy here I was sent up here.

Others talked about how deteriorating health, such as increased falls, had led to them moving to residential care.

> Sarah: I fell and broke my hip…I had to ring up and tell them at the convent that I wasn't coming back because I had to be taken in to have the hip seen to.

> Don-Juan: I felt that I was losing grip on things…I was losing the use of my legs, and had several nasty falls…although I was driving right up until the day I came here, walking, even a short distance, became a great difficulty…all the time, I was having to ask people to help me, which they did, for a little while, but not the sort of situation where you could depend on people for more than a short while. So, the obvious conclusion was to find somewhere…where I could be looked after.

> Mary: I happened to get a stroke… I ended up in hospital and I came back and I was looked after in the convent for a time and then I had a fall and fractured my hip…I had another stroke at that time.

> Martin: I went to this home, because I was starting to have a lot of falls in the house.

Some participants talked about coming to residential care after a particular event or crises.

> Georgina: I came on respite because I couldn't get back to the flat again. It kind of … I think I was the longest person on respite, getting finances and stuff sorted out and everything and I gradually said, "This is it, I'll stay."

Elizabeth experienced a severe stroke whilst she was asleep. She said, "I just woke up and was trying to get a drink of water, that was the first thing I knew and then I couldn't swallow properly." However, her move into residential care was as a direct result of domestic violence, where the police intervened -

> Elizabeth: Because my partner couldn't cope with me when I was disabled. He was abusive to me…so the police came one morning and that was the end of that. And he got taken to the police station and I was escorted to the nearest care home where at least I was safe. Sad, but this happens, doesn't it? He had no patience at all, far too frequently…

Some of the participants talked about the move as being the right thing, particularly for others.

> Charlotte: Well I had to accept it, didn't I, with deaths in the family as well? I just had to accept it didn't I?...she said, "It's not safe to be on your own," like that, so I didn't know many people in the district so …

> Claire: I thought it would be the best for all concerned, especially the community, you know?

There was little discussion about choice, planning or autonomy in decision making when talking about a time they needed help and support.

> Pamela: Well, it was the only choice…There was nowhere else to go really, and some of the sisters were already here and were very happy…I visited the Christmas before I came myself and I never thought I'd land up here.

> Jane: How I landed here…I was actually in the house in Barking…and funnily enough, it's still a bit of a puzzle to me, I must do a little bit more research on it and see actually how I did land up here, you know…And it's just one of those things, you know.

The care I receive

Recipients of care were asked about what they liked about the care they receive. The responses here should be read in conjunction with the challenges and silences that are discussed later, as at times positive aspects of care will be the absence of experiencing poor care.

Practicalities

There was much focus on the practical detail of care. Nearly everyone talked about the food that was provided, and many of the women referenced being able to access a hairdresser as something that was important to them. Others mentioned what level of care they received, whether help with personal care, or the help in having their room cleaned, bed made, and being helped to move around.

> Claire: if there's food that you're not able to eat, or you don't like, it doesn't agree with you, they'll give you something else

> Pamela: the food is good. I've no complaints about the food and I really, I couldn't complain

> Charlotte: That you get a shower each day and there's a hairdresser's downstairs so… because it wouldn't be so easy washing yourself all over every day, but that's what they do every day.

Attention to detail

Those receiving care noticed how staff paid attention to the detail. For Georgina, this was represented in how staff took particular care to dust her things and put them carefully back. Martin commented, "you can ask for anything, nothing is too much trouble".

For Elizabeth, the most important aspect of the care she received was the "general handling", she commented, "sometimes they're not, occasionally not. Just taking an interest in what you need, I suppose." Conversely, Elizabeth talked about someone who did pay attention to the personal care they provided;

> (He is) very careful with everything he does, like he was giving me a shower one morning. He didn't say something was wrong while he was washing me, waited for a senior carer to come in and said, look at this…You know, I thought he was very good, took the trouble to wait and ask someone to check it with him.

Don-Juan also talked about different experiences highlighting how staff pay attention, or otherwise, to the detail of care;

> …the caring way that they deal with you, you know? Make sure you're washed and dried after a shower, and while others will just say "oh here's a towel, dry yourself"…I went to the bathroom to wash my hands, and I said "could I have a towel please?", and the carer comes along with a big bath towel folded up and said "there you are", and I have to struggle to unfold it and use it.

Relationships of care

Those that were seen as caring were described as kind and pleasant, putting people at ease, friendly; they do not talk down to people. Recipients of care noticed a relationship that reflects the closeness of family. Don-Juan felt that the carers attitude demonstrated how caring they are, noticing when they paid attention to the detail of his care:

> Claire: I know their kindness, and their pleasantness is genuine…Well you can tell by their attitude, and they really are good, you know? You just feel at ease, I do anyway

> Georgina: I think they're friendly, and they don't talk down to you. This is me, they treat me like a person. I can chat to them. I don't feel … they're just right somehow.

> John: Their attitude, their relationship with you is not I'm the nurse and you're my duty, and that's really about the only way I can explain it. And that was a shock, it really was. Because in the place I was in, the nursing home that I was in, they were not people, they really were not people. They were just patients and they just got what they had to get, and if I have to leave it on the table, that's tough nuts. And they'd never do something like that here.. it's like, it's like a family.

When participants were asked what they understood care to mean, people who provided care talked about how it was essential to relate to the person, and understand and respond to individual need. As Ellen comments;

> …relating to the person as a person…. good care is when you treat that person with love and compassion as a person not as an object…as the person of who that person is, who that person was.

Joy also makes a similar comment, about how people are met and supported. She said,

> We're not just looking at their physical needs; we're looking at their mental health needs, we're looking at their ... everything about the person as a whole that we're providing care in all aspects.

Sally commented on the challenge for carers where there are limited resources, where they need to balance the time that is required to provide a relational caring response with the requirement to provide support to a number of residents.

> Sally: …it's being with that person, giving them your whole attention and it's not easy in today's society in the care sector, because the staff are limited so they tend to hurry, hurry, hurry and I think if we're not careful we all do it, if we're honest with ourselves.

Joy talks about how this works in the home that she manages -

> …it's just the general atmosphere as well, when you walk into some of that general atmosphere, it's a feeling of calm, of tranquillity, of the residents being...having had time to sit with the carers as well.

Observing others receive care

Throughout the interviews with those receiving care, it was evident that observing the care others received had an impact on individuals' understanding of care they were receiving, and how they might be treated if their circumstances changed. The most powerful experience of observing care was seeing how other residents were cared for at the end of their lives, explored later in the report.

Both John and Mary talked about how they noticed the care offered to others. John thought he might be getting 'special treatment' because he was a priest, but he said he "watched other people and they do exactly the same thing for everybody. It really knocked my socks off". Mary, who had visited the dementia wing, noticed the excellent care and commented on the careful and thoughtful way carers looked after residents. Jane and Georgina also commented about the care they had observed;

> Jane: I was kind of more observing here, you know, and it was amazing how so many things you see. And they're very, very attentive. I couldn't fault them in any way.

> Georgina: I notice that they're very kind to people and they treat them with a lot of respect…

One of the participants of the CM focus group talked about the care her father received.

> FCM: we witnessed good care… It was the fact that when they came in they were very respectful of his needs, and if he didn't want them to do anything for

> him, then they wouldn't, but they would ring us and tell us…

Much of what the residents were talking about when observing good care is arguably described in literature as relational care. The participant, FCM above, talked about the importance for her father to build up relationships, seemingly of trust, with carers. Another of the participants (MCM) at the same focus group noted; “I think this relationship with the same person is so important. It’s rather akin to us, I’m sure we’d all say we’d sooner go and see the same doctor every time.” In another group a participant framed this idea about relationships in terms of the connections made between carer and recipient of care:

> FTM: You do see some really good ones in there, and then recently, it’s lovely … It’s the connection that they've got to want to do it to connect to people and have that passion…It is the connection. I think that’s where, to be a carer, that’s what you should need.

Feeling a connection is key, according to Joy (care provider), particularly for those who have dementia:

> Joy:…one of the key things, and certainly with people with dementia, is to feel that connection, to feel that they can hug still and be held and, you know, as we're moving into later stages, that feeling of being able to hold a hand or hold somebody is really, really important.

Findings: Caring for others

Discussions on caring for others ranged from it being enjoyable and rewarding, to something that was tough, frightening and horrible. Those receiving care talked about caring for other residents, and attention was brought to how we care for carers.

Enjoyable and rewarding

Those providing care and support were asked what aspects they enjoyed most when helping and supporting others. Participants made it clear that caring for others was something they enjoyed doing, rewarding, and part of who they are.

> Joy: I think it's just part and parcel of my life. I don't think I could do anything else now. I mean I've been doing it for such a long time but it is ... you just get a sense of wellbeing about it, don't you…
>
> Sally: It makes you feel good too and we all need to feel good about ourselves, but also make the other person feel good. I did a good thing there.

Ellen talked about how positive comments from those she cared for encouraged her:

> It's not a burden, it's not a job, it's not anything like that, it's companioning, you know, just like every now and then you will get a little kind of comment, like oh I'm delighted to see you…when you get a comment that kind of is positive it's lovely. Whether one should be looking for that I don't know, but it does help because it encourages you.

Jean refers to her spirituality and how it informs her desire to help others:

> It's a very rewarding feeling that I get when...inside me, there's a deeper joy inside me that wanted to do more so that's what I get when I help others. I suppose I'm referring back to the spirituality because it's something in me because I was born a Catholic so it's always there.

