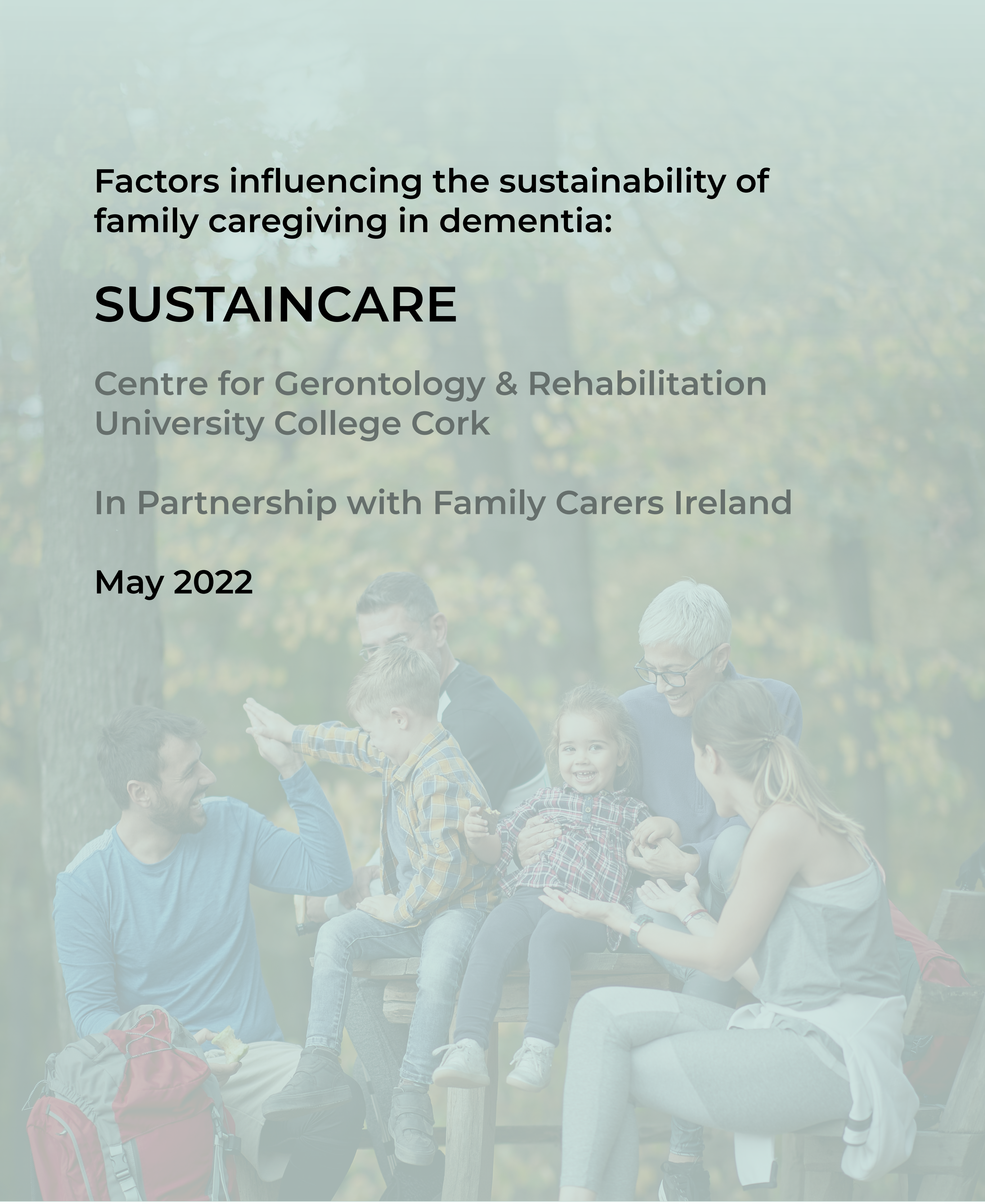

Factors influencing the sustainability of family caregiving in dementia:

SUSTAINCARE

Centre for Gerontology & Rehabilitation
University College Cork

In Partnership with Family Carers Ireland

May 2022

IRISH RESEARCH COUNCIL
An Chomhairle um Thaighde in Éirinn

Family
Carers
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No one should have to care alone

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An tIonad Seaneolaíochta
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CONTENTS

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Family Carers Ireland

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Visit: https://www.familycarers.ie/about-us

National Freephone Careline: 1800 24 07 24

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Research Participants

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EXECUTIVE SUMMARY

Background

Currently, there are approximately 64,000 people living with dementia in Ireland (Health Service Executive, 2020). By 2046, we estimate that there will be 150,000 people living with dementia in this country (Pierse et al., 2019). This rising prevalence has several implications for society and for health and social care provision.

Those who will be most affected by this upward trend include the family carers of people living with dementia. There are many positive aspects to the experience of family caring. However, caring for a relative with dementia can also be extremely challenging, particularly as the condition progresses (Pinquart and Sörensen, 2005; Goren et al., 2016).

While there has been much research on family carers of people with dementia, the focus is typically on the primary carer(s) and/or the care dyad. This research seeks to take a more holistic view of family caring, by acknowledging and exploring the role of family dynamics, as well as the influence of local communities, health and social care provision, and the wider socio-political landscape. The aim of this study is to better understand the factors influencing the sustainability of family caring for community-dwelling people with dementia.

Methods

Design, Sampling & Recruitment

This qualitative study had two phases. Phase one involved optional ‘Family Story’ work. Phase two involved in-depth semi-structured interviews and/or family focus groups. Twenty participants supporting a person with dementia from across 10 family units were included. All participants in this study were ≥18 years of age and aware of the dementia diagnosis.

The sampling method was purposive. It was important to us to represent as much variation in family characteristics and circumstance as possible, e.g., those living rurally versus in urban areas, those supporting people with younger- and older-onset dementia, and different family sizes and structures (e.g., nuclear, and blended/complex families), etc. Study advertisements were mailed to a sample of GP clinics country-wide, and were circulated through the Family Carers Ireland network, as well as through social media (Twitter). Potential study participants contacted the researcher directly for further information about the study. Prospective participants were asked to discuss the study with family members, to encourage wider participation.

Data Collection & Analysis

This data was collected from May-October 2021. In phase one, each family was asked to complete an optional ‘family story’ booklet, briefly detailing family history, and their experience of the dementia diagnosis and caring since then. Four families completed a booklet, and the other six families reviewed the questions in the booklet but didn’t complete it.

Phase two involved families doing individual and/or family group interviews with a researcher, either by phone or Zoom. Each family decided for themselves whether they would like to be interviewed together, or separately. In the case of family focus groups, the researcher acted as the facilitator.

The duration of interviews ranged from 42-84 minutes. All were audio-recorded using a password-protected recording device. The data were transcribed verbatim, but all identifiable information was redacted. The audio recording was permanently deleted. NVivo software was used to manage the data.

Braun and Clarke's (2006) approach to thematic analysis was used to analyse the data.

Ethical Approval

Ethical approval was obtained for this research from the local research ethics committee.

Findings

Twenty family carers supporting a person with dementia, across 10 different families, were included in this study. Firstly, a brief outline of the main factors influencing sustainability is provided. Secondly, four conceptual themes are described, representing the experiences and perspectives of families supporting someone with dementia, as they relate to the above factors.

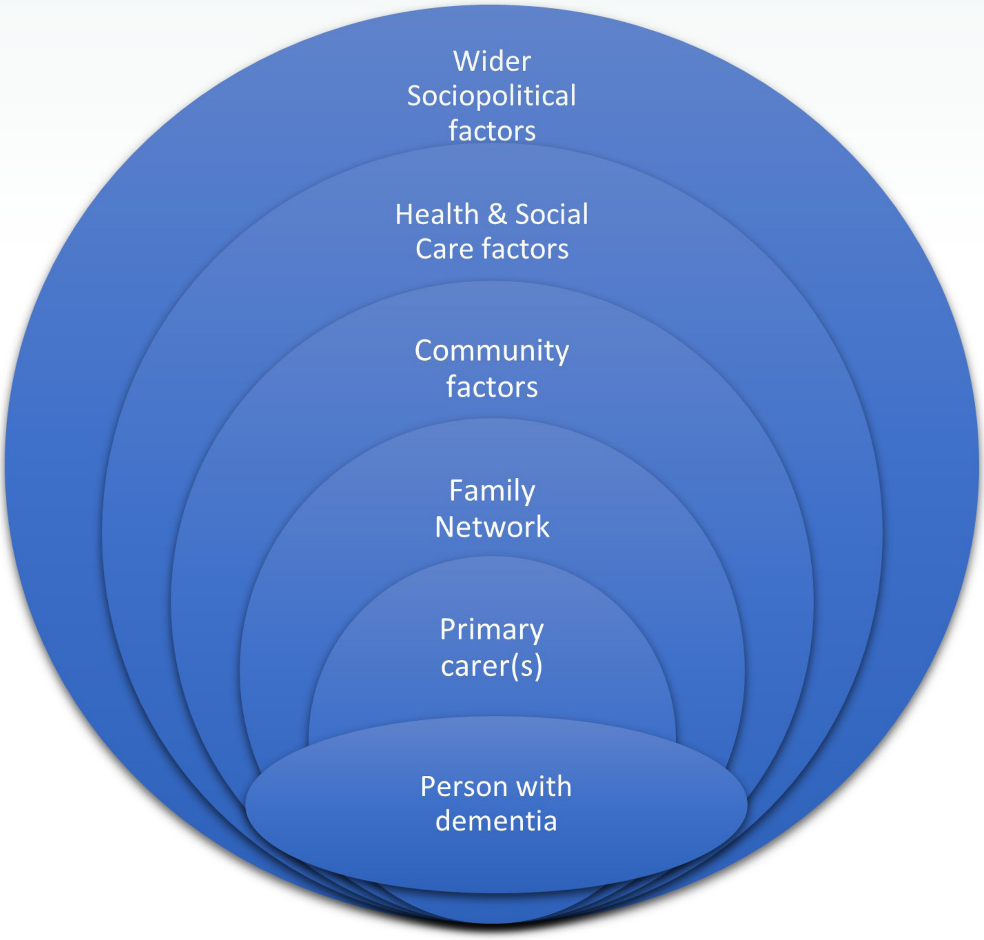
Factor Influencing Sustainability

Six factors were found to influence the sustainability of family caregiving in the case of supporting a relative with dementia in the community (see Figure 1):

The Person with Dementia; The Primary Carer(s); Family Network and Dynamics; Local Community; Formal Health and Social Care Services; and Wider Socio-political factors.

These six factors differentially affect the family system's ability to achieve stability, in the endeavor to support a loved one with dementia.

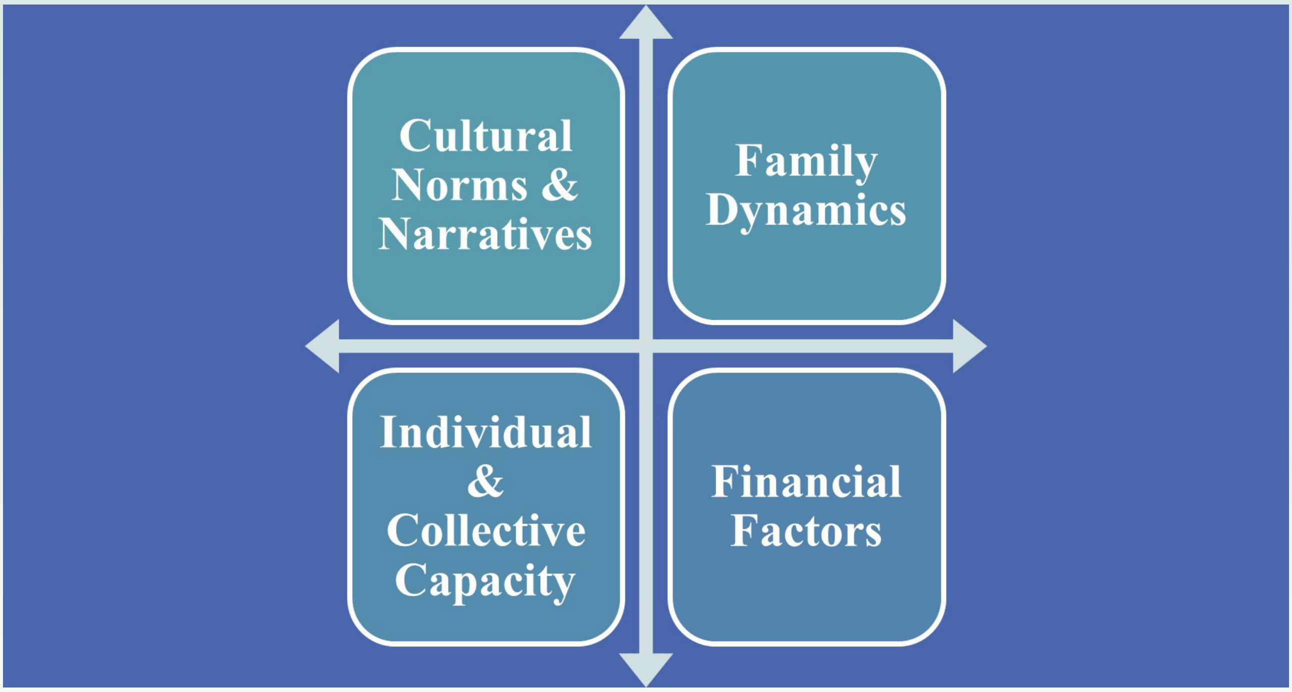
Figure 1: Factors Influencing the Sustainability of Family Caregiving in Dementia



Conceptual Themes

Four important conceptual themes crosscut the six factors depicted in figure 1, to influence the sustainability of family caregiving in the context of dementia. The conceptual themes are outlined in Figure 2 below and a summary of each theme, including participant quotes, is subsequently provided.

Figure 2: Cross-cutting themes influencing sustainability



Cultural Norms & Narratives

Each interviewee spoke to differing degrees about how cultural norms and narratives about dementia and family caring have influenced their experience and the perceived feasibility of providing ongoing dementia care to a relative, at home. Three sub-themes were generated reflecting perspectives on the influence of cultural norms and narratives. These relate to 1) the meaning of dementia; 2) duty of care; and 3) the role of gender. More in-depth analysis and supporting illustrative quotes for each of the sub-themes are outlined in the main report.

The Meaning of Dementia

Several participants noted that the main narratives in the media and the clinical arena, surrounding what dementia is, and what it means for families, are anchored on notions of progressive loss, decline and deficit. This creates cultural fear and stigma around dementia, both for people diagnosed with dementia, and their family members.

"All I had to go off is what I'd seen on TV or read... And those depictions are so, so bleak."
[Family A, participant 4; Granddaughter]

"I didn't know much about dementia, but I knew that dementia is one of the scariest diagnoses a person could get, that it robs you of the person each day."
[Family I, Participant 18; Daughter]

Duty of Care

Other prominent cultural narratives relate to care responsibilities, and to whom the duty of care should fall, i.e., the family versus the State.

"There's no roadmap or book of instructions, it's just your lot. There's this undertone that, if you care about the person then you should care for them, not hand them over to the state." [Family B, Participant 6; Son]

"I felt that by ringing [a helpline] they might talk me through the process of moving to a nursing home...I thought they would give me support, tools, anything that might help me see what way this might go. But the response I got was not that... You could tell the attitude was, 'you shouldn't be thinking of putting her in a nursing home, you should support her as best as possible at home'."
[Family C, Participant 7; Daughter]

The Role of Gender

Some interviewees, both male and female, further defined the notion of cultural familialism, indicating that family-led dementia care is somewhat of a euphemism for what is largely female-led care.

"I feel like I have very little choice in my situation. As his wife, you know, I'm supposed to be there for him..."
[Family F, Participant 12; Wife]

Daughter 1: *"We all want the best outcome possible. It's just that the boys [adult brothers] don't quite understand all that we do and deal with."*
Daughter 2: *"That's true. It's easier for them to hold onto the idea that we can keep him at home forever more."*
[Family A, Participants 2 & 3; Daughters]

"If the roles were reversed, and I were sick, she would be able to do it all. She wouldn't need to draw on all these other people like I have to."
[Family D, Participant 8; Husband]

Family Dynamics

All participants agreed that when supporting a person with dementia, relationships amongst family members, including the person with dementia, the primary carer(s) and the wider family network, have a substantial effect on family capacity to function as an aligned unit. Three sub-themes were generated reflecting perspectives on the influence of family dynamics on care sustainability. These relate to 1) changing roles; 2) becoming the primary carer; and 3) patterns of communication.

Changing Roles

Participants indicated that when caring for a family member with dementia, family members' roles and responsibilities tend to shift. Several interviewees, especially spousal carers, emphasized how the changes in the person with dementia over time made them appreciate the person's premorbid contribution to family life in a new light, as their responsibilities were reassigned to other family members.

"Before she got this [illness], she did everything around here... Our house was always pristine, like a showhouse. She made it look easy. I had no idea how much work it takes to keep a house like ours."
[Family D, Participant 8; Husband]

One commonly described effect of this, is that the person with dementia can experience a felt loss of autonomy and control, which can lead to instability and conflict within the family unit.

"Anything that was pointed out to her, when other people would remind her of things, or point out omissions, she was seeing that as things not being OK, and she'd get very defensive. She was feeling that loss of independence."

[Family E, Participant 10; Daughter]

"After she was diagnosed, my relationship with my mother got very bad. In me trying to help her, she accused me of trying to control her, and bullying her. It was a very bad situation and I had to walk away completely for about six weeks as it was too upsetting for her, and for me."

[Family C, Participant 7, Daughter]

Other participants noted that a particularly upsetting role change relates to the loss of normative intergenerational experiences between grandparents with dementia and their grandchildren.

"My son, he's just 10 and I've stopped bringing him out to [her parent's house] because he gets upset. I try to explain to him why granny is pacing around and won't talk to him or make eye contact. It's hard for him because for a while, he was the only person she would respond to, and now that's gone too"

[Family E, Participant 10; Daughter]

Becoming the Primary Carer

A significant role change, discussed by all interviewees, focused on becoming the 'primary' carer within the family. Some interviewees indicated that stepping into the primary carer role felt all-consuming, and sometimes eclipsed the familial relationship.

"Soon after that [diagnosis], rather than being her daughter, I became her carer…"

[Family C, Participant 7; Daughter]

For some carers, especially spouses, the pathway to becoming the primary carer was reasonably clear; they were expected to be the primary carer where possible, and most did so willingly, and as a matter of duty and/or love.

"I feel like I have very little choice in my situation. As his wife, you know, I'm supposed to be there for him…"

[Family F, Participant 12; Wife]

However, for non-spousal carers, the pathway to becoming the primary carer was less straightforward. Several adult children of people with dementia acting as primary carers noted that they entered the role by 'default', or because of their 'circumstances'. This typically meant that they had fewer reasons than other family members, not to assume the primary carer role, e.g., the person with the fewest child-rearing, work, and other responsibilities, lives geographically closer or can relocate more easily, etc.

"It wasn't exactly part of my plan, but I didn't feel I had much choice because I'm the only one who could uproot her life to come live with dad. It's not easy, but someone has to do it, and I was the only real candidate."

[Family G, Participant 14]

Patterns of Communication

Participants in this study described numerous patterns of family interactions regarding the care of the person with dementia; some are constructive and reinforce the capacity of the family, while others are destructive and serve as barriers to sustainable family care. These two patterns are not mutually exclusive but are embodied to varying degrees depending on context and circumstance, in ways that are unique to each family's dynamics.

Constructive Patterns

An important element of constructive interactions is that they come from a place of empathy for the experiences of other family members, including the person with dementia.

"We all knew that these peaks and troughs pass, so on the days she was very difficult, I knew I had to let it go, because you know every teenager fights with their mother, but I always knew that it was the illness. And after a while, it became water off a duck's back".

[Family E, Participant 11, Daughter]

Brother: *"I know you have taken so much of that role of keeping structure for her and keeping her safe. I know it's not easy. When I see everything that you have taken on, I admire it and you know we are all grateful"*

Sister: *"Yeah, and I know you work long and hard and can't be at every appointment or consultation. I don't mind relaying to you because then yourself and [sister-in-law] use the information to help me."*

[Family B, Participants 6, 5 respectively]

Destructive Patterns

Destructive patterns of interaction which impeded sustainability were also identified, including (i) disengagement and (ii) enmeshment dynamics.

Family members contribute variously to care discussions and activities; however, many interviewees noted how some siblings disengage when it comes to the issue.

"My brother in [foreign country] has no idea what's going on really. He's been there a long time. He's basically out of the equation, so you can forget about him."

[Family H, Participant 16, Daughter]

Some interviewees make peace with sibling disengagement, acknowledging that it is their own choice to make; however, several clarified that a fair trade-off for this, was that those who are least engaged, have less decision-making power.

"We are here doing the work, dealing with the good, the bad, and the ugly. I think we have an understanding that because the two of us are here with her, we have more of a say in how things are handled."

[Family B, Participant 6; Son]

Many participants also described scenarios indicating enmeshment dynamics, i.e., where family members become over-involved in each other's relationships, behaviours, and emotional processes, in ways that can be emotionally harmful for all parties. These can include alliances amongst subgroups in families; repressing one's true self to conform to family norms; absorbing others' negative emotions and moods; and/or wielding shame on family members to make them conform.

"You know sometimes it isn't about them [the person with dementia] at all. One of the things that goes on with us anyway is just you know, because of looking after her, we are living on top of each other more than ever, and I've found that knowing too much about each other's business can lead to drama."

[Family I, Participant 19; Daughter]

"I'd get onto my family and I'd be asking them, 'can you please call her?'...and when no one called, I would get very annoyed."

[Family C, Participant 7; Daughter]

A sentiment echoed by several interviewees is that remedying destructive patterns of family interaction involves establishing and maintaining emotional boundaries with other family members:

"One thing I've learned is that you can't control other people, and you can't let other people control you or your emotions."

[Family A, Participant 2; Daughter]

Individual & Collective Capacity

Capacity refers to the internal resources and capabilities of the primary carer(s), and the capacity of the networks and systems available to support them to continue providing family-led care. This theme is comprised of three sub-themes: 1) Internal Resources of the Primary Carer; 2) Support from Family, Friends and the Local Community, and 3) Health and Social Care.

Internal Resources of the Primary Carer

The internal psychosocial resources of the primary carer are particularly important to sustainability. As mentioned previously, some interviewees divulged doubts about their capacity to provide appropriate, person-centred dementia care, owing to lack of knowledge/training, and the added pressures that emotional ties can bring, in the context of family caring:

"I do my very best, but we are not equipped. Some days I think, 'am I making this worse for her, or both of us'. Or days when I'm grouchy and tired, I might say something snappy, and then the guilt sets in. If I saw a professional acting as we sometimes do, I'd think, 'this is bad care'"

[Family B, Participant 5; Daughter]

Behavioural and non-cognitive symptoms, including agitation, aggression, sleep disturbance, paranoia and apathy were cited as key behaviours which can exacerbate carer strain.

Wife: *"He would be agitated a lot of the time. Like antsy... And he gets cross easily."*

Daughter 1: *"And he was never a cross man, but now he can get very bad... A bit aggressive at times. And he says mean, and sometimes inappropriate things."*

[Family A, Participants 1 and 2, respectively]

The physical and mental health of the primary carer is another significant factor influencing the sustainability of their role and several primary carers acknowledged their own health issues/concerns, e.g., including autoimmune conditions, depression, heart problems, cancer, chronic pain issues, etc.