Tough, frightening, and horrible

This positive experience of caring is not replicated amongst some of the working age adults who had cared for parents. Some of the participants of the focus groups talked about how caring for others is tough, frightening, horrible and a significant responsibility.

> FCM: My brother is brain damaged due to a hospital accident…my mother was dealing with Alzheimer's. At one point I was sitting between my mother talking rubbish and my brother talking rubbish to each other, and I was sitting in the middle. I don't know how, and this all happened in the space of a year, it was horrible.
>
> FCM: It is very hard to look after somebody who's got Alzheimer's, if someone's got dementia, it is very tough because they're just lost their dignity...when I saw my mum, it's not a good thing to say, I just kept it in my heart, to myself, that, "Mum, I don't like seeing you like this"…because it's like everything about her went. She was just…everything was gone. So it's hard, it is difficult…

Another participant of this focus group said how much she agreed with the comments above:

> My sister went around one day and she banged on the door and there was no

> answer…she said, “I was so frightened. What if he’d collapsed? I thought I was going to find him dead. I don't want to find him dead.” And I just said, “Don’t worry about it, if it ever gets to that situation don’t worry about it at all. Ring me.” Then once I put the phone down my husband said, “What’s wrong?” I said, “I’ve just told my sister that whatever happens, don’t worry about it. If it’s any sort of, don’t worry about it, I’ll be the one to find him dead.” You never imagine yourself having that kind of conversation…I know it would be different, but getting your head around that, that’s something you’ll never think you're going to have to do.”

Another one of the participants in this focus group had been a nurse, and she comments on the difference of caring for others compared for caring for your family.

> FCM: I felt that I’d got lots of empathy because I would put myself in that other person’s place, all my nursing life I would try to say that could be my mother, that could be my father, that could be my brother, that could be my sister. But then when you come to look after your own, it’s completely different and it’s a different...

This then led to a discussion about the responsibility of care, and one of the participants reflected on the decisions she had to make on behalf of her father at the end of his life.

> FCM: …at the time I was fine with it, but as time went on I wasn’t, because it was actually taken out of our hands in the end, and the decisions were made for us and we had to go along with it. They were the right decisions but you do feel a huge responsibility…there were decisions that we had to make in the end that weren’t nice decisions, stop feeding him, stop giving him fluids, those sort of things.

Being involved

One of the residential homes involved in the study had a varied and well-supported activity programme, which included a choir and a space for residents to involve themselves in arts and crafts. Georgina had made significant use of this. Having never been interested in any art activities before, she had found something she enjoyed doing, and spent every day in the art room creating various works that were displayed around the home. Georgina had also encouraged another resident to join her, and commented about this:

> …she said that I’ve made a big difference to her life because when she came here, I think she was a bit lost because she’d worked hard all her life in the community and she said I have changed her life and we get on like a house on fire, she is so sweet and we sit there and we just...it’s a lovely, friendly, friendship that we’ve got.

Pamela talked about her role in the dining room setting the tables in the evening and how important this was to her:

> It's important to me. Well, I've always done, you see. I did for myself years, I did 16 years by myself until I came the Sunday, I'd worked right up to the Sunday and came the Sunday afternoon….when they asked me to be involved and help with the suppers at night, you know, just lay the table, or

> whatever, I was delighted because it's something I ... and now they give me an apron so I'm fully-fledged.

Claire and Jane talked about caring for other residents, reflecting the work they have done previously as religious sisters in the community:

> Jane: if I have any spare time, I go around and I visit some of the people in their rooms and things like that, and especially some of them that are, you know, in bed and they don't kind of see many people. And if they want little things, I'd get it for them, you know.

> Claire: There’s another old lady, dear old lady, Norah, and I take her down every morning to chapel, for Mass, yes, we come down together, yes. She’s a bit more feeble than I am, but she hasn’t reached 90 yet. So, I say to the carers “I’m her semi carer”…

Caring for carers

Within the concerns about how care was paid for, and what was good care, arose comments about how carers are cared for. These mostly came from people providing care. For example, Joy was very clear how important her consistent and committed staff team were to deliver care for the residents, and how she and colleagues supported the carers. One of the challenges that Joy noted is that when in affluent areas, there are less people who are willing to take on the role of carer in a residential or nursing home. She talks about how people perceive the worthwhile nature of the job of carer, and the failure to recognise the work carers do.

> Joy: its a major challenge and I think it's a challenge that is still going to be there and unless somebody alters the whole aspect and criteria of care, per se, in the sort of psychology of how people perceive the job because I think the job is still perceived by many, ‘oh, she’s just a carer’. And I think until we alter that perception of ‘oh, they’re just a carer’, because nobody’s ‘just a carer’. It's an incredibly worthwhile job and, you know, as the population’s ageing we need more and more people to take on this role and to change that sort of perception of the wider community…I think people perceive nurses very, very differently to the perceived carers and I think there needs to be more recognition of the qualification that a carer gets.

‘Good’ care is recognised by those who receive it; it is noticed. Claire (recipient of care) commented how she recognises this and understands how staff may appreciate hearing it.

> Claire: I’ve always said, “I’m really pleased I came here.” I tell them. Because sometimes they need to be told, you know? They need someone to encourage them, to keep up the good work. And I say “I’m delighted I came here, I love it”…and I mean it, I mean every word I say.

Nancy commented that it was important to thank staff “when things go right, and celebrate successes”. She talked about the various awards given to staff to recognise their impact and service. However, there is a challenge here that they are unable to recognise the value of the staff in financial terms, hence why awards and highlighting good practice is so important.

> So, things like that we try, because we can't always give our staff a pay rise every year because of financial constraints, but I think making them valued in small everyday ways is important, because we can't manage without our staff at the end of the day.

Joy continued her thoughts on how **carers should have more recognition for what they do**. In particular she noted how the organisation supported staff "taking a lead in their own training… and the staff have taken it on board. They have ... they've started going to College which do different training things. And they go home and they do their own training…they come back to me and they say, "look, you know, I've done this and I've done that".

For Joy, empowering staff was essential to how care is delivered and received by the residents, she explains;

> "there aren't many care homes that empower their staff…but once you've empowered your staff you get a lot more from your staff. And if you empower your key staff members, the ones that are perhaps a little bit more vocal, your strong members of staff, you'll find the ones that perhaps just come to work just to work will perhaps follow a bit more in their footsteps and you get a far more stable staff team, so we're very lucky we've got a stable staff team here. "

Caring for the staff team involved being aware of the things that might be going on in their lives, and reality that the lives carers live outside of their work has an impact on their work. A number of participants commented on how paying attention to, and supporting carers, was part of creating a stable staff team.

> Nancy: on a day to day basis being aware of … not their needs as such, but you know sometimes you have somebody that something's happened in their home life, and okay you always say, "You have to leave your home life at the door. You're coming in to do your job," but of course it does impinge on you your home life. So, if somebody has lost somebody or somebody's ill and they've got that on their mind, it's being aware of that and just saying to them, "How is your mum? How is whoever?" because staff do appreciate that.

Presence talked about how important it was to keep an eye on the staff. Not only is their job difficult, but "they have their problems and they often share them, and they have family bereavements and one thing and another and problems at home, and money problems and children in school…Not that you can offer a lot of help, but you can listen".

The fact that staff come to work to care, and how they care, intersects with the things that are happening in their own families. Also, through working in a home they become part of another structure, one which Joy refers to it as **a family structure**, where long standing staff members know the residents, are confident in their roles, know the management team and are comfortable going to them to discuss concerns or otherwise.

> …if you go into any environment and you've got a stable staffing structure it is going to make the delivery of whatever you're doing better, but certainly in care when you've got residents as well that have been here for a long time, you know, they...it becomes a family. It becomes that family structure and they care very deeply then for their residents and once you start to care deeply for your residents then they will provide a far better quality of care for the resident.

The leadership and management of care was considered imperative to the way care was received. Lucy commented, “I think it’s very important when we are running our own care homes that we take great care in who we appoint to manage them…If you get a good manager you’re away with it.”

Jean commented how the support from managers and leaders had a direct impact on her:

> That makes me happy to provide care. It's the atmosphere. Sometimes what makes me happy it's the workplace, the whole environment and when you feel supported by the manager and/or the leaders within that, provides the joy to go forward.

Presence talked about observing how the manager behaved and the impact it had:

> She knows what’s needed, and she always has time for you. She never closes the office door unless it’s a private thing…but the door is always open…It’s open there for anybody, even residents sometimes will wander in and she might say, “Do you want something Mary?” and they won’t even hear her, they just wander around and walk out again, but she doesn’t say, “You shouldn’t be here,” or anything. That’s what I mean, that kind of acceptance. She’s a good woman, a very good woman.

Findings: Future care

The working age adults involved in the focus groups made a number of assumptions about their future selves and who would care for them, they also had many views about the nature of (paid) caring, how carers should behave, and who can care.

Care: Who will provide it?

A significant number of participants assumed that they would be able to stay in their own homes, with not much changing in their life. Where participants did not seem to assume they would be able to continue living in their own home, they clearly stated a hope to stay there.

> FCS: I think the idea then we'd all like to be able to live in our own homes until we're carried out in a box is the ideal, nobody wants to feel that they're going to be put into a care home sitting around the edge looking in.
>
> MCM: I think most of us are envisioning staying in our own home as long as possible, and the thing we don't want above all else is to go in a home.