"I have my own health issues...There are days that I'm in pain, completely exhausted, and I'm just not able to do it."

[Family F, Participant 12; Wife]

There are also qualities and traits which can serve to enhance capacity in primary carers, e.g., leadership ability, optimism, levity/humour, and adopting a solution-focused approach to daily living.

"We're very lucky that dad is so well equipped in himself, to see and make the changes that needed to be made, and to do things for himself, and for her. He put the structures in place...She was only so well for so long because of dad believing she could do things... That's his makeup and that outlook works well for him and us"

[Family E, Participant 10; Daughter]

Support from Family, Friends and the Local Community

In families where there were 'auxiliary carers', i.e., relatives who contribute to care in a way that regularly relieves the primary carer(s), the primary carers felt more optimistic about sustainability.

"From early 2019 it was evident to me and my sisters that dad needed to have someone at home every weekend...Someone had to be there to relieve dad. So, we stepped up."

[Family E, Participant 10; Daughter]

"We're lucky really that there are four of us to help out and we all do our bit and it kind of balances out, you know?"

[Family E, Participant 11; Daughter]

This kind of family cohesion was not necessarily the norm, and some primary carers felt they had very few people, if any, that they could share care responsibilities with.

"There's no-one else to help, that's what it comes down to... He has one sister, she lives in [USA]. His children don't help, so it's just me."

[Family F, Participant 12; Wife]

The absence of felt support from family members can contribute to loneliness in the primary carer, especially as the dementia advances, and it becomes less feasible for the dyad to leave the house. The isolation and loneliness were exacerbated for carers and people with dementia during the COVID-19 pandemic.

"It was very sad to see her go downhill. She didn't speak as much. I could tell she was miserable. But there was nothing open, nowhere to go, no one to meet. And it wasn't safe either to be meeting people. You'd feel a bit out on your own."

[Family B, Participant 5; Daughter]

Some interviewees noted that they also draw on support from friends and neighbours, both in an informal and paid capacity:

"I feel lucky. As well as my daughters, I have local people and neighbours helping me, and the private carer who comes in - she's local too."

[Family E, Participant 9; Husband]

Participants also indicated that services and establishments in the local community are not always dementia-aware, which is one of the reasons that carers tend to stop bringing the person with dementia with them when they leave home.

"Mum doesn't want to leave the house now... And if she does go and we're sitting somewhere for more than 5 minutes, she can throw a strop. She wants to leave, gets upset, says she's getting a taxi home... I do think there has to be more consideration for people with dementia."

[Family C, Participant 7; Daughter]

One husband described the difference it can make to outings, when businesses/services are dementia-friendly and understand that people with dementia may need additional support.

"We've always loved going away for a few nights. She loved going to a spa and getting pampered. One place was great because I told them about her issues, and they provided a staff member to help her around the ladies' changing room and make sure she could find and do everything."

[Family E, Participant 9; Husband]

Health and Social Care

Most interviewees highlighted the role of formal supports and services for dementia; and how they are mired by issues relating to under-provision, timely access, fragmentation, poor dementia care capacity, and low client acceptability.

The under-provision of formal dementia care services and supports was one of the strongest messages from family carers, many of whom made direct links between the absence of sufficient formal support, and care home admission:

"The lack of support from the HSE means we have to think about nursing home care"

[Family A, Participant 2; Daughter]

Indeed, many carers pointed out that even basic physical/personal care needs are sometimes not adequately met through current State provision of homecare.

"We needed home-help for mum and dad, but the local district nurse said that will take a while to set up and you won't get all the hours that you actually need. She was right on both counts." [Family A, Participant 3; Daughter]

Furthermore, half of families reported losing homecare hours since the COVID-19 pandemic began:

"Since COVID, were not even getting half of the home-help hours we should be getting. We had 16 or so hours before COVID and we don't even have 8 now."
[Family E, Participant 10; Daughter]

Another frustrating aspect for families is the fragmentation in the health system, which makes it difficult to identify and access services and supports in a timely manner. Many called for a single liaison to be made available, e.g., a dementia adviser, to help them navigate the health system.

"It would be handy if there was one person we could go to and say this is the person you deal with, and they get you the support or direct you to it."
[Family B, Participant 5; Daughter]

Other problems, which have long-preceded, but have been exacerbated by the COVID-19 pandemic, relate to poor continuity of care, especially in the public health system, e.g., vacant consultant positions, substantial periods without specialist medical review, dropped correspondence, etc.

"...We were completely without a consultant for over 18 months. And we had to find a private consultant to take her on in a clinic in Dublin."
[Family E, Participant 11; Daughter]

All interviewees pointed out that the single largest gap in need nationally, is for home-based social care, which can also provide respite for the family carer(s). The preference for additional community- and home-based respite options was clear amongst interviewees. Low acceptability of traditional residential respite for people with dementia (especially early onset), was a prominent barrier to using existing services.

"A lot of the other supports like day centres and all that, mam would have been too young to go there, she was 57/58 when she was diagnosed. That kind of environment, the idea of it, freaked her out."
[Family E, Participant 11; Daughter]

Furthermore, two families indicated that even in the hospital setting, dementia care capacity is sometimes poor. One daughter outlined how she felt the system had taken advantage of her during an acutely stressful time.

"When the eye thing happened last year, I had to stay in hospital 24/7. They kept saying there was no aide available to be with her. I think because I was there, they just thought, she's there, she will do it...They knew I wouldn't leave her."
[Family C, Participant 7; Daughter]

Finally, it is worth noting that COVID-19 has played a significant role in patterns of access to health and social care, since March 2020. Some families reported having not had input from a healthcare professional since before the pandemic began.

"She hasn't been seen by a specialist in over 2 years, since before COVID."
[Family H, Participant 16; Daughter]

Financial Factors

A key concern for interviewees was how little value the government appears to place on the care work undertaken by family carers of people with dementia. One important issue relates to failure to compensate carers appropriately and fairly for their time and work.

"Informal carers need to be properly recognized money-wise for what we do."
[Family B, Participant 5; Daughter]

"We don't get the Carer's Allowance because no one wanted to be the official carer on paper. So we pay for most things ourselves. We are not wealthy people, which is why none of us can afford to take on the official carer role."
[Family I, Participant 18]

Some of the costs that are absorbed by families include personal care materials and medications. A few interviewees pointed out that even though dementia is an economically burdensome condition for families, it doesn't qualify for the Long-term Illness scheme. Another significant cost shouldered by families relates to purchasing materials needed for care, e.g., continence wear (and its disposal):

"All you get is the bare minimum continence wear. So not only are you providing care with no support, you are also having to fork out for extra continence wear..."
[Family C, Participant 7; Daughter]

"The PHN came to do an evaluation and told us what we could buy in the store. But the packs are €10 or so, and on a bad day she could go through a whole packet. It's just another expensive thing we pay for."
[Family B, Participant 5; Daughter]

An additional factor, noted by a handful of interviewees, is how money can become a point of contention in families, especially if the person with dementia doesn't recognise their own need for formal care.

"We don't have that money to pay privately. And we never got her finances in order because she wasn't going to give us control over that... She's adamant she can control everything herself. She won't pay for care because she thinks she doesn't need it. She says there is nothing wrong with her and we should mind our own business."
[Family C, Participant 7; Daughter]

Some interviewees who were in a more financially secure position, and able to pay out-of-pocket for the materials and services needed to provide dementia care at home, acknowledged the strain this must put on families with lower incomes and/or those who are surviving just on the Carer's Allowance.

"We're lucky dad has a good job...You could see how people might have to make a choice between buying medication and buying groceries."
[Family E, Participant 10; Daughter]

One family that needs, but cannot afford, more in-home care agreed that nursing home admission is likely imminent, not because they want this, but because they are left with no other viable option.

"It would be fantastic if we could have a professional come help us out to take some pressure off me and [sister], but you know that's not really an option for us financially. We're not left with any options, only to go the nursing home route."

[Family G, Participant 14; Daughter]

Several interviewees insisted that Government should commit to redirecting funds that would otherwise be used for residential care, toward developing community and home-based care models.

"If the HSE were to provide you with the funds they would be spending on residential care, so you could get in-home care, you would know she had someone there with her and was safe. That would be the ideal scenario. I think if that were the situation, some of the family would call more often... The pressure would be off to care, we could just be family".

[Family C, Participant 7; Daughter]

Interviewees across most families noted that the opportunity costs of caring must also be factored in. Many of the participants included here reported forgoing opportunities for employment and career progression, both at home and abroad, either to be, or support the primary carer:

"I was offered an opportunity abroad that was very attractive to me, but I knew that it really wouldn't have been feasible for my home life to make it work."

[Family E, Participant 11; Daughter]

Conclusions and Implications

This study aimed to explore the range of factors that influence sustainability in family care. We conducted in-depth interviews with 20 carers from 10 different families supporting someone with dementia, across every province in Ireland.

Four key themes were identified and are summarised in Table 1 below. The factors influencing sustainability across each of the four themes are divided into potential barriers and facilitators.

Table 1: Factors which influence the sustainability of family caring in dementia

Theme	**Factors Influencing Sustainability**	
	Barriers	**Facilitators**
Cultural Norms & Narratives	Deficit views of dementia	Strengths-based views of dementia
	Stigma	Recognition of personhood
	Duty of care presumed to lie with family	Questioning the family as a neutral point of care provision
Family Relationships & Dynamics	Poor quality pre-morbid family relationships	Primary carer has leadership and coordination skills
	Changing roles within the family	Open, empathic communication
	Conflicting perspectives on formal social care use	Good listening skills and ability to perspective-take
	Enmeshment dynamics	Setting emotional boundaries
Individual & Collective Capacity	Poor carer physical health Presence of behavioural/ non-cognitive symptoms	Dementia care education for families Dementia-friendly communities & businesses
	Poor carer mental health	Supportive social network
	Other responsibilities (e.g., childcare, employment)	Presence of other family members to relieve the primary carer
	Poor access to health and social care (especially community-based respite options)	Timely access to acceptable models of respite Peer support, Counselling
	Poor dementia care capacity across health settings	Family carers having supportive employers
Financial Factors	High cost of care for families Hidden out-of-pocket costs	Financial advice Financial supports (but existing supports are inadequate)

In the full report, we discuss what the findings mean for policy and practice within the Irish context in light of a number of factors, including 1) shifting sociodemographics and cultural norms 2) health system factors, 3) the policy and legislation landscape and 4) financial supports. Below is a summary of this discussion.

1. Shifting sociodemographics and cultural norms

Role of Women

When planning for future dementia care in Ireland, the shifting sociodemographic profile must be considered. Family care is gendered, in that women are more likely to occupy care roles than men. According to the most recent census in Ireland, approximately 60% of carers are female (CSO, 2016). However, too often we ignore other parallel trends, e.g., how 1) growing female participation in paid employment, 2) increased geographical dispersal of extended family, and 3) increased average age of first-time mothers, are diminishing the availability of family-provided care. The State is therefore relying on a precarious situation, whereby under-valued family members are increasingly less likely to forgo paid work, to undertake a caring role.

While state and market-based care provision are regularly measured, Russell et al. (2018) point out that family-provided care is rarely quantified. Folbre (2015) argues that by not representing unpaid care work in National Accounts of economic activity, the total care work that is done in Ireland remains unknown. According to Russell et al (2018), the first step towards truly valuing care work, is measuring it. There are many ways in which we could capture such data, one of which is to establish a National Carer's Registry. A key benefit of a Registry would be that data regarding the number of carers and their basic demographic characteristics (e.g., sex, age group), the diagnosis of the care recipient, and the time spent caring, would be available to inform the development of a more responsive health and social care system. A registry would also enable more efficient identification of family carers who are entitled to various financial supports, e.g., the carer's pension.

Meaning of Dementia

In addition, while views on dementia are slowly changing, the experiences of family carers here indicate that we have much more work to do regarding creating non-stigmatising public awareness and narratives of dementia. This includes ensuring that dementia is not characterised solely by loss and disability, in a way that implies diminishing personhood. Depictions should be more balanced, and should emphasize the importance of how the environment and interpersonal interactions and relationships can support personhood and offset some of the limitations associated with the dementia condition. The 'Understand Together' campaign has been one such positive national awareness campaign, led by the HSE's Health and Wellbeing division, in partnership with the Alzheimer Society of Ireland and Atlantic Philanthropies.

Media reporting guidelines may play a crucial role in reshaping dementia constructions and narratives, especially in news media. The Alzheimer's Society of Ireland have created Dementia Friendly Language guidelines which are helpful in this respect. The Alzheimer's Society in the UK have also published detailed guidelines on media reporting of dementia, as have other dementia organisations worldwide (e.g., Dementia Australia). It is important that those who shape narratives on dementia are made aware of existing reporting guidelines, and that editors and content curators enforce them.

2. Health System Factors

The Irish health system is unusual within the European context in how it is characterized by two tiers, i.e., public and private (OECD, 2017). The inequity associated with this system is well-noted (Burke et al. 2018), and the findings here indicate that this structure adversely impacts patterns of access to formal health and social care for families dealing with dementia. Those with more personal resources who can afford private health insurance, gain speedier access to assessment, treatment and/or care than those in the public system, irrespective of need. A second characteristic of the Irish health system which was reflected in the present findings is a long history of under-resourcing community care.

This shows up in many of the findings here from the family carer perspective, in terms of poor availability and access to homecare support, respite and day services, lack of financial supports for materials and medications relating to the dementia condition, etc. In the 'Paying the Price' survey of family carers by FCI, almost half (49%) said that formal health services and supports were not available to support them in their role. Perhaps the most urgent need currently, based on the present findings, is to address the shortage of formal homecare workers. As participants in this study explain, getting approval for the amount of homecare hours needed is increasingly difficult, and even where home support hours have been approved, the service sometimes can't commence because a homecare worker isn't available locally (FCI, 2021).

The most pressing unmet formal service need reported by participants in this study is for community- and home-based respite care. The 'Paying the Price' survey found that almost three-quarters (74%) of older adults requiring substantial care (i.e., 100+ hours/week) had no access to home support services that permit the family carer to leave the home. Each of the families in the present study indicated that in order to facilitate sustainability, effective models of community- and home-based respite must be made widely available to family carers. Access to other psychosocial supports for carers, including formal counselling and psychotherapy was also extremely poor. The Programme for Government has committed to developing a 'Carer's Guarantee' proposal that will provide a core basket of services to carers across the country, regardless of where they live. Despite €2 million being dedicated to this in Budget 2021, just €100,000 of it had been allocated by November 2021. Unfortunately, no concrete progress has been made in relation to developing such a proposal, as of January 2022.

Finally, as most families outlined, one of the biggest access barriers across health services for dementia is the absence of a dedicated key worker or point of contact, within the health system, to help families source appropriate services to meet their needs, in a timely manner. This is a known gap in need and is addressed in most relevant policies relating to family carers and dementia care. In response to this gap in need, the Alzheimer Society of Ireland created the 'Dementia Adviser' service, an individualised information, advice and signposting service for people with dementia and their carers. The service is currently funded by the HSE and operationalized by ASI. As of February 2022, there were 29 dementia adviser posts across Ireland, with one covering every county. Work is ongoing to develop awareness of the role amongst health and social care professionals who encounter people and families, in the context of dementia.

3. Policy & Legislation

National Strategies

The National Carer's Strategy was published in 2012, outlining cross-departmental actions which were intended to improve the wellbeing of family carers. In 2020, the Government, acknowledging poor implementation of the Strategy actions, committed to developing an updated National Carer's Strategy in the Programme for Government (p.76). Unfortunately, as of January 2022, preparatory work for this is still not underway, despite Government having pledged it as a priority for 2021. It is crucial that an updated Carers' Strategy and action plan is developed in 2022, in collaboration with representative stakeholder groups and organisations, and that ring-fenced funding is allocated for its delivery.

Another relevant policy is the Irish National Dementia Strategy (NDS). This was published by the Department of Health in 2014 and outlined 35 key actions to improve dementia care in Ireland. To facilitate implementation, an investment of €12.5 million was made by Atlantic Philanthropies, and an additional €15 million was committed from the Department of Health and the HSE. In May 2018, a review of the NDS implementation process was conducted. Progress was noted in 17 of the 35 action areas, which was facilitated by the establishment of the HSE's National Dementia Office in 2015. The remaining 18 action areas had not yet been fulfilled, though promisingly, some preliminary work has been conducted on 17 of these outstanding areas.

EU Directive on Work-Life Balance for Parents and Carers

In line with experiences regarding supportive employment environments, the State of Caring (2020) survey found that 52% of employed family carers said more flexibility in their work hours would help them to continue working. One-in-five working family carers reported that allowances for working from home would play another important role in sustainability. The COVID-19 pandemic has shifted patterns of working in some sectors, in line with this.

The European Union Directive on Work Life Balance for Parents and Carers, legislates for i) the introduction of a minimum of five days of leave each year for family carers who are also in paid employment and (ii) the right to flexible working to facilitate them in their care role. This directive has been entered into European law and is expected to be transposed into Irish law in August 2022. In terms of practical initiatives and awareness raising, FCI provide the 'Caring Employers' programme; this aims to deliver education and advice on fostering inclusive work environments, which are understanding of the needs of employees with family care responsibilities. Importantly, it also educates companies and services on the evidence that not considering the needs of family carers can have negative impacts on businesses. Another way in which companies could be incentivized to provide a more carer-friendly work environment, would be to introduce a tax break for companies that incur expenses through establishing such policies and practices.

Statutory Homecare Scheme

The 2012 Primary Care Strategy advocated a shift from hospital to community- and home-based care. Many other policy documents have echoed the need to build formal care capacity in the community, e.g., the National Carer's Strategy (2012), the National Dementia Strategy (2014), the National Positive Ageing Strategy (2013), and of course, the SláinteCare reform policy.

It is in line with the above, that the Statutory Home Care Scheme is currently being developed, using a whole-of-Government approach. It is also important that any statutory scheme does not have too narrow a focus, e.g., personal/physical care only, older adults only, etc. Homecare packages should be tailored to the needs of each recipient family, based on the Single Assessment Tool (SAT; including the Carer Needs Assessment, when finalised) and should include, as appropriate, a range of home-based supports, including assistive technology, aids and applications, respite, personal care, meaningful and engaging activities, housing grants to adapt environment based on needs, etc.

Critics have pointed out that while many national policies clearly communicate an intention to develop community health and social care capacity, resource allocation decisions are inconsistent with this. In 2018 the Government published the Health Service Capacity Review. The review showed that €408m was allocated for homecare in 2018, while more than double that (€962m) was allocated to the Nursing Home Support Scheme. In a 2018 Department of Health submission, FCI highlighted several significant concerns about the proposed Homecare Scheme, including: 1) the co-payment approach to financing, 2) restriction of remit to 'older people' only, and 3) the absence of a statutory definition regarding where the ultimate responsibility for care should be located, between State and Family.

Given the financial pressures that many families living with dementia are under, it is important that other financing approaches are considered, along with co-payment, e.g., general taxation, social insurance, private insurance. An important finding of this study is that family carers of people with young-onset dementia are particularly disadvantaged when it comes to accessing support from formal health and social care services, because the person with dementia doesn't fall under the remit of Older Persons Services. The third concern, i.e., the failure to clearly define the boundaries of state versus family responsibilities in relation to homecare provision, is of particular importance based on the perspectives of family carers in this study. Unless the boundaries of responsibility are transparent and well-delineated, we will not have a reliably regulated or equitable homecare system.

Assisted Decision-making legislation

The Assisted Decision-making Act was signed into law in December of 2015, replacing the Wardship system; however, it has still not been commenced in full, as of February 2022. The Act is an important and progressive piece of legislation, underpinned by a flexible, functional approach to capacity. This means, instead of a person being deemed categorically 'incapacitated' and losing their decision-making rights, the new legislation decrees that capacity should be determined on 1) an issue- and 2) a time-specific basis. The Act places a legal responsibility on health service providers, clinicians, and other health professionals to include those appointed to participate in decision-making processes, in relevant discussions relating to the person's Advance Care Directive. Undoubtedly, the Act will influence family care relationships. Carers in this study noted the conflict that can arise within families, because they feel they need to make decisions on behalf of the person with dementia, in accordance with what they believe is in the persons' best interests. This speaks to how family carers struggle because they want to respect and support autonomy and independence in their family member with dementia, while also striving to minimize risk. Common examples of this tension in practice occurred about living arrangements, driving cessation, day care and respite attendance, etc. Current understanding of the Act amongst family carers is poor, with the State of Caring survey reporting that three-quarters (73%) are not aware of the Act, while a further 13% noted that they have heard of the Act but do not understand the implications.

4. Financial Supports

The findings of this study indicate that family carers continue to feel significantly under-valued and under-supported. While family carers are understanding of the fact that the COVID-19 pandemic disrupted many planned Government commitments, many also indicate that the lack of appreciation and adequate financial support for family carers, have long-preceded the pandemic. In FCI's 'State of Caring' (2020) report key findings were that 79% of those in receipt of the Carer's Allowance find it difficult to make ends meet; and approximately 1-in-3 (29%) carers have a total household income of less than €20,000. Another finding, one which was strongly echoed in this study, is the expense associated with care-related materials, e.g., incontinence materials, and their disposal.

At present, financial support for family carers of dependent adults consists principally of direct income supports, i.e., either the Carer's Benefit which pertains to pay-related social insurance contributions, or the means-tested 'Carer's Allowance' scheme and the annual Carer's Support Grant (formerly known as the 'respite grant'). Noting the low thresholds in the means-testing process for the Carer's Allowance, FCI made two important reform submissions in relation to income and capital disregards. Between budgets 2021 and 2022, some progress was made; there was an increase in the annual Carer's Support Grant, from €1,700 to €1,850. Income disregard for the Carer's Allowance means-testing process was increased to €350 for single people, and €750 for couples, again demonstrating progress, but falling short of FCI recommendations. The capital disregard for the Carer's Allowance was increased to €50,000, in line with FCI's recommendation.

Other financial support issues relate to reforming the system of tax reliefs and credits, and pensions. Currently, the only tax relief available to a single person caring for an adult relative is the Dependent Relative Tax Credit, which amounts to €240. It is also a cause of frustration for many that single carers cannot avail of another form of tax relief, i.e., the Home Carer Tax Credit. This credit of €1,600 is only available to married couples or those who are jointly assessed for tax.

A 2021 report from the Commission on Pensions, which has been established to examine pension reform options, has made vital recommendations. These include introducing a ‘Total Contributions’ approach to pensions for long-term carers, which will serve to better reflect the contributions family carers make to society through their care work. This will involve the Exchequer applying credited contributions, to ensure that family carers are not at a systematic disadvantage, because of their care role. The recommendations are now being examined by the Cabinet Committee on Economic Recovery and Investment for consideration, and a response is expected within the first quarter of 2022.