It was also evident that a number of those attending one of the focus groups were confident in having the finances to pay for care in the future.

> FCS: I would hire again somebody to live in, they could have their room and go to work, whatever, but cook for me and do the homework and shopping, I would pay for that. I would not have Social Services' carers.

Participants talked about how they know they need to consider potential future care needs, although do not seem to have thoughts about how this would work.

> FCS: I think coming to terms with the idea that you've got to accept some sort of help would be extremely difficult for all of us because…well, it'd certainly be very difficult for me because I think we would feel invincible really and this is never going to happen to us, but of course it does. So I do think that we really do need to focus on it a bit more than perhaps we do and have a plan…I still feel that I'd want to stay in my own home…

Many of those who had not had to provide care for relatives talked about how they expected their family would support them in the future.

> FCS: Family for me, hopefully my closest members being there to help me…So immediately I would, yes, expect to have family members to be there to help me, but if I became a burden and I needed hospital care, obviously I would hope that there would be care for me, that NHS would be able to give me that support, that you've paid all your taxes over the years, and you hope that you do have people to look after you when needed. But yes, family first.
>
> MCS: I'd hope that my children would look after me in some way. I wouldn't be too fussed about how they did it, I'd leave it to them in their capacity of how they're doing it and hope that they would just do their best.

Whereas others, particularly those who had experienced providing care and support for relatives, were keen not to be a burden to their children.

> FCM: I said to my son, “Don’t worry, I don't want to put you through this. I will choose where I go”…because I think that’s the only power you're going to have, to have the plan - what kind of care do I want, what kind of home do I want to go to and be there when it happens, and I hope I’m at – Now, my son said, “Trouble is, Mum, that you’ll have Alzheimer's and you’ll have forgotten, so you’ll be as bad as…my mum wasn’t bad, it was the stress of trying to decide what to do.
>
> FTM: I would like to be at home but with my children visiting me, and I wouldn't like to be a burden on my children.

Common themes across the focus groups of working age adults were the views held about paid carers and how they should be trained. These ideas appeared to come from experiences of visiting relatives and friends in a nursing home, visiting care homes in a professional or pastoral capacity, or understanding gathered from news reports and documentaries.

A discussion at the CS group started with a comment that, “a lot of these places are only as good as the people working there”. The group discussed how it just takes a change of leadership or staff and the care can be very different, referencing documentaries that had caught on camera carers abusing patients. One of the group commented, ”I’d like to think that there's more monitoring of these sorts of homes now”.

The comment about how much carers paid was a frequent topic, although this should be read alongside the cost of care discussed later in this section. Additionally, a thread that runs throughout all the interviews and focus groups is about people just doing the job to earn money, suggesting that those doing it just for the money are less caring.

> FTM: …a lot of them, as you said, they are very lowly paid. Some of the jobs aren’t very good and they might just do that because they've got to earn some money, but maybe if they’re with somebody else that really does show that they care and build up a relationship, then that might encourage them to see it as more than just a job and build relationships, that sort of thing.
>
> MTM: I just see it as, well, they can’t get a job anywhere else so they're working in a care home.
>
> FTM: I have seen it with my own eyes, the care is not 100% up to scratch. Several things, carers in a care home don’t get an awful lot of pay, they're not well paid. Secondly, they're very young in there as well, so I don't think they've got that professional way and I don't think the training is proficient enough to take care. And I think for carers they need that training.

There are some comments by those receiving care that they make the categorisation between carers that care and those who they consider are less caring. Also there are a couple of comments from those providing care that there are some carers that they would prefer to be “more caring”.

> Ellen: we have very good appointed managers and very good staff and caring staff. For the most part. You get an odd one who is maybe not quite so caring. Caring, but lacking the warmth.

Planning and funding care

Amongst the working age adult focus groups, there were discussions around the provision and funding of care. Common themes included that the government needs to take action; that people do not consider their future potential care needs until too late, and that current experiences of care and its associated cost result, in part, to changes in how the family unit operated, with comparisons to the way people thought other cultural or religious groups cared for their relatives. Alongside this were challenges to take action now, and considering the roles of the community and church to respond.

One focus group participant was very clear that the government has to do something.

> MCM: It's Parliament who's failing, in kicking this can down the road and filling hospitals with older people, because there's no care. We can have very little effect on that, it's up to the government to do something about it, and they don't….You've got an ageing population … They keep dodging the issue.

In another focus group participants questioned if they should make their voices heard, to take part in making some difficult decisions how about how care would be provided, such as paying more tax. Some of the group saw paying more tax as the fairest way to alleviate the situation.

In two of the focus groups participants saw the challenge that people do not think about care until it is too late. One participant had a professional role and wanted to challenge those sons and daughters who complain that their parents can no longer do certain things, and get them to reflect that they would also experience age degeneration. He commented, "we do need to think about care for ourselves, and whether that's looking after ourselves now or how we think we can prepare for it in the future, financially, family or otherwise." Elsewhere, there was a discussion about how frightening the idea of receiving care was, and the last thing people want. One of the participants commented,

> MCM: I suspect that's true universally, no one wants to get to a state where they can't see to themselves…but it does occur to me as we're talking that there should be some provision in society as a whole to perhaps teach people the fact that they're going to need caring and they're going to have to learn how to be cared for…

Participants in all focus groups commented on the changing nature of the family and how it cared for its older relatives. Some felt that this was related to a breakdown in communities, higher mobility leaving extended family scattered far from relatives. One participant observed, "I don't think that these days families look after the elderly the same as they did years ago".

Others saw it as a cultural difference. One of the participants in CM commented,

> I think it’s also a cultural thing as well. Because from my own background it’s completely different from how the care is over here. I remember when my mum passed away a few years ago, she had dementia but she was looked after at home. We just took turns, because that’s how we were brought up.

All groups had a discussion on what they saw as good practice amongst other countries, cultures and religious groups.

> MTM: In the Asian community they will look after their parents. In the white community, care home, carers in…you've only got to nip over to Spain, the family unit is much stronger than the family unit here.

All focus groups were asked about the role they thought they had in ensuring care is available for those who need it now and in the future. In all the groups there were some quite extended discussions about what they could do and the role of the church in doing something.

It seemed that one of the biggest challenges would be how to bring about action. People either did not know where to start, or were unsure how to overcome presumed barriers. There was an agreement that the ‘church’ had a role to reach out beyond its walls and beyond its perceived role of providing Mass on a Sunday, but participants were unsure how to make this happen.

> FCM: Some of us have no family, but the other family they have is the church family, and that is the aspect that really needs to be looked at more seriously so that we can actually create, maybe that’s not the right word, but encourage a closer ... [sentence left unfinished]

> MTM: Actually the church and people who come to church, almost there's that sense of outreach and the challenge is, actually you do this on Sunday, what do you do the rest of the year? And somehow get that element of reaching out in small ways. Part of the problem I think we have in society is that it is so complex and so big, we feel helpless and so we end up doing nothing because we’re paralysed.

However, one of the participants pointed out how personally beneficial caring for others in the community can be, reflecting on the rewarding experience of helping those who are homeless. He felt that helping others is an opportunity that should be made available to as many people as possible, because the rewards are so great.

> MTM: …in fairness, on the whole what you find is if you do it properly you want to give as many people the opportunity to volunteer to help as many homeless as possible, rather than a limited number, because when the relationship status is a win-win, people get what they didn't know they were going to get. It’s very rewarding.

Findings: Spirituality and care

Spiritual needs and being catholic

A large number of recipients of care involved in this study talked about the chapel on-site and the daily Mass that they could attend. Pamela commented, “they take me to Mass every day…that’s a bonus”. Sarah commented similarly, “It's lovely because we can go down to Mass every day and there is a Mass and there's always somebody to take me”. Nancy commented that they needed to “provide spiritual care in the sense of church experience, for want of a better word, for all of those people, not just the Catholics…it’s providing for that the individual’s needs are, not just in a general sense…I think spiritual for everybody is individual as well, it’s what they want out of it.”

For other residents the chapel onsite provided them with the much-valued opportunity to continue their ministry. John commented that his “ministry as a priest is satisfied here”, and Don-Juan said, “I love celebrating the Eucharist”. Charlotte made the point, that it is not just her spiritual needs that are met attending Mass, but also that this was something she had done since a child, it was part of who she is. She said, “I manage to get to the church most Sundays for Mass…being brought up in the Catholic school it’s nice to be able to go isn’t it?”. This is also observed by some of the sisters. For example Lucy commented, “I think it supports their faith and their living if they come to something that has a similar ethos…a lot of people in this area went to the schools run by the sisters over the years in the past, and they are very happy to come into a care home where they know there’s that Christian ethos”. For residents with dementia, Sally had noticed the impact attending Mass had on them;

> Take them into church it’s a different ball game, and why, I don’t know. I suppose maybe that’s the way they’ve been brought up or the way they’ve practised or what, but there’s some calming influence on them when they’ve been into church.

However, Theresa commented a number of times throughout the interview that she would like more opportunities to meet her spiritual needs, and gave the impression that her current experience was falling short in comparison to her previous experience in a convent. She said, “you get Mass every day, but…but we would want a bit more”.