Conclusions

This study has explored the constellation of factors that influence the sustainability of family-led dementia care in the community at many levels, i.e., individual, relational, community, health systems and sociopolitical. The findings indicate that while some progress has been made in recent years in relation to supporting family carers, there is still a long way to go to future-proof this situation, by better supporting and valuing family carers of people with dementia. The ‘Understand Together’ campaign has increased dementia awareness at population-level, however there is still much work to be done to change public perception and narratives of what it means to live with dementia; balanced, non-sensationalised media reporting is essential. It is clear than home- and community-embedded supports are greatly lacking, particularly outside of urban areas. Some families feel somewhat abandoned by the state, in the absence of having a point of contact for advice and signposting, timely access to acceptable respite, peer support, psychoeducational and counselling services, and/or appropriate recognition and monetary allowances/compensation for the care work that they do in the home. To complicate issues around sustainability further, some families have maladaptive relational dynamics (e.g., power struggles, enmeshment, disengagement behaviour) which can hamper sustainability, e.g., thwarting decision-making processes relating to the person with dementia and their care; and causing fatigue, frustration and even burnout for carer(s). Some families need a moderating presence to support constructive familial communication and decision-making, in a way that is empathy-driven, and person-centred. Given Ireland’s ageing population and shifting norms pertaining to gender roles, the prevalence of dementia will continue to rise as the availability of potential and/or willing family carers diminishes. The need for the State to take greater responsibility for functionally, psychosocially, and economically supporting families to provide sustainable dementia care at home has never been so pressing. Building the necessary capacity in home care services, and within local communities is paramount.

BACKGROUND

Ireland's population is ageing. As we live longer, the risk of developing a wide range of conditions increases, including dementia. Currently, there are approximately 64,000 people living with dementia in Ireland (Health Service Executive, 2020). By 2046, we estimate that there will be 150,000 people living with dementia in this country (Pierse et al., 2019). A more recent study published by The Lancet (Nichols et al., 2022) reported similar prevalence projections for Ireland, indicating there will be approximately 142,500 people with dementia by 2050. These estimates are showing that there will be more than double the current number of people living with dementia over the next 25-30 years.

This rising prevalence has several implications for society and for health and social care provision. However, those who will be most affected by this upward trend are the family carers of people living with dementia. The findings below demonstrate the magnitude of our reliance on family carers in Ireland when it comes to dementia care (see Cahill et al., 2012; Connolly et al., 2014; O' Shea et al., 2017).

60% of people with dementia are living in the community, supported by family

Dementia care cost €1.69 billion per annum in Ireland in 2010

Almost half the cost of dementia care is absorbed by families

There are many positive aspects to the experience of family caring, from carers' perspectives; these can include a sense of reciprocity, discovering personal strengths, building self-efficacy and coping strategies, and feeling closer to the person (Peacock et al., 2010). Family carers who have positive feelings about their role, experience lower levels of depression and 'burden' and report better self-rated health (Cohen et al., 2002).

Many family carers also report experiencing significant stress as a result of the carer role; coordinating and providing care for a family member living with dementia can be highly challenging, particularly as the condition progresses (Reed et al., 2014). Indeed, compared to carers of people without dementia, carers of people with dementia report:

- higher stress levels
- poorer quality of life
- greater sleep disturbance
- more absenteeism at work
- poorer psychological status (depression, anxiety)
- poorer physical health outcomes (more comorbid conditions, higher levels of pain)

(Pinquart and Sörensen, 2005; Goren et al., 2016)

There has been a great deal of research into the factors that contribute to carer stress and strain in the context of dementia. Of course, all carers' experiences are unique to their individual situation. However, patterns of experiences can be discerned, such as adult offspring of people with dementia tend to have different health profiles, routines, and responsibilities (e.g., young children, employment), compared to spousal carers. International research on this topic indicates there are some common trends across family carers' experiences, and the main factors that contribute to stress in family carers of people with dementia include:

- being female, a spouse, and/or live-in carer
- lack of support from other family members
- additional stressful life events
- poorer physical health
- poorer dyad relationship quality
- lower carer self-esteem
- behavioural symptoms in the person with dementia
- poorer functional ability in the person with dementia
- lack of timely access to health and social care services

(Brodaty and Donkin, 2009; Campbell et al., 2008; Alvira et al., 2015; Kim et al., 2012; Conde-Sala et al., 2014; Pillemer et al., 2018; Li, 2012; Tatangelo et al., 2018).

Another factor to consider is that most family carers and people with dementia would prefer the person with dementia to remain living in the community for as long as it is safe and feasible. Care home admission is not a desirable option where it is not necessary, not just considering family preferences, but also given that quality of life is diminished among people with dementia in residential care (Barca et al., 2011; Olsen et al., 2016). Care home admission is related to a two-fold rise in mortality risk for people with dementia, even after controlling for the person's health status on admission (Aneshensel et al., 2000).

While there has been a great deal of research on family carers of people with dementia, the focus is typically on the individual level, and specifically on the primary carer(s) and/or the care dyad. This research seeks to take a more holistic view of family caring, by acknowledging and exploring the role of family dynamics, as well as the influence of local communities, health and social care provision, and the wider socio-political landscape. More specifically, this research is focused on exploring the range of factors that influence the sustainability of family caring, in the context of dementia.

It is important to define the term sustainability, and what it means in the context of this research study. Our framing of 'sustainability' is in line with the concept of "perseverance time", i.e., the time that a family carer anticipates being able to continue to care, under their current conditions (Kraijo et al., 2011). However, we must clarify that 'sustainability' is not about merely keeping the carer's head above water; it is about understanding how to best support their needs and wellbeing. Fostering sustainable family care situations is about addressing 1) the many unmet needs of family carers and people with dementia, at the individual and relational level, and 2) the absence of support, at multiple levels, from wider society and Government.

The aim of this study is to better understand the factors influencing the sustainability of family caring for community-dwelling people with dementia.

METHODS

Design

Phase one of this qualitative study involved optional ‘Family Story’ work. Phase two involved in-depth semi-structured interviews and/or focus groups with participating family members.

Participants

Twenty participants supporting a person with dementia from across 10 family units were included (N=20). All participants in this study were ≥18 years of age and aware of the dementia diagnosis.

Sampling Procedure

The sampling method was purposive. It was considered important to capture and represent as much variation in family characteristics and circumstance as possible, e.g., those living rurally versus in urban areas, those supporting people with younger- and older-onset dementia, and different family sizes and structures (e.g., nuclear, blended/complex families), etc.

Recruitment

Study advertisements were mailed to a sample of GP clinics around the country, and were circulated through the Family Carers Ireland network, as well as through social media (Twitter). Potential study participants then contacted the researcher directly for further information about the study. Prospective participants were asked to discuss the study with family members, to encourage family participation.

Ethical Approval

Ethical approval was obtained for this research from the local research ethics committee.

Informed Consent

All potential participants had an opportunity to discuss the study protocol with the lead researcher. Once the researcher was satisfied that the participants understood the nature of the study and what was being asked of them, signed informed consent, and proxy consent for two participants with dementia, was obtained before data collection commenced.

Data Collection

This data was collected between May and October of 2021. In phase one, each family were asked to complete an optional ‘family story’ booklet, briefly detailing family history, and their experience of the dementia diagnosis and caring since then. The purpose of the family story was to get participants thinking and talking with each other about their perspectives on this topic, ahead of the interviews and/or focus groups. Four families completed a booklet, and the other six families reviewed the questions in the booklet but didn’t complete it. Where completed, the information provided in the booklet gave some context and background information to the researcher ahead of the main phase of data collection.

Phase two involved families doing individual and/or family group interviews with the study researcher. Five individual interviews and five group interviews were conducted, with groups ranging in size from 2-4 family members.

The interviews were conducted by telephone or by Zoom, with each participating family unit. The interview schedule included similar topics for every family, but was tailored for each family, based on the content provided in the family story booklet, where available, and/or information arising during the interviews that was pertinent to the research question, but not probed in the interview schedule.

Each family decided for themselves whether they would like to be interviewed together as a family unit (focus group format) or separately (individual interviews). In the case of family focus groups, the researcher acted as the facilitator and agreed some ground rules at the outset of the interview, about being respectful and letting each person contribute their perspective in turn, without interruption. The duration of interviews ranged from 42-84 minutes. Whether interviews were conducted by phone or Zoom, only audio data was recorded, using a password-protected, encrypted mobile recording device. Once the data was transcribed verbatim, all identifiable information was redacted, and the anonymised transcription file was saved securely in a private folder on the UCC network, the audio recording was permanently deleted.

Data Analysis

Braun and Clarke's (2006) inductive approach to thematic analysis was used to analyse the data. This involved reading and re-reading participant transcripts and making memos prior to, and during the coding process. Particular attention was paid to the positionality of different participant groups, e.g., spousal carers, adult children, grandchildren, etc.

Meaningful sections of the transcripts were assigned 'codes' (short descriptors), based on their relationship to the research question. Initial codes were used to inform the coding of later transcripts, through the development of a coding frame, whereby codes were iteratively updated as more data were analysed. 'Updated' refers to the removal/merging of duplicate codes, renaming and restructuring of initial codes, and the addition of novel codes, with each subsequent interview. This process continued until all data were coded. Subsequently, the codes and the associated raw data were re-examined and compared within and across participant interviews. This process informed the grouping of codes into standalone categories, which over multiple iterations, were fashioned into defined themes.

FINDINGS

Participant Characteristics

Twenty family carers supporting a person with dementia, across 10 different families, were included in this study. Their characteristics are outlined in table 1 below.

Table 1: Participant Characteristics

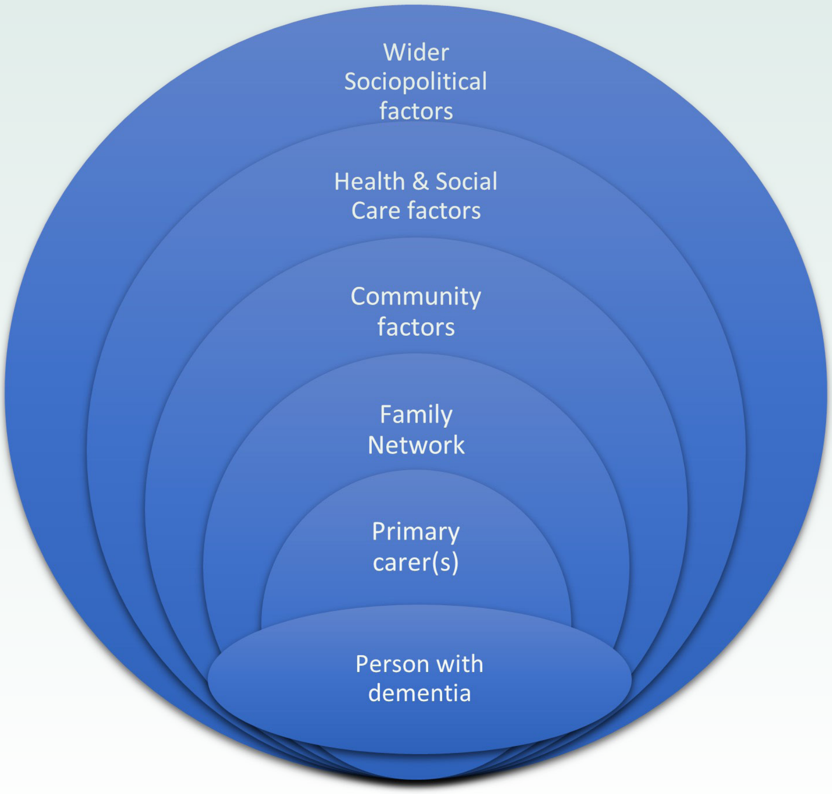
No.	Family Unit	Relationship to*	Sex	Age	Lives with*
1	A	Wife	F	78	Y
2	A	Daughter	F	51	N
3	A	Daughter	F	49	N
4	A	Granddaughter	F	24	N
5	B	Daughter	F	52	Y
6	B	Son	M	47	N
7	C	Daughter	F	45	N
8	D	Husband	M	68	Y
9	E	Husband	M	69	Y
10	E	Daughter	F	38	N
11	E	Daughter	F	27	N
12	F	Wife	F	62	Y
13	F	PWD	M	68	NA
14	G	Daughter	F	38	Y
15	G	PWD	M	73	NA
16	H	Daughter	F	34	N
17	I	Wife	F	71	Y
18	I	Daughter	F	40	N
19	I	Daughter	F	42	N
20	I	Niece	F	35	N

PWD=person with dementia
* = the person with dementia

Elements influencing Sustainability

Six elements influence the sustainability of family caregiving in the case of supporting a relative with dementia to remain living at home. These elements are: The Person with Dementia; The Primary Carer(s); Family Network and Dynamics; Local Community; Formal Health and Social Care Services; and Wider Socio-political factors (see Figure 1). These elements are important as they differentially affect the family system's ability to achieve stability, in the endeavor to support a loved one with dementia.

Figure 1: Factors Influencing the Sustainability of Family Caregiving in Dementia

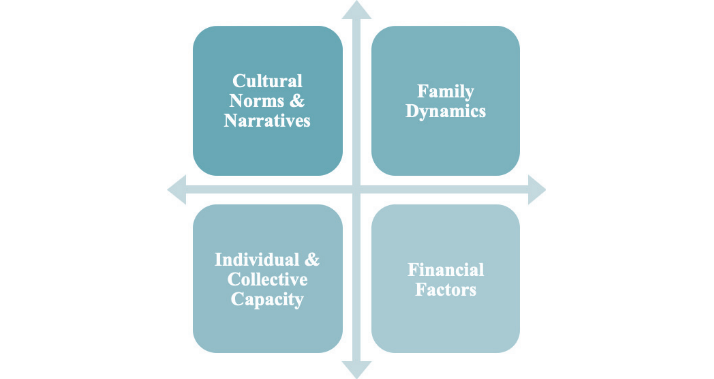


Conceptual Themes

Four important conceptual themes crosscut the six factors depicted in figure 1, to influence the sustainability of family caregiving in the context of dementia. The findings of this study will be outlined, in turn, as per each of these four distinct, but interconnected themes (see Figure 2):

- Cultural Norms & Narratives
- Family Dynamics
- Individual & Collective Capacity
- Financial Factors

Figure 2: Cross-cutting themes influencing sustainability



Cultural Norms and Narratives

Each interviewee spoke to differing degrees about how cultural norms and narratives about dementia and family caring have influenced their experience and the perceived feasibility of providing ongoing dementia care to a relative, at home. Three sub-themes were generated ('the meaning of dementia'; 'duty of care' and 'the role of gender') and will be outlined in turn below.

Meaning of Dementia

Prior to the diagnosis, most families were not knowledgeable about dementia and what to expect when caring for someone with a dementia. Several participants noted that the primary narratives in the media and the clinical arena, surrounding what dementia is, and what it means for families, are anchored on notions of progressive decline and deficit.

"All I had to go off is what I'd seen on TV or read... And those depictions are so, so bleak."
[Family A, participant 4; granddaughter]

"Until [mom] was diagnosed I didn't know anything at all about dementia. Then you get the news and you get a small bit of information, which basically tells you, 'it's all downhill from here'..."
[Family B, participant 5; daughter]

One interviewee outlined the fear and stigma that accompanies the term 'dementia', because of the narrative that, along with cognitive or functional decline, personhood is also progressively diminished:

"I didn't know much about dementia, but I knew that dementia is one of the scariest diagnoses a person could get, that it robs you of the person each day."
[Family I, Participant 18; Daughter]

One carer noted that her grieving process began at the point of her mother's diagnosis. This anticipatory grief occurred, because of her beliefs and expectations about what was ahead of them as a family, in the endeavour to support a person with dementia to remain living at home.

"When we got the diagnosis, I started grieving right away... I was grieving because I knew what was to come... I was very bad in myself mentally, I can't even tell you how many times I cried in work."
[Family C, Participant 7; Daughter4

Consistent with deficit-based understandings of dementia, an associated narrative is that people with dementia will inevitably require nursing home care, which can cause significant anxiety in people living with dementia:

"I think mam's worst fear is because of her diagnosis, she will be put in a home. I think that's why she won't get in the car anymore-she thinks we'll ferry her off to a home."
[Family E, Participant 10; Daughter]

Given the stigma and fear around what dementia means from a biomedical perspective, i.e., characterised by loss and decline, it is unsurprising that some people with dementia refuse to acknowledge or accept the dementia diagnosis.

"It was just 4 years ago I managed to convince her to go to the doctor... I had seen signs of it myself in the run up to that, but she doesn't accept her diagnosis at all... Absolutely not!"
[Family C, Participant 7; Daughter]

According to two of the ten families, there can be a hesitancy, even amongst dementia specialists, to disclose a diagnosis of 'dementia', because of the public stigma associated with this diagnosis.

"When she was diagnosed, the geriatrician had told her she was a wonderful woman and very stylish and outgoing. He never once mentioned a diagnosis to her. He just sent us next door to see a 'dementia advisor'."
[Family C, Participant 7; Daughter]

This can reinforce patients' denial, which can adversely affect efforts by the family to get the appropriate structures, routines and supports in place post-diagnosis. It can also create distance mistrust, and conflict, between the person with dementia and the people supporting them.

"Things just fell apart after that. I felt very let down in that meeting by the doctor because I just felt that she needed somebody to tell her straight out. It's very difficult because my mum and I had been very close, but at that point there was a lot of paranoia in my mum that I was trying to make her out to be something that she's not."
[Family C, Participant 7; Daughter]

This can also cause arguments between family members supporting the person with dementia, when some recognise the diagnosis, and others do not. These types of arguments can impede the family mobilising as a unit to appropriately support the person with dementia, as one daughter pointed out in her individual interview:

"My dad and I had arguments over it. He didn't know for sure what was going on with her and the specialist wasn't using the word 'dementia'... It's only in the last few years that he has come to any sort of acceptance of it. He'd say, 'there's nothing wrong with her, she's fine'. He is the only person at home with her, so when you have him saying that she's fine, it's very hard to get anywhere."
[Family H, Participant 16; Daughter]

Duty of Care

Along with the cultural narratives associated with the dementia diagnosis and stigma, there are other prominent narratives relating to care responsibilities, and to whom the duty of care falls. Many interviewees identified a cultural narrative hinging on notions of familialism, i.e., that the duty of care falls on the family of the person with dementia first, and that the state will only assume responsibility for their care, if a fall-back is required.

"There's no roadmap or book of instructions, it's just your lot. There's this undertone that, if you care about the person then you should care for them, not hand them over to the state."

[Family B, Participant 6; Son]

"I feel like I have very little choice in my situation. As his wife, you know, I'm supposed to be there for him…"

[Family F, Participant 12; Wife]

Several interviewees across three families pointed out that while family-led care is a cultural norm for people with additional needs, it doesn't always fit in the context of dementia. Firstly, participants pointed out that families are expected to provide complex care for people with moderate-severe dementia at home, without the appropriate education or training having been provided to them, to equip them for this challenge. One daughter summarised this as follows:

"It's beyond our pay grade, you know? We're not trained in this. And dementia is very tricky to handle even if you are trained. So, at a certain point, it's about what dad will need, and there will be a point where it wouldn't be fair to anyone for him to be at home."

[Family A, Participant 3; Daughter]

Another interviewee explained that it's not just about lacking formal education and dementia care training, but that it is especially difficult to provide care for someone that you have emotional attachments to:

"The government are shamelessly relying on regular people to care for people with serious diseases like this. And not only that, but they are asking us to do it while our hearts are broken, because all these changes in personality and behaviour… It's happening in someone close to you."

[Family B, Participant 5; Daughter]

Another interviewee pointed out that, typically, medical professionals are strongly discouraged from providing healthcare to their own family members, because of how the potential lack of objectivity might affect patient care and outcomes. However, when it comes to family-led dementia care, this issue is typically ignored.

"It's contradictory that family should provide this level and type of care. Healthcare professionals are not meant to provide care/treatment their own family members, but we, untrained people, are meant to get on with it"

[Family I, Participant 20; Niece]

It is clear to all interviewees that the duty of care, culturally, lies primarily with the family. However, many interviewees pointed out that it is not just societal expectations that influence their family caregiving situation; the preferences of people with dementia to remain living in their own home, or 'age-in-place' is another strong driving force.

"I know he wants to stay at home, so I'm really trying my best"
[Family F, Participant 12; Wife]

However, many carers felt that the ageing-in-place movement, while positive in its endeavour to advocate for the preferences of people with dementia, can become damaging when the necessary infrastructure, resources and supports don't exist in the community, to facilitate this for families.

"I wouldn't ever have wanted to see him go into a home. But then, what's the alternative if you don't have the help and are run into the ground?"
[Family A, Participant 1; Wife]

Such campaigns encouraging families to continue supporting people with dementia at home, run the risk of being dogmatic; this can be damaging for family carers, particularly in cases where the family believe it is no longer in the person's best interest to remain at home.

"I felt that by ringing [a helpline] they might talk me through the process of moving to a nursing home. It's not something I'm in favour of, going against my mum's wishes, but it's in her best interest safety-wise, so I feel forced to go that route. I thought they would give me support, tools, anything that might help me see what way this might go. But the response I got was not that... You could tell the attitude was, 'you shouldn't be thinking of putting her in a nursing home, you should support her as best as possible at home'."
[Family C, Participant 7; Daughter]

Most interviewees were in favour of supporting their relative at home; however many point out that the necessary structures are not in place to facilitate this, and the only feasible option is to pursue nursing home admission.

"If I want to look for a care home, I can find one no problem, but if I want to find something else like a day service or homecare, then it's never clear..."
[Family G, Participant 14; Daughter]

Several family carers outlined a common dilemma that families face, i.e., when care at home is no longer feasible or safe, but nursing home admission is not acceptable to the person with dementia. One daughter of a woman with dementia described how health professionals advised her against pursuing legal action to facilitate nursing home admission for her mother, citing the arduous nature and uncertain outcome of the court process. This shows how even families that are at the end of their tether and have substantial concerns about the persons' safety, are being directed to wait until an emergency occurs (e.g., fall, hip fracture) with the person with dementia before the state will intervene.

"What's really getting to me now is all the closed doors. We have no options. You put up and shut up, and then when something drastic happens, we'll look at the situation for you."
[Family C, Participant 7; Daughter]

Role of Gender

Some interviewees further defined the notion of cultural familialism in dementia care provision, indicating that family-led dementia care is a euphemism for what is largely female-led care. Several male and female interviewees addressed the role of gender in family care, and what this can mean for family dynamics and the sustainability of the care situation.

In one family focus group, the following exchange between sisters sharing carer duties for their father, captures the gendered nature of caregiving practices in some families. It also shows how a lack of understanding and appreciation of the work involved, especially from their male relatives, can create conflicting views between family members regarding sustainability.

Daughter 1: *"We all want the best outcome possible. It's just that the boys [adult brothers] don't quite understand all that we do and deal with."*
[Family A, Participant 2; Daughter]
Daughter 2: *"That's true. It's easier for them to hold onto the idea that we can keep him at home forever more."*
[Family A, Participant 3; Daughter]

These sentiments about the perceived nature of care as a female endeavour, were echoed by others:

"My brother doesn't seem to get it. Men are a bit clueless on how to deal with this. I don't know if he's not aware, or he just doesn't want to see it."
[Family H, Participant 16; Daughter]

"Six out of seven of us are for it [care home admission] now. There's one more brother who hasn't been involved in the care at all, and of course he wants her to stay at home..."
[Family C, Participant 7; Daughter]

This point about the gendered nature of caring was also reinforced by one husband, who cares for his wife with moderate dementia.

"If the roles were reversed, and I were sick, she would be able to do it all. She wouldn't need to draw on all these other people like I have to."
[Family D, Participant 8; Husband]

This perspective may reflect societal expectations that women are better able to manage care-related tasks, which also makes women less likely to ask for help. He elaborated that, without the support of his sister, and his wife's sister, the situation would not be sustainable for him:

"I can't do some of what they do. They know I need them. You'd feel useless sometimes. I don't like asking for help but it's the only way to keep our heads above water."
[Family D, Participant 8; Husband]

Conversely, the daughter of another man caring for his wife with early onset dementia, indicated that an important factor influencing sustainability for their family, is her father's aptitude for domestic planning and duties, which she notes is not necessarily consistent with conventional gender role norms.