Caring: Faith and values

Not only did the sisters talk about spiritual care, but also a number talked about how their faith underpinned the care they provided to others. Lucy commented that she thought, “Everybody in this world is God’s creature and is loved by God, and whatever, I have to love them as well, that’s what the Gospel says…and it’s not that I have to, but I want to, and I enjoy doing it”. Presence also talked about how she got her strength to care: “We’ve God’s grace working in us and through us. It’s not me. What am I? Only skin and bone, but I believe that God is working in me and through me”.

The sisters involved in this study talked about the values of their orders and how they were trying to share these values with the wider staff team, with a view to ensure the way they offered care continues as the number of religious sisters dwindles in England and Wales.

> Nancy: I would like to think that our values … we call them our core values, but really they're values that anybody in care should have really…and I always say to people at interview, "These values are not something we want sitting up on the wall in nice pictures and they're all very good for people to look at, but we want people to practise them." So, they are love, compassion, hospitality, respect, justice and patience. They're all values you need when you're caring for somebody, and we try and imbue our staff with that and pass on that ethos to our staff. As I say, they are values that anybody in care should have, because you need a lot of patience in care. You need compassion, certainly. You need love. Hospitality has always been one of our big things as a congregation, so welcoming people in. And, justice. We have to be just in all our dealings with everybody, our staff as well as everybody else.

End of life care

All the groups of participants involved in this study mentioned end of life care. For the focus groups this was with either oblique mentions to how they wanted to go in their sleep, or with personal reflections on death and how it was considered in the Catholic faith. However, they allude to their **concern around the process of dying** rather than death itself. This is summed up by some of the participants at the CM focus group:

> MCM: It's a difficult question for me, that, because I haven't got any problems about dying, I don't think. I mean, when I get nearer to that point I may have a bit more of a problem and try and resist it, but I'm a bit obsessed with that, so I'm very untypical. If I was told that tomorrow I'm dying, I'd rather do that than spend time in pain…
>
> FCM: I think we'd all like to go in our sleep, wouldn't we?
>
> MCM: I think I'd certainly want a quiet exit. The last thing I would want to be is hanging on for years in a residential home.

The sisters involved in providing care also talked about how central providing end of life care was in their work. As Ellen commented, "it's an unwritten kind of thing for us that we try to care for them until they die. And the families are so grateful for that, and it's wonderful to witness the peacefulness..."

Presence talked about how she is with people at the end of their lives.

> I pray with them a couple of days a week, especially at the end of life care. That's when really I come in to my real place, because the staff know that the end is near, but they can't always be there, but they try. They try and be with them. So, if I'm there they leave the door open and I've got a bell, so if I see any change I can ring the bell and they'll come. Then, the relatives will stay as well. So, I'm there for the relatives, and even after the end of life care I'm there and we pray together. The staff come in and we come out and everything else is

> seen to, and if we can we attend the funerals of all the residents.

The sisters are very clear in their role in supporting residents in their final days and why it is so important. Nancy commented that their “big thing” was to care for people at the end of life and points out the benefits of having the sisters in the residential homes, as they are “able to go and sit with people who are dying”. Nancy commented that this was something they try and pass on to their staff. She was very clear that they “don’t like to leave people alone when they’re dying”.

Presence explains why this care is important for residents and their relatives:

> …it’s very important to be there as much as you can, because the hearing is the last thing that will go. So, they’ll hear a prayer, they’ll hear a word, they’ll hear their name, because sometimes you think people are nearly gone and they’ll open their eyes.

It was evident in the interviews that end of life care was important for the sisters themselves, and Jean talked about why this was:

> It's very important for us from the spiritual side of things when someone is dying, to be around that person, to support that person through prayers. And for someone who doesn't believe in God there’s a lot of experiences that I can see how they are calm and have that trust in them that oh, at least there’s someone here next to me. So that’s our care, when our residents are dying we usually go and pray with them and sit with them and until they passed away or take their last breath…

The power of being present and being with the person is echoed throughout these accounts by those who provide care. Here Sally can’t find all the words she is seeking to describe this act of being with someone at the end of life, but she is clear, it is “being with the person”.

> Sally: Well even the quietness of a person, if a person … you know sometimes, even if a person is dying, you don’t have to go in and be saying a whole load of prayers. You can be just in there, holding their hand, saying a few prayers… I think there’s no need for all the prayers really. You just need to be … and I keep coming back to this just being, being with the person.

This delicate act of being present, providing support for residents and their family, whilst also giving family space, clearly comes from experience. As Presence says, “it’s important too that you don’t overstay your time with them too, because the relatives want to be there, and they want their own conversation. You never know what they want to say at the end. It might be reconciliation, so you have to know when to withdraw”. She comments that “knowing your place” is something that comes with experience.

Where residents observed other people receive care, they also witnessed end of life care. It was evident in the interviews that this has an impact on individuals’ confidence about how they might experience dying and understand how they will be cared for. Georgina, who states that she is not a Catholic, illustrates the impact of having seen others cared for at the end of their life has been particularly powerful for her, and she now knows how she thinks she will be treated when the time comes.

> …if somebody is at the end of their life, I have never seen such care that they are given if they want to stay here until the very end, it's just so amazing. Yes, they are looked after right until the very end with just non-stop care. They're not shuffled off, but then…if you want to end your life here, they will look after you and be with you and look after you right until the very end…I think that when I come to the end of my life, I think that I know that this is how I will be treated if I don't have to go in a hospital and end it there. It's such devotion if you're at the end of your life. I mean, my friend who came here with me just after I came…she passed away about 18 months ago, and she was really, really poorly for quite a few weeks and she was looked after. I've seen it. I've just seen it…I saw it especially with her. It's just amazing what they do and how you're treated right until the end.

Mary, a religious sister, also talked about witnessing good end of life care: "The doctors and nurses that tended them were very good, and I think they got excellent care…I think if it came to my time and I was here I wouldn't worry about it, I know I would be looked after". Mary, who prior to receiving care at the residential home was active in her community providing care and support, went on to reflect;

> …most people it's often their worries, how is it going to happen, if they know they have got an illness. Well they're not so much worried about dying as worried about how it's going to happen, what's really going to happen to them. I mean to explain to them that nobody will be left in pain, and then people can be a bit frightened, especially nowadays when they've got signed forms whether they want to be resuscitated.

Findings: Challenges of care

The challenges of receiving care

Throughout the interviews there were times when those receiving care challenged or disagreed with the care they had received whilst living in residential care. For Don-Juan, it was a failure by carers to pay attention to the detail which meant so much to him, he feels he should not have to tell people to do things that seem so obvious to him.

> And others do not, you have to tell, and things like putting the cover on the bed, and folding up the blankets, and tidying the table up, like that, and picking up paper from the floor. Like, for instance, today I dropped some paper on the floor, and I obviously couldn't pick it up. And two people walked over it, you know? Wouldn't pick it up. Not their job….little things like that, to me, make all the difference to life. It may be simple to them. On one occasion I said "You should put the cutlery on the table this particular way." And they just slammed on the cutlery and said, "There you are."
> I don't like that attitude at all.

Whilst for John not being able to go out of his room made his time in a previous care home "lousy" and "terrible". Elizabeth talked about not being sure if you can completely trust someone who is providing personal care for you if you don't know them, imperative when in chronic physical pain. She brings attention to her preference for having trusted and established carers:

> You need to trust the carers completely, so if someone lifts this arm too quickly, it's painful of course, 'cause my shoulder's stiff from all that time being in one position. And I squeal a bit, you know, stop. Like dressing and undressing, obviously they have to move it for me and that's not easy.

Challenges experienced by those providing care

The challenge of finding staff that care and will stay with the organisation longer than six months was voiced by several religious sisters who provided care. As noted above, Joy talked about the challenges of finding staff in rural and affluent areas, and how the role of carer is perceived and valued.

> …less people wanted to do the work in those areas so that was...is a major challenge and I think it's a challenge that is still going to be there and unless somebody alters the whole aspect and criteria of care, per se, in how people perceive the job because I think the job is still perceived by many, 'Oh, she's just a carer'.

Rita said that the main challenge at her home was that staff gain experience with them, then leave to work at the hospitals who pay better. She explains, "the main problem is staff and we couldn't blame them, they get their experience here, they go to the hospitals, they've got to have experience, and they say once you have experience, the hospital will take you quickly because you know how to deal with it".

The low pay that carers receive is also noted, as Rita comments, "the pay too low and the work is very hard". Earlier Nancy recognised that they had to find other ways to value and recognised their staff, as they were unable to do so financially. The low pay and hard work becomes even more challenging for carers in post as homes struggle to find staff to join them, and then staff leave because the work is just too hard. Rita notes that just one person not turning up to work is “a big thing to lose” in a care home.

Amongst these challenges are finding and keeping staff that care. As participants across all groups noted, there are some staff for whom this is “just a job” (Nancy). Rita sums up some of the challenges of finding staff that care -

> …well maybe some of the staff just maybe came here because they needed a job and you can tell them, [by] the way that they do the caring. There’s also a challenge because we needed staff and sometimes we just accept them…It’s always a challenge for us to find real staff that might last a little longer and that really show a real care for our residents, a true care.

Ellen also brought attention to the stark realities of funding for care, and regulations they must adhere to. She commented that one of the significant challenges they faced came from the regulators and all the standards they have to meet. Whilst Ellen notes that they did have inspections in the past, they were very different and there has been much change over the years. Also the way that residential and nursing care has been funded over the years has impacted on the way the homes operate, and as Nancy explains makes the organisation is very different from that which their founders envisioned.

> Nancy: It’s very different from when our founders started, and everything has changed and there have been so many changes over the years, and it is very difficult to accept them and look at what’s happened. Also, there’s not an awful lot you can do about it if you want to continue in the care field.

Sally points out how these challenges ultimately have an impact on the care individuals receive.

> …because we haven’t got the funding that, as I say, you're not able sometimes to give the quality of care because this person needs this and this person needs that, and there’s a time factor and we’re kind of losing a bit of that…and the paperwork. See, some of these things that I’m talking about, when you can’t put into … well I can’t put into words on paper how I’m feeling and how that person’s feeling. It gets lost in paperwork, that to me, you can’t put that on paper.

Paying for care

It was striking that when asked about what they understood care to be, or what they thought it looked like, all of the three focus groups moved directly to a conversation about the cost of care and care as a business, and what they saw as value for money in terms of the care they had witnessed. There seemed little awareness or discussion about how little councils paid per week for those needing residential or nursing care, the cost, or the difficulty of providing care at that level.

One the participants was clear how he thought care homes operated;

> MTM:…a bit of me almost thinks care homes are popping up almost like a McDonald's and they're getting the cheapest staff they can because it’s a business. It’s not care, it’s a business….So, if you can't keep the business running with cheap staff, you can’t have a care home. Now, you get your spreadsheet out and work out staff costs, accommodation costs, and the people that budget for it, it’s like anything that gets budgeted always budgets low cost for everything, and then they get the go ahead to go and do it, then the costs double. And oh, okay, let’s pay more to get the building on the ground, they will just have to pay the staff less. But that’s what care homes to me seem like at times. If you go to a nice new McDonald's, it looks great, it’s all nice and clean. You go into a care home, it looks nice and clean, but…

This participant from the same focus group had interactions with care staff via his professional role and talked about his observations of care staff not knowing how to fix a disability aid, something that he felt should be basic knowledge as the majority of people receiving care would have one of these aids. He is frustrated that alongside this lack of knowledge, “people are paying these ridiculous amounts of money for this provision of care, and that doesn't matter about whether it’s a [redacted] care home or another that’s opened…So care is expanding like no tomorrow at this moment in time, the prices are just (frightening)….and these are going to affect all of us”.

It is also interesting here, when referring back to earlier discussions on the assumptions of families caring, that not having families caring is expensive. That is, if you have to have carers into your home, it is expensive.

> MCM: if the situation is serious or there's no family, then you've got to go for carers, and if it’s expensive it’s still very much cheaper than a care home.

One of the participants in the CM focus group was concerned in the future who would be able to access care, and said “care should not depend on status, it should not depend on your bank account. It should be equal for everybody”.

The funding available from local authorities has impacted on the homes involved in this study to varying degrees. Joy noted how ‘lucky’ they were at the home she managed, because they weren’t experiencing the financial strains that were felt in other areas. However, the realities of how care is funded are starkly set out by Nancy:

> Some of the authorities haven’t raised their fees for ten years…we have money because we’re a charity and we do get some legacies and things that support, but they’re getting less and less as well…So, it is a fact that the private people supplement the people that are not private, but it’s the same in all the care homes. Obviously, because we are a charity we do build into ours a charitable element and we will take some people, but we can’t afford to take everybody either at a lower fee, otherwise it’s not sustainable.

Nancy goes on to talk about how councils are getting care providers to bid for care packages, and brings attention to how individual wishes and needs are lost amongst this.

> …in some parts of the country they've even got this bidding which is terrible for residents. There are four authorities that we deal with a lot who have this system where they put somebody…so, say you needed care, they put your care plan onto this portal…it's open to people that are providing care, and you can log into it and you put your bid in of how much you're going to take them for. So, say I was looking at yours and I said I could take you in and give you your care for £500.00 a week, and some other home might say they could do it for £450.00, so then they go to that home. If you said, "Well, I really want [redacted] Care Home," so then they come back to us and they say, "The person really wants [redacted] Care Home, but you'll need to lower your bid, because this other home will give them the care, but not the spiritual care that you're going to provide." It's terrible, it really is.

Findings: Silences in care

Trying to establish what a silence is and what it looks like is of course impossible to correctly identify with any certainty. The identification of silences has occurred by the judgements made from what has been heard during the interviews and focus groups themselves, and also what was seen in the transcripts. In order to guide the identification of silences and note the times where it appears that things were not being said, we considered:

- What do the silences look like and how do they appear?
- Are there times when things appear not to be said?
- What instances are there, where the interviewer may have had an impact?

Putting thoughts into words

There were a number of times throughout the interviews where participants seemed to struggle to put their thoughts into words. There seemed to be two reasons for this. Either it was something they felt strongly, but had never been required to put into words, or it was the first time that they had been asked or thought about the question.

The quote here from Sally, one of the sisters providing care, demonstrates how she struggles to put her understanding of good care into words.

> Sally: …some of these things that I'm talking about, when you can't put into…well I can't put into words on paper how I'm feeling and how that person's feeling. It gets lost in paperwork, that to me, you can't put that on paper. That interaction with the person, you can't put that on paper. Unless another person was in the room, they don't see that. You don't see that on paper. You couldn't, because it's your feeling and their feelings. How can you put that on paper? I'm lost at that. You can't.

This quote from Joy also illustrates the difficulty to put something into words, she is responding to a question about what she enjoys about providing care for others.

> Oh, gosh, I mean the whole aspect of it. I mean it's ... the whole ... I think it's just part and parcel of my life. I don't think I could do anything else now. I mean I've been doing it for such a long time but it is ... you just get a sense of wellbeing about it, don't you. I mean it is ... I think each day you just see something ...

Throughout the interview Joy struggled to define what care was in words, but offered a range of examples of practice where she feels good care was evident and the impact that this had on its recipients. Her passion and commitment to caring was evident throughout the interview.

It is also possible, that where the interviewer does not share the same spiritual experiences and faith as some of the participants there will be times when the meaning may be lost between the two different world views, alongside the challenge of translating complex feelings into words that have meaning. For example, it seems in this quote that Jean assumes a level of knowledge about her spirituality and the impact of being born a Catholic.

> Jean: I know myself I like to help people. It's a very rewarding feeling that I get when ... inside me, there's a deeper joy inside me that wanted to do more so that's what I get when I help others. I suppose I'm referring back to the spirituality because it's something in me because I was born a Catholic so it's always there. It's something that pushes me to do more so that's how I feel when I help people.

Unable to answer and glossing over

Focus group participants were often unable to answer questions, particularly about their potential support needs in the future and the role that they may have in ensuring care is available for those who need it now and in the future.

One of the participants in the CM focus group talked about wanting to feel safe in the future, but when we explored what this meant to people; it took some time for ideas to come forward. There are different ideas about what safety means for people, and it was as if people were considering much of this for the first time.

> FCM: Someone doesn't come to harm.
>
> FCM: Someone doesn't take advantage of them, you have to protect people from outside influences, from themselves.
>
> MCM: In a way you try to keep people happy. Safeguarding is a slightly different issue, isn't it? You're not just necessarily going to make them happy just by making sure they don't fall over something. You're trying to give them a feeling of wellbeing.

The CS group seemed to really struggle with having ideas or words to explore their role in ensuring care is available.

> FCS I have only young members. When I say young, you know, 50s in my family but I don't anticipate anything going wrong, and if so there's enough of us to look after each other.
>
> FCS: Oh, that's nice In my case it wouldn't be because my daughter's got a permanent back condition and she can't lift much, so would have to have some sort of care. But I'm afraid it would have to be somebody who's good, otherwise. [Interviewer:] How do we make sure that happens?
>
> Female Voice: The problem is I don't think you can, not if you're relying on the national health I mean, I can't even get through to my GP so ...

There were a number of times throughout the interviews that participants seemed to gloss over subjects, not go into detail, seemingly being polite, or conscious that this was a recorded conversation. There seemed to be a subtlety in what was said, or not said. For example, amongst those providing care there were times when comments such as (emphasis added), “they're very well-cared for, I must say. Anything I see, most of the time, is positive…*Most of the time*” (Presence). Charlotte, a recipient of care, commented, “they're quite kind *most* of them, and obliging, so I've no complaints.” The following are slightly different examples of where recipients of care make a positive statement, then follow up on things that they are missing, ‘I can't complain, but'.

> Theresa: It works all right here now. I can't complain. But it doesn't fulfil my religious things, is what I'd like, for me, yes. I'm very sorry to say that.
>
> Pamela: I really, I couldn't complain. I couldn't complain…if you ring the bell they come. They're there, you know, they take me to Mass and they're there to do it and you have to have a carer wherever you go so that's why we don't get out much, you know. I used to love walking. I know I'm a bit lame but it used to ... and I walked all round the area right up to the moment I came here…

When talking about her move into a residential home, Claire said, "I thought it would be the best for all concerned, especially the community, you know", but said little about if this had been the best thing for her. There are a number of times throughout interviews with recipients of care, particularly about their journey into care, where there is notable silence in the autonomy of choice and decision-making.

Things that are not talked about

There were times when reviewing the focus group transcripts that there are 'silences' on particular topics, or the things that aren't talked about. There were two clear examples. One relates to gender and caring, and the other is the expectation of family to care and look after individuals in the future. All groups made references to the changing nature of the family and how geographical mobility had split family units that previously would have cared for each other. They also talked about their observations of how different cultures or religions seemed better at caring for elderly relatives. However, only the group in CM, started to think about women are often in the role of carer and how women's involvement in the workplace varied across time and in different cultures and countries.