"He's very independent. You know he can use the washer and dryer and all that. He can do things on his own. If it happens to other men, that their wife gets dementia, that's the person who has done those things for them. But mam and dad were always both very independent and their gender roles weren't exactly traditional. We knew he wasn't going to be like a man in need of a wife..."
[Family E, Participant 11; Daughter]

Family Relationships & Dynamics

All participants agreed that when supporting a person with dementia in the family, relationships amongst family members, including the person with dementia, the primary carer(s) and the wider family network, have a substantial effect on family capacity to function as an aligned unit. Three subthemes were generated from the perspectives of family carers, including:

- Changing Roles
- Becoming the Primary Carer
- Patterns of Communication

Changing Roles and Responsibilities

A diagnosis of dementia impacts in many ways upon daily family life and dynamics. In particular, family members' roles and responsibilities tend to shift. Several interviewees, especially spousal carers, emphasized how the changes in the person with dementia over time made them appreciate the person's premorbid contribution to family life in a new light, as their responsibilities were reassigned to other family members.

"Before she got this [illness], she did everything around here... Our house was always pristine, like a showhouse. She made it look easy. I had no idea how much work it takes to keep a house like ours."

[Family D, Participant 8; Husband]

"I noticed things that I had taken for granted, things that were always sorted by him... I suppose they started to slip a bit and that was never like him. Dealing with bills and what have you."

[Family A, Participant 1; Wife]

However, not all carers had excellent relationships with the person with dementia, and/or other family members, prior to the diagnosis, and of course, the nature and quality of premorbid relationships typically heavily influences how role changes occur.

Family members noted that the changing roles were especially difficult for the family member with dementia, particularly when they felt their autonomy was being threatened.

"She would be calm until she felt she was being micromanaged, and then it was like, red rag to a bull."

[Family E, Participant 11; Daughter]

Many family carers have experienced conflict in the care relationship, arising from circumstances in which their behaviour inadvertently exacerbated the person's feelings of diminishing autonomy and control.

"Anything that was pointed out to her, when other people would remind her of things, or point out omissions, she was seeing that as things not being OK, and she'd get very defensive. She was feeling that loss of independence."

[Family E, Participant 10; Daughter]

This type of dynamic can be psychologically harmful for both the carer and the person with dementia, with one carer describing how this is especially tough when the person with dementia doesn't acknowledge their diagnosis; and how 'caring' behaviours in this instance can be experienced by the person with dementia as a form of disrespect or mistreatment.

"After she was diagnosed, my relationship with my mother got very bad. In me trying to help her, she accused me of trying to control her, and bullying her. It was a very bad situation and I had to walk away completely for about six weeks as it was too upsetting for her, and for me."

[Family C, Participant 7, Daughter]

One specific issue, echoed by multiple families, was in relation to driving cessation, and the sense of loss and frustration that can be associated with this for the person with dementia:

"There was a real frustration in mum. One of the big things that caused daily upset was about driving the car and being able to go places on her own."

[Family E, Participant 11; Daughter]

A particularly upsetting role change, according to members of two families with young children, is the loss of normative intergenerational experiences between the grandparent with dementia and their grandchildren, and the devastation this can cause.

"[Nephew] would've been 2 or 3 [years old]… Him being the first grandchild, he was the apple of her eye, but she knew she couldn't mind him on her own. It was upsetting for her…"

[Family B, Participant 6; Son]

"My son, he's just 10 and I've stopped bringing him out to [her parent's house] because he gets upset. I try to explain to him why granny is pacing around and won't talk to him or make eye contact. It's hard for him because for a while, he was the only person she would respond to, and now that's gone too"

[Family E, Participant 10; Daughter]

Becoming the Primary Carer

A significant role change, discussed by all interviewees, focused on becoming the 'primary' carer within the family. Some interviewees indicated that stepping into the primary carer role felt all-consuming, and sometimes eclipsed the familial relationship.

"Soon after that [diagnosis], rather than being her daughter, I became her carer. I would organize appointments, bring her to appointments, I would do her shopping for her… everything."

[Family C, Participant 7; Daughter]

One woman who married mid-life, just two years prior to her husband's early onset dementia diagnosis, noted how the decline in reciprocity she felt so soon into their marriage, further complicated her acceptance of their changing roles.

"When we married, I felt like I had a real partner, we were equals. It doesn't feel like that anymore. I still love him, and I want to do my best, but all this change in a short amount of time has been a lot to swallow."

[Family F, Participant 12, Wife]

Primary carers in this study differed in their experiences of the pathway to becoming the main carer. For some carers, especially spouses, the pathway was reasonably clear; they were expected to be the primary carer where possible, and most did so willingly, and as a matter of duty and/or love.

However, for non-spousal carers (e.g., adult children, grandchildren), the pathway to becoming the primary carer was less straightforward. Several adult children of people with dementia acting as primary carers noted that they entered the role by 'default', or because of their 'circumstances'. This typically meant that they had fewer reasons than other family members, not to assume the primary carer role, e.g., the person with the fewest child-rearing, work, and other responsibilities, lives geographically closer or can relocate more easily, etc.

"It wasn't exactly part of my plan, but I didn't feel I had much choice because I'm the only one who could uproot her life to come live with dad. It's not easy, but someone has to do it, and I was the only real candidate."

[Family G, Participant 14]

"We both live near her, but the other two [siblings] don't, so it's kind of just happened this way."

[Family B, Participant 5; Daughter]

Some carers felt that as they successfully took on more caregiving activities, other family members retreated to auxiliary roles. This specific pathway to becoming the main carer can foster resentment, particularly when other family members become less engaged and/or increasingly reluctant to share care responsibilities.

"I'm totally resentful... They all know it that I don't want to be the person doing this..."

[Family C, Participant 7; Daughter]

Patterns of Communication

Participants in this study described numerous patterns of family interactions regarding the care of the person with dementia; some are constructive and serve to reinforce the capacity of the family as an aligned unit, while others are destructive and serve as barriers to sustainable family care in the community. These two broad patterns are not mutually exclusive, but are embodied to varying degrees depending on context and circumstance, in ways that are unique to each family's dynamics.

Constructive Interaction Patterns

An important element of constructive interactions is that they emanate from a place of empathy for other family members. Interviewees indicated that the presence or absence of mutually empathic interactions, and a shared positive psychology, significantly influences the quality of family relationships. Empathy for the person with dementia was identified as especially important amongst family members and lessened the risk of them taking behavioural/non-cognitive symptoms personally, or otherwise misattributing their meaning. One daughter, just a teen at the time her mother was diagnosed, speaks to this:

“We all knew that these peaks and troughs pass, so on the days she was very difficult, I knew I had to let it go, because you know every teenager fights with their mother, but I always knew that it was the illness. And after a while, it became water off a duck’s back”.
[Family E, Participant 11, Daughter]

Primary carers indicated that understanding and appreciation from other family members in relation to their care work, served to make them feel valued, and reinforce their self-efficacy. This was demonstrated in a family group interview, where a brother expressed family members’ appreciation and gratitude for his sister as the main carer for their mother; his sister subsequently reciprocated, acknowledging that he also gives what he can to support her in that role.

Brother: *“I know you have taken so much of that role of keeping structure for her and keeping her safe. I know it’s not easy. When I see everything that you have taken on, I admire it and you know we are all grateful”*
Sister: *“Yeah, and I know you work long and hard and can’t be at every appointment or consultation. I don’t mind relaying to you because then yourself and [sister-in-law] use the information to help me.”*
[Family B, Participants 6, 5 respectively]

Conversely, when primary carers felt other family members did not appreciate their work, this was a particularly damaging dynamic. One daughter, who jointly cares for her mother with one of her brothers, described such a situation with their other siblings:

“They think that my brother who lives with her, that he is doing nothing. At this stage she needs 24/7 care. She has continence issues too, so he’s constantly busy. I wish they would just visit for a day. They have no concept of what’s involved at all.”
[Family C, Participant 7, Daughter]

All family members who support the person with dementia, not just the primary carer(s), need to have their contribution acknowledged and appreciated; this can serve to further strengthen the support offered by auxiliary family carers to the care dyad. One woman, living near her parents, acknowledged the sacrifices and opportunity costs of caring, for her younger sisters who don’t live close by, the youngest in particular:

“My little sister is only in her twenties so her whole adult life, her college experience, everything was cut short so she could come home and help out. And we do it with a heart and a half, but I think about what they’re missing out on...They haven’t had a chance to meet anyone or build their own lives.”
[Family E, Participant 10, Daughter]

In a family group interview, one wife of a man with dementia expressed her concern for her two adult daughters, who were supporting her to keep their father at home. She acknowledged that they have other responsibilities and that she was worried about ‘burdening’ them.

“I was concerned for the two girls that we were becoming a burden and taking up a lot of their time. You have your own families and issues to be dealing with, on top of everything else.”
[Family I, Participant 17; Wife]

Destructive Communication Patterns

Destructive patterns of interaction which impeded sustainability were identified, including disengagement and enmeshment dynamics.

Family members contribute variously to care discussions and activities; however, interviewees note how some siblings disengage when it comes to the issue.

"My brother in [foreign country] has no idea what's going on really. He's been there a long time. He's basically out of the equation, so you can forget about him."

[Family H, Participant 16, Daughter]

"My sisters and the other two brothers are not involved in any care or any decisions, and they really don't want to know anything about it to be honest."

[Family C, Participant 7, Daughter]

Some interviewees make peace with sibling disengagement, acknowledging that it is their own choice to make; however, several clarified that a fair trade-off for this, was that those who are least engaged, have less decision-making power.

"We are here doing the work, dealing with the good, the bad, and the ugly. I think we [siblings] have an understanding that because the two of us are here with her, we have more of a say in how things are handled."

[Family B, Participant 6; Son]

Many interviewees also described scenarios indicating enmeshment dynamics, i.e., where family members become over-involved in each other's relationships, behaviours and emotional processes, in ways that can be harmful for all parties.

Enmeshment dynamics can take many shapes. Some of the enmeshment dynamics described by interviewees here include alliances amongst subgroups in families; repressing one's true self to conform to family norms; absorbing others' negative emotions and moods; and/or wielding shame on family members to make them conform. One primary carer, while under intense strain, was attempting, with her sisters, to access respite care. She gave an example of how subgroup alliances within families can impede sustainability for primary carers, particularly when it comes to conflicting opinions on the acceptability of formal support and respite services:

"We really hoped to get dad into a day service. He wasn't very open to that at first, but not completely against it. Then one of our brothers agreed with dad and backed him up on it, saying 'he's not going to any day care' and that made the situation worse because it made dad more reluctant to try it. We didn't pursue it at that point, and then COVID-19 happened."

[Family A, Participant 2; Daughter]

Interviewees across multiple families noted that an unintended consequence of coming together to support a person with dementia is that family members can become too involved in what is going on in each other's lives:

"You know sometimes it isn't about them [the person with dementia] at all. One of the things that goes on with us anyway is just you know, because of looking after her, we are living on top of each other more than ever, and I've found that knowing too much about each other's business can lead to drama."

[Family I, Participant 19; Daughter]

One primary carer, experiencing particularly high levels of strain during the COVID-19 ‘lockdowns’, described how focusing on her siblings’ behaviours, i.e., lack of communication and contribution, produced feelings of anger and resentment, aggravating her stress:

“I’d to get onto my family and I’d be asking them, ‘can you please call her?’ They could have provided more support to her over the phone, even though they couldn’t visit. And when no one called, I would get very annoyed. My sisters, they might call once every three months, but they could have done weekly calls. That never materialized, and I’d get so angry.”

[Family C, Participant 7; Daughter]

A sentiment echoed by several interviewees is that remedying destructive patterns of family interaction involves establishing and maintaining emotional boundaries with other family members:

“One thing I’ve learned is that you can’t control other people, and you can’t let other people control you or your emotions.”