> MCM: That's in many ways due to working, I'm not denigrating working wives, but in the old days wives didn't work and they were available to look after the elderly, and now most of them are working and they're not available full-time. FCM: Well, I won't comment on that about whether wives should or should not be working.
>
> MCM: Oh, no, I'm not putting that…I'm just saying that's a fact of life, isn't it?
>
> FCM: The fact is when people expect to have a decent standard of living and they look after their families, they've got to pay the bills, it's not often nowadays that you can manage on one person's income.

Equally, it was noticeable that those who expected families to care for them in the future gave no indication that they were providing care for other family members or had any intention to. However, those who had cared for family members did not want to be a burden to their children. The experience of caring is one that brings into close focus the reality of what deteriorating health in older age can bring, and the experience of caring for someone in this position.

Exploring Care

The findings of this research are discussed below. In this section the different understandings of ‘care’ are explored, important aspects of receiving care are considered, thinking about care in the future, the narratives of those providing care and support, and the different types of care and what are the things particular to Catholic care that add to the foundations of basic care and distinctive relational care.

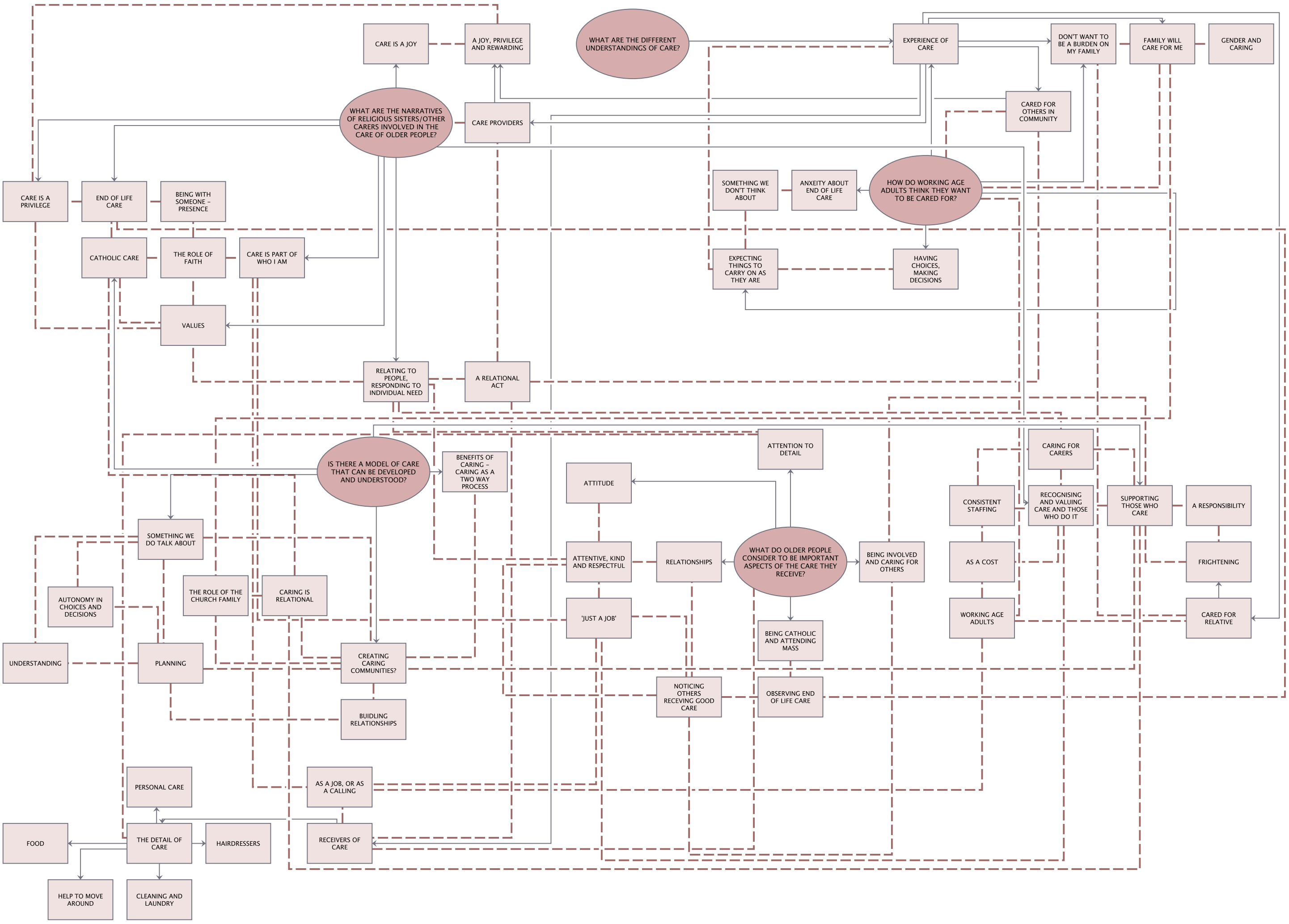

Diagram 3: Exploring care themes

The different understandings of ‘care’

There were dissonances between the different groups and their understanding of care. This, in part, is understandable, as each person’s direct interaction and involvement in care giving and receiving varied. However, these tensions seemingly result from different interactions and involvement with different facets of care (Rummery and Fine, 2012).

Cost of care

When asked what they understood care to be, all three groups of working age adults responded with long discussions about the cost of care. This broadly fell into discussions around the spiralling costs that they had heard others experience, and their thoughts on the value and quality of care in comparison to its cost. Additionally, there were comments relating to documentaries that had paid witness to carers behaving badly to those they were paid to support. This view reflected an understanding of care (Rummery and Fine, 2012) as the work, its related physical activity and carers’ competency. The issue of cost was one groups returned to throughout the discussions. At times some of the ideas shared seemed to lack all the factual details about why care was expensive, or the limited funds that local authorities used to pay for care and the impact this had more broadly.

It is not surprising that those who are not directly involved in caring for others or supporting relatives who need care, moved straight to the issue of the cost of care, when this is frequently how we hear care discussed in the press and by politicians. The comment Philpot (2002, p.5) made seventeen years ago, feels very current, where he notes that the ”biggest source of friction between the independent sector, government and local authorities has been the level of the fees which local authorities pay, which, the independent sector claims, fall seriously short of the money needed to provide high standards of care for each resident as well as allowing private homes to be profitable”.

Since Philpot wrote this summary in 2002, the situation has not just remained unchanged, it is arguably worse. For example, care home providers are reportedly increasing the prices for those residents that self-fund, with fees in 2015/16 for self-funders 41% higher on average than for local authority-funded beds in the same care homes – equivalent to an extra £235 per week (Competition and Markets Authority, 2016). The 2019 ADASS Survey (2019, p.35) firmly sets out the impact of the on-going funding crisis, bringing attention to the “very real and damaging effect on the day to day lives of people who need and provide care”. The realities of these financial challenges were heard in the interviews with those providing care, particularly where Sr. Nancy recounted how individuals’ care packages were being put out for care homes to bid for; she questioned where in this a person’s wishes and feelings were considered, particularly their spiritual care. Sr. Nancy commented, “It’s very different from when our founders started, and everything has changed and there have been so many changes over the years, and it is very difficult to accept them and look at what's happened…there's not an awful lot you can do about it if you want to continue in the care field".

As a responsibility, frequently frightening

Focus group participants, who had been involved in the care of a parent suffering ill-health in later years, saw care as a responsibility which was frequently frightening. This understanding of care was also evident in their thoughts of how they might want to be cared for in the future: they did not want their children to go through a similar experience. Echoing the findings of Rummery and Fine (2012, p.323), who comment that where care is "understood as a feeling or emotion involving a disposition towards others" it can often be a form of "stressful and emotional labour". One of the participants who had cared for a parent had also been a nurse. She noted the difference between the experience of caring for someone outside her family and caring for her parent; she had expected herself to manage the latter as she had so much caring experience - but found it very hard.

A relational act

It is essential to recognise that caring is not just something that is done to another, but rather that the care giver, alongside the care recipient, can feel as if they are losing their autonomy as they accept responsibility and associated sacrifices in their life (Rummery and Fine, 2012). Whereas, for those participants whose pastoral or paid role was to provide care, care was a relational act, it was a joy and privilege. One of the participants said that caring was 'part of who she was'. Also amongst the focus group participants were those who volunteered and cared for others (varying ages) in the community, who commented on the powerful experience of caring for others and wished that more people could have this direct experience. Caring for others (not relatives) was considered as something enjoyable and rewarding.

Those receiving care talked about both care as the physical work that they observed, and how they experienced care as a "social relationship" (Rummery and Fine, 2012, p.324). The majority of those receiving care, when asked about the care they received, first responded by talking about the food, the personal care, help to move around, and access to services such as the hairdresser or chiropodist. However, they also talked about the relationships they had with carers, the way that particular carers talked to them, or they observed carers talking to others.

One of the most repeated observations expressed by all groups involved in the study was of some treating caring as 'just a job', comparing a person who just did the tasks required of them compared to those that went beyond their job description. This difference appeared to reflect the relational acts, demonstrated through listening, having conversations, taking time to think about the detail of an individual's particular needs. In the working age adults' groups, the term 'just a job' seemed to reflect their understanding of someone who didn’t care or provide care that would fit understandings of the importance of the relational aspects of ‘meeting people’ (McCluskey, 2005) and the attachments made. This distinction of care, as something which is done or something which individuals intuitively undertake, was also present in the narratives of those providing care, as one participant commented that they wished they could find more staff that “care, but with a little more warmth.”

Receiving care: Important aspects of care

Those receiving care talked in the main about the social relationship of care, particularly as they explained most important aspects of the care they received.

The detail

For those receiving care, they noticed when carers paid attention to the detail, and when they didn’t. This detail would range from knowing that someone would struggle to unfold a towel, to the way they were anxious about being handled when being washed, or the way that a cleaner paid close attention to dusting a resident’s personal effects. Whilst often on the surface this can seem like small practical actions, the relational aspect of the interaction matters: getting to know someone, understanding what is important to them, and paying attention to this when you meet them. Elizabeth talked about her experience of how a carer paid attention when helping her wash, and this should also be read in comparisons to when she was less happy about the way personal care had been provided. She thought this carer was “very good” because he “took the trouble to wait and ask someone to check” something that was causing her discomfort. This was a person she went on to trust and she preferred it when he helped her wash. This trust was also developed from the dignity and respect that she felt some carers afforded her; she noted another carer who did not do this and how this made her feel.

Caring for others, being involved

In social care more broadly, the relationships that care givers and care receivers make are the “primary means of intervention” (Ruch, 2005, p.113), rather than the transactional approach that has developed over the years (Unwin, 2018). As noted earlier, caring is not a one way street, where something is being done to another, and this was voiced by a member of the focus group who wished more people could volunteer to support individuals who were homeless, because ‘the relationship is a win-win, people get what they didn’t know they were going to get…it’s very rewarding”, reflecting Unwin’s (2018) comment that there is a human need for kindness. This human need for kindness and relationships was evident as those receiving care talked about how caring for others and being involved in the life of the home was important to them. For some this was a continuation of a previous life of service to others, particularly for the religious sister receiving care. If caring for others has been something which has brought you ‘joy’ and is ‘hugely rewarding’, comments voiced by those who provide care, then it is not surprising that caring for others and being involved in the life of a home is an essential aspect of individual’s lives.

Faith

For many people living in care, faith remained of vital importance. Some of the religious sisters and priests had been active in their communities until the day they entered the residential home. Many were grateful for being able to attend Mass every day. For some of the resident priests this meant that their ministry as a priest was ‘satisfied’. However, for some it was evident that they wanted more, such as further opportunity to pray with others or for there to be more religious iconography. It is worth noting that there are potential silences here, in how the interviewer captured the detail of a faith experience and participants being careful how they talked about what they felt was lacking.

End of life care

As clearly iterated in the findings, those receiving care observed the care that others received. Their witness to this care told them much about how they could expect to be treated if they needed further help and support. This was particularly evident in the way that some observed others receive end of life care. One of the religious sisters (Mary) who was a resident in the home, but had also involved herself in caring for others, talked about being with other residents in the final days and hours of their life. During this time, she witnessed the medical and pastoral care, and commented how this made her worry less about when “it came to my time”, as she knew she would be looked after. Georgina made similar comments that, having observed excellent care at the end of people’s lives, she knew how she would be treated, noting the level of devotion she witnessed. It is important to note here that Georgina would not identify herself as someone of Catholic or any other faith, but she was deeply moved by the pastoral care that she observed when others were dying.

Care in the future

As noted earlier the cost of care was a central narrative to the working age adults’ focus groups, but so were the silences on whether and how they had planned for any care they may need in the future. Participants found it difficult to respond to the question of what they hoped care would look like if they needed support in later life.

Not to be a burden

The majority of those that had thought about any care they may need in the future, had been involved in providing care to their relatives. They were clear that they didn’t want their children to care for them, reflecting on their experiences of the responsibility and frightening aspects of providing care. This echoes the finding of Preston et al., (2018, p.8) that an enabler to planning future care was “wanting to avoid a perceived risk”, whereas a barrier to planning was found in low personal exposure to the issue or risk. One focus group was in a more affluent area, and whilst they talked about the cost of care, they also talked about buying the care they needed to remain in their own homes.

My family will care

Some of the participants saw life continuing as it was, and expected any future care to enable this, whether living in their homes or retaining their independence. For some who had not had the experience of caring for relatives, they thought that their family would care for them. There was an expectation that their family would step up and intervene when needed. Across the groups there was an expectation of choice and autonomy in decision making about care, that homes would be adapted, and care arranged to support their lifestyle. However, when reading the narratives of the journeys that individuals had into care, for many their arrival in residential care arose out of a health crisis, such as a fall or a stroke, something that they had not planned for. There was an interchange in one of the groups that highlights this -

> FCM: think we'd all like to go in our sleep, wouldn't we?
>
> MCM: I think I'd certainly want a quiet exit. The last thing I would want to be is hanging on for years in a residential home.

However, a participant of a different focus group commented, "I think we're assuming that we're going to be in a position to make those choices. If we suddenly get a stroke or a heart attack, then we don't have that freedom to simply look at all the choices and make a decision…very often…it's going to be circumstances that's going to force their hand". It is of course very difficult and unsettling to think about the potential of a life-changing event and consider planning for it.

The role of women

All of the groups talked about the how other communities and cultures were better at supporting older relatives, or that needing to find paid care for relatives was a relatively modern concept. However, there was seemingly a silence about the role of women in caring. Whilst, as noted earlier, spouses tend to care equally for each other, it is primarily women who take on the caring roles of relatives, (Arber and Ginn, 1990; Carers UK, 2018). Much is written about the double or triple burden facing women as carers for their own children, their parents, whilst having an active role in the labour market. This expectation of others to care, because of their personal concern for the well-being of another, is often experienced as a stressful emotional labour, an experience voiced by participants who had cared for relatives. Where individuals lacked exposure to what caring for others looked like, it left many expecting family to accept what can often be a stressful and difficult experience.

The church family

When participants were asked to explore what role they thought they had, in ensuring care is available for those who need it now (and in the future), they struggled to answer. One group started to develop some ideas and saw their role as a 'church family' going beyond the walls of the church and creating some kind of helpline and associated support. In another group, a participant commented that they felt ‘paralyzed’; they wanted to do something but did not know where to start. There were some stories of individuals and the things they did in their local community, such as holding coffee mornings, inviting neighbours for dinner, and taking people shopping. For many, there was a desire to do something, but lack of clarity on what and therefore how to proceed.

Care providers: narratives of religious sisters and other carers

In contrast with the experiences of those in the focus group who had cared for relatives, those who cared for others either in a pastoral or paid capacity commented that caring was a ‘joy’ and ‘privilege’. They talked about how they personally benefited from the act of caring for others – whether it was the kind words they received, observing people’s wellbeing improving, or knowing that individuals had found some calm.

Relational care

When describing what they thought was good care, those providing care only talked about the relational aspects of care. This was where they aimed to relate to the individual and respond to their need. Presence talked about knowing a person and thinking about how they were feeling; she talked about dimming lights, or putting the television on, only “if they’ve been television people”. Engaging fully in relational care is something that takes time, and as Sr. Sally commented this is often very difficult: we all tend to “hurry, hurry, hurry” and “if we’re not careful we all do it”. For Joy, creating a place of tranquillity and calm enabled this relational care. Creating an environment where there is time to get to know someone, understanding their likes, dislikes, wishes and feelings, and their life and experiences before entering a care home, may enable carers to better ‘meet people’ (McCluskey, 2005). This is of course a challenge when resources are limited. It also speaks to a question of how Catholics understand their roles in building places of welcome both as members of parish communities and as agents of hope in their own neighbourhoods.

Rarely are professional caregivers trained to understand the mechanics and dynamics of interactions, with the focus often on the skills of “listening, observing, clarifying, negotiating, empathy and goal setting”, which fails to address the complex dynamics of careseeking and caregiving (McCluskey, 2005). However, by developing an understanding of interactions between caregivers and careseekers, caregivers can make sense of the emotions and feelings of those they support, and “achieve a compassionate and intelligent response” (McCluskey, 2005, p.2). If the goal of careseeking is ‘effective caregiving’ – and when this is unsuccessful those who seek help withdraw, become frustrated and upset - then attending to the ability of professional caregivers to understand these dynamics and be able to respond is essential.

Values of faith and presence at the end of life

It was evident how faith, and the values of their faith, underpinned the care provided by the sisters, not only in the values, but also in their prayer and presence with others. As Sr. Presence commented, “we’ve God’s grace working in us and through us…I believe God is working through me”. The descriptions of being present at the end of life were powerful, particularly alongside the observations and experiences of those receiving care. As noted earlier, anxieties about how one would be cared for at the end of life were diminished having seen how others are cared for. A number of the sisters involved in this study provide pastoral care, enabling them to have the time and flexibility to stay with people for as long as needed. This is clearly a unique resource, but arguably an essential aspect of care, to offer a presence to those that are dying and support to their families. The sisters had much experience of being with people at the end of their lives, and this was something that they seemed to do intuitively, being able to respond according to the needs of the resident and their families. There is recognition that spirituality at the end of life may look and feel different for those of faith or otherwise, but however it is measured, those who witness this care notice the sense of calm and comfort.