[Family A, Participant 2; Daughter]

“I’ve tried to stop concerning myself with what the others do or don’t do. You can end up ruminating and making yourself more upset. I still catch myself doing it, but when I do, I try and just say to myself I’m already stressed enough by the situation, I don’t need to sabotage myself too.”

[Family I, Participant 18, Daughter]

None of the interviewees in this study had been offered counselling through the public health system, nor had the person with dementia they are caring for; however many indicated an unmet need for counselling either for themselves, other family members, and/or the person with dementia.

Individual & Collective Capacity

Capacity refers to the internal resources and capabilities of the primary carer(s), and the capacity of the networks and systems available to support them to continue providing family-led care. This theme is comprised of three sub-themes:

- Internal Resources of the Primary Carer
- Support from Family, Friends and the Local Community
- Health and Social Care

Internal Resources of the Primary Carer

The internal psychosocial resources of the primary carer are particularly important to sustainability. As mentioned previously, some interviewees divulged doubts about their capacity to provide appropriate, person-centred dementia care, owing to lack of knowledge/training, and the added pressures that emotional ties can bring, in the context of family caring:

“I do my very best, but we are not equipped. Some days I think, ‘am I making this worse for her, or both of us’. Or days when I’m grouchy and tired, I might say something snappy, and then the guilt sets in. If I saw a professional acting as we sometimes do, I’d think, ‘this is bad care’”

[Family B, Participant 5; Daughter]

A particularly important factor here relates to the presence of behavioural and non-cognitive symptoms in the person with dementia, which can be especially challenging for family members to understand and manage. Agitation and aggression were cited as prominent behavioural features, which exacerbate carer strain:

Wife: *"He would be agitated a lot of the time. Like antsy... And he gets cross easily."*

Daughter 1: *"And he was never a cross man, but now he can get very bad... A bit aggressive at times. And he says mean, and sometimes inappropriate things."*

Daughter 2: *"It's a struggle. Sometimes you can distract him, but other times, there's no talking to him."*

[Family A, Participants 1-3, respectively]

Sleep disturbance was another behavioural symptom that interviewees noted wears down, not just the person with dementia, but the carer(s) also, and can impact upon their capabilities in other aspects of their life, as well as in the carer role.

"It's hard because dad is still working from home and minding mam. On days where she is in bed until noon or 1 o clock, its manageable for him. But the day before yesterday for instance she only slept for 2 hours. That means he can't have had more than 1 hour of sleep. And then she is pacing and agitated, and he still has to deliver his work. We don't get a week where she sleeps ok... She could not sleep for 2-3 nights and then sleep for 20 hours in one go"

[Family E, Participant 10; Daughter]

Psychotic symptoms were also cited as a great source of stress and strain for families, particularly when paranoia, delusions and/or hallucinations were centred on family members.

"It's very difficult because my mum and I had been very close but at that point there was a lot of paranoia in my mum that I was trying to make her out to be something that she's not. She felt that I was trying to control her every move, her money..."

[Family C, Participant 7; Daughter]

Externalising behaviours were not the only source of upset; apathy in the person with dementia was also upsetting for family members, particularly when the person becomes indifferent to things or activities that once gave them joy:

"I think to before, she loved animals and flowers... She would bring apples for the racehorses in the field nearby and feed them. And that all stopped. She stopped seeing the animals and the flowers. She just seems to have no interest in anything. It's sad."

[Family E, Participant 9; Husband]

One sentiment, which was echoed by interviewees across several families, was that the stage of dementia is also a factor, noting that it is not just moderate-severe dementia that is challenging for carers. One daughter pointed out how distressing it can be in mild-moderate stages, when the person with dementia has greater insight into what is happening to them.

"As mam got sicker, in some ways it was easier for us. It just got easier for us to manage her than it was at the beginning, when she knew something was wrong, and she couldn't cope with that. That time was more traumatic for her, and more traumatic for us too."

[Family E, Participant 11; Daughter]

The physical and mental health of the primary carer is another significant factor influencing the sustainability of their role and several primary carers acknowledged their own health issues/concerns, e.g., including autoimmune conditions, depression, heart problems, cancer, chronic pain issues, etc.

"I have my own health issues. Sometimes I get bad flare-ups, and he needs help now with showering, dressing, all those things. There are days that I'm in pain, completely exhausted, and I'm just not able to do it."

[Family F, Participant 12; Wife]

Other family members also acknowledged the important influence of the primary carer's health on sustainability. This sentiment was echoed by two sisters, in separate interviews; they both felt that the primary carer (their father) was just as vulnerable in terms of his health:

"He's going to burn himself out. His own health has gone downhill. He has heart problems, and the stress isn't helping. Our biggest fear now is his health, and that something will happen to him."

[Family E, Participant 10; Daughter]

"We say that we think mam will actually outlive dad, because outside of the dementia, mam is very healthy, but dad has a lot of his own health issues."

[Family E, Participant 11; Daughter]

However, some primary carers noted when you are responsible for someone with dementia with complex needs, it sometimes doesn't feel right to dedicate time to your own needs:

"I know that I need to put my own [oxygen] mask on first, but it just feels wrong."

[Family F, Participant 12, Wife]

While there are many factors that can serve to diminish caregiving sustainability in the primary carer(s), there are also qualities and traits which can enhance capacity. One daughter indicated that her father's robust leadership qualities have strengthened their capacity as a family, to continue caring:

"We're very lucky that dad is so well equipped in himself, to see and make the changes that needed to be made, and to do things for himself, and for her. He put the structures in place, rather than there being a structure given to us by the HSE for how to do this"

[Family E, Participant 10; Daughter]

She elaborated that his leadership style was underpinned by optimism and a solution focused approach, and accordingly, he led with a strengths-based view of dementia:

"She was only so well for so long because of dad believing she could do things. Even if we were going out for dinner, when it got to the point of it becoming difficult to bring her, he would still do it. That's his makeup and that outlook works well for him and us"

The strengths-based view of dementia, she added, has benefitted her mother, supporting her to be as independent as possible:

“The fact that he believes she can do things, and encourages her to try, that makes a big difference to her too.”

A few interviewees noted that humour can be a helpful coping mechanism in awkward situations, which might otherwise be upsetting, as outlined by one husband:

“This might seem a little dark, but we often laugh about it… One night we were in bed, and she turned to me and said, ‘what’s your name again?’ [laughs]. It is sad, but I have to say it was a hilarious situation in another way. So that’s to say we have had some funny and very nice times too, with the difficult ones. You need humour to get through. If you can laugh about it, it’s lighter…”
[Family E, Participant 9; Husband]

Support from Family, Friends and the Local Community

In families where there were ‘auxiliary carers’, i.e., relatives who contribute to the care in a way that regularly relieves the primary carer(s), the primary carers felt more optimistic about sustainability.

From the perspectives of interviewees who consider themselves engaged auxiliary carers, it is important that family members support the primary carer to achieve a physical and mental break from caring.

“From early 2019 it was evident to me and my sisters that dad needed to have someone at home every weekend. He couldn’t do a weekend on his own because he couldn’t leave the house anymore. Someone must be with mam all the time. It’s 24/7 care. Someone had to be there to relieve dad. So, we stepped up.”
[Family E, Participant 10; Daughter]

This works particularly well when multiple family members agree to share auxiliary care duties on a scheduled basis, to relieve the primary carer:

“We’re lucky really that there are four of us to help out and we all do our bit and it kind of balances out, you know?”
[Family E, Participant 11; Daughter]

This kind of family cohesion was not necessarily the norm, and a few primary carers felt they had very few people, if any, that they could share care responsibilities with.

“There’s no-one else to help, that’s what it comes down to… He has one sister, she lives in [USA]. His children don’t help, so it’s just me.”
[Family F, Participant 12; Wife]

The absence of felt support from family members can contribute to loneliness in the primary carer, especially as the dementia advances, and it becomes less feasible for the dyad to leave the house.

“It was a lot easier when we could still venture out into the world, be part of society.”
[Family A, Participant 1; Wife]

These feelings of loneliness and isolation further intensified during the COVID-19 lockdowns, both for carers and people with dementia:

"It was very sad to see her go downhill. She didn't speak as much. I could tell she was miserable. But there was nothing open, nowhere to go, no one to meet. And it wasn't safe either to be meeting people. You'd feel a bit out on your own."
[Family B, Participant 5; Daughter]

One of the benefits of having engaged family members, with whom they share responsibilities, is that they can contribute to planning and decision-making:

"We had to just come to terms with it and make a plan. My brother organized us all to meet to talk about how we would handle what might be coming down the line."
[Family A, Participant 3; Daughter]

Another benefit is that family members can share their care experiences and troubleshoot how to handle difficult care situations, for example, handling instances of confabulation (i.e., false memories or ideas, which the person believes to be real).

"We are still learning. A delusion she has sometimes is about things being taken. At first, we would try to convince her it wasn't real. But then we realised, it was real to her, and she was genuinely upset. We decided that instead of saying, 'no, they didn't take anything', we might say, 'will we help you look for it?'"
[Family H, Participant 16; Daughter]

Some interviewees here noted that they also draw on support from friends and neighbours, both in an informal, and a paid capacity:

"I feel lucky. As well as my daughters, I have local people and neighbours helping me, and the private carer who comes in - she's local too."
[Family E, Participant 9; Husband]

One husband described the power of his wife with dementia having a close friendship, as the dementia progresses. He notes that the friend encourages his wife to engage in leisure and domestic activities, in a way that meaningfully engages her, and lifts her mood.

"Yeah, [friend] is [wife's] best friend for years. She still comes once or twice a week and sits with her, or they go for a walk. She's great for her spirits. And she is good for [my wife], she will have herself and [wife] folding clothes, while listening to the radio or watching telly. Whatever ways she approaches it, it just works"
[Family D, Participant 8; Husband]

Not all primary carers have a supportive family network, and in these instances, having support from friends and neighbours becomes especially important. A few family members noted that it was comforting when neighbours, friends and even acquaintances were aware of the dementia diagnosis, because this enables a kind of 'community watch', which looks out for the person's safety, etc.

"Then she started taking off up the road. She'd be gone way up the bóthareen ('little road') and you'd have to jump in the car to go after her. But our neighbours are great, if they saw her walking by herself, they'd be over straight away making sure she was ok…"
[Family E, Participant 9; Husband]

In terms of the wider community, one aspect refers to employers of carers for people with dementia. For those who both provide dementia care and are in gainful employment, having understanding, flexible employers, is essential.

"Where I work there are a few people who have caring responsibilities and the bosses are very flexible in terms of where and how people wanted to work. I think if I were in a different work environment, it would be much harder for me to keep working"
[Family C, Participant 7; Daughter]

Some interviewees also indicated that services and establishments in the local community are not always dementia-aware or -friendly, which is one of the reasons that carers tend to stop bringing the person with dementia with them when they leave home.

"Mum doesn't want to leave the house now… And if she does go and we're sitting somewhere for more than 5 minutes, she can throw a strop. She wants to leave, gets upset, says she's getting a taxi home… I do think there has to be more consideration for people with dementia."
[Family C, Participant 7; Daughter]

One husband described the difference it can make to outings, when businesses/services are dementia-aware and understand that people with dementia may need additional support.

"We've always loved going away for a few nights. She loved going to a spa and getting pampered. One place was great because I told them about her issues, and they provided a staff member to help her around the ladies' changing room and make sure she could find and do everything."
[Family E, Participant 9; Husband]

Health and Social Care

Most interviewees highlighted the role of formal supports and services for dementia; and how they are mired by issues relating to under-provision, timely access, fragmentation, poor dementia care capacity, and low client acceptability.

The under-provision of formal dementia care services and supports was one of the strongest messages from family carers, many of whom made direct links between the absence of sufficient formal support, and