Caring for carers

Amongst the sisters and manager of one of the homes, there was extensive commentary about how hard paid carers worked and how difficult their work was, but how they were undervalued by wider society, with their roles receiving limited recognition. Many wished that carers could be paid more, and the challenges of finding good staff that stayed with organisations was frequently mentioned. Joy was clear how important it was to care for the carers, so that they would be in a better position to support residents and continue working for the organisation. Consistency of staff was seen to be essential, particularly to enable relational care. Joy likened this to a family structure, with longstanding staff knowing the residents, confident in their roles and comfortable in accessing the management team when they needed to.

Joy talked at length about the investment the organisation and the carers made in their own development, recognising how this had a positive impact on staff wellbeing and value of self. However, training is another cost competing with multiple demands on resources. A number of the participants, along with Joy, talked about the importance of caring for the carers. They wanted wider understanding that paid carers, who are primarily women, are often already caring for others in their lives outside of work and have other challenges that make life difficult at times. Listening, supporting and giving time to thinking about how carers come to work, what they leave behind, and what they bring with them is essential. It is vital for the caregiver to be attuned to the needs of recipients of care. McCluskey (2005, p.247) sets out nine unique forms of interaction that take place between careseekers and caregivers, resulting from the "verbal, non-verbal and emotive messages and their response to each other". Caring for others is undertaken through relationships, and as Unwin (2018, p.19) comments (here she is talking about policy, but the point is useful), "to assume a clean and tidy approach to decision making ignores the messiness of human emotions". The attuning and presence of those who are caring for others is essential. Caring for them at work and understanding that we all have difficulty in our lives at times is one way of helping with this.

Caring for staff also means caring for their leaders. Managing a care home is complex and difficult, as shown in this study and by Moriarty, Manthorpe and Harris (2018, p.18), in work on recruitment and retention in social care, where they comment that, "leadership is thought to influence organisational culture strongly". They agreed on the need to pay greater attention to improving the "quality of leadership at all levels". Sr. Lucy was clear about the value of good leaders, and talked about the care that was taken when appointing managers: "I think the appointment of staff is extremely important, particularly managers and senior carers…If you get a good manager you're away with it". It was clear that the religious community linked to this home were highly supportive and appreciative of the manager and her team. They talked extensively about how they witnessed her care and compassion of others, and how she met people.

Developing a model

From this study, there appear to be two areas of work that can be explored and developed. The first relates to the role of the church family in creating communities of care in its parishes and associated communities, and the second considers the particular aspects of care that are interconnected with Catholic faith and activities of Catholic organisations.

The role of the church family in creating communities of care

It was evident when hearing from the working age adults in the focus groups, that there was a want to help older people in the community. Some were already doing this under their own volition. However, in one of the groups there was much thought and debate about how they could develop a supportive network, providing a place for those in need to contact them. The group understood that it is sometimes difficult for people to ask for help, and there were challenges when trying to find those in need of support. This conversation went on for some time, with one member of the group commenting on how paralysed they felt and just not knowing where to start. There was, however, a desire to create a network of support that extended beyond the church walls.

After the planned release by CSAN, in December 2019, of new guidance for parishes on reaching out to older people, it will be helpful to explore further what if any extra support parishes need to self-organise, whether that be through providing facilitators to help develop ideas, training, suggested methods of working, connections with schemes that have worked well elsewhere, or bespoke support in response to individual parish development. CSAN should play a key role in raising awareness and readiness to share information between local churches and people co-ordinating activities (whether voluntary or paid). However, successful evaluation of what is working well will stem from understanding the nature of the problem and the value of investing time in learning, often with limited data. Arguably, as time passes, greater exposure and involvement through a network of support will develop understanding. Caring for others can be a joy and a privilege and something that can enhance lives. Additionally, as one the focus group participants commented, “The whole ethos is that you should exercise your lay ministry of care to each other, but that requires organisation and you've got to have sufficient support from the community, volunteers to look out for each other” (FCM). By creating a network of support now for the community, provides a network of support for the future selves of parishioners involved. This echoes and develops recommendations made by Philpot (2007) and Ryan et al (2009) on how parishes develop their networks with local provision.

Additionally, a supported network of parish churches would provide an important means to support informal caregivers, such as parishioners caring for parents and other close family or friends. This is a current concern for many; having a network of support that you know are present if you need it could help people feel less alone and provide practical, emotional and spiritual support.

‘Catholic care’

The number of Catholic care homes have diminished as a result of the dwindling numbers of vocations and the broader social care landscape, as has been recorded extensively in the previous studies of Ryan et al., Philpot (2007, 2002). Philpot (2007, p.11) noted that observers felt “Catholic homes offered a different ethos from other kinds of homes…Catholic homes offered a sacramental and spiritual life in a society that does not find it easy to accept spirituality generally, as well as seeing it as integral to good social care”. Philpot (2007) goes on to point out that there was no reason that the Catholic ethos could not continue as homes were run by lay staff, offering the example of Catholic schools having high reputations in part because they have an overt Catholic ethos.

Much of this change has already taken place, with many homes now in charitable trusts, some of which are overseen by orders, but staffing and management of the homes no longer involving many religious sisters. In a number of homes, sisters retain a presence, often in a pastoral capacity. This study has illustrated the impact of their presence, particularly in relation to end of life care, and to some extent providing pastoral support for staff. Whilst there is much written about end of life care, and different faiths will also have commitments to caring at end of life, this is unequivocally Catholic care embedded in the prayer and faith of the individuals providing it. There needs to be consideration about how this care will be provided in the long-term as the number of vocations dwindle and older people become an even more dominant proportion of the Catholic population in many places.

Additionally, many of those receiving care who participated in this study talked about their faith, and whether or not they felt their spiritual needs were being met. Being Catholic was an essential part of their identity; for quite a few involved in this study it had been their life as a priest or religious sister. One can see that their needs are more likely to be understood by someone else who is Catholic and can broadly understand and empathise with their faith experience.

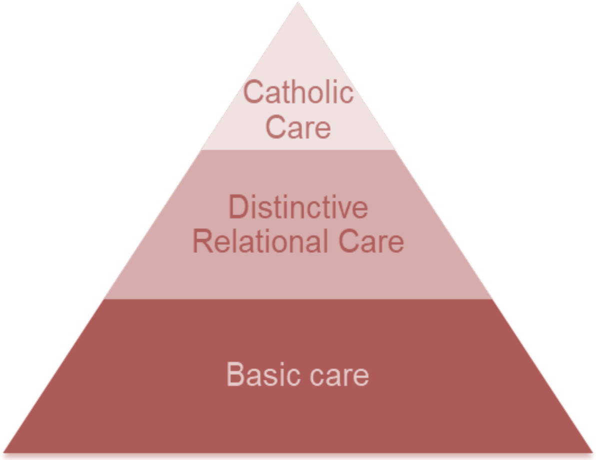

Diagram 4: Foundations of care

This diagram sets out the different types of care and where the things particular to Catholic care add to the foundations of basic care and distinctive relational care. At the foundations is everyone's need for basic care, such as personal care, help with mobility, health care and medication, that is the kind of needs that are often recorded on assessments and care packages are built around. Perhaps one could understand providing this level of care as "just doing a job", as it explains the tasks of care, the things that are done to another.

Building on basic care is distinctive care; it is the relational aspect of care, where care recipients are 'met' by caregivers. There is an understanding that care is delivered through relationships that are two-way in nature. This care requires consistency in caring relationships, carers that are supported and cared for themselves, so they can be attuned to the needs and experiences of care receivers.

'Catholic care' then intersects and is in addition to distinctive care, providing spiritual support to both Catholics and those who are not Catholic. The particular aspects of this care rest in the spiritual experiences of those of faith, and the presence offered through end of life care.

Concluding comments

This study has drawn attention to the different understandings that people have of care, the way care is experienced by older adults in residential care, the narratives of religious sisters providing care, and thoughts of working age adults about potential future care.

A number of messages emerge from this study:

- The distinctive Catholic care that is offered at end of life is at risk of being lost with diminishing numbers of priests and religious in England and Wales, and their availability to be present with individuals in their last days and hours. Consideration and action are needed to ensure this powerful act of presence continues, and is encompassed in wider care standards.
- Supporting paid carers to provide relational care requires organisations to commit to providing an enabling environment and effective support. Catholic care providers should bring together their expertise and values to develop care practice that prioritises relational care. This will require a focus on how organisations care and value those they employ to care, and how this focus can be sustained among a shrinking group of small, independent Catholic care providers, by co-operation or more radical partnering.
- Caring for others can be rewarding and joyful. It is also a huge responsibility and a stressful emotional labour. Given the steep increase in ageing in the Catholic population of England and Wales, many parishioners and priests will be involved in caring for others, and there needs to be action taken both at a national and local level to value and support them in this role
- In conjunction with Catholic charities involved in care (where these exist), parishes need to find the support and confidence to self-organise and extend Catholic care to older adults in the community and their carers - additionally creating and providing reliable networks of pastoral care for those receiving residential and nursing care. The Church is well placed to provide this, but it is a significant undertaking requiring long-term resourced networks of support.
- Receiving care, providing care, and planning for future care, will affect all members of the Catholic community at different points in their lives, and in fulfilling their distinct vocational responsibilities. Additionally, Catholics have made a lot of investment in care, as individual donors of land and buildings, and by enabling Catholic charities to build expertise as care providers. Therefore, it is essential that the Catholic Church hears the experiences of care and brings its voice to the wider policy debate to champion care.

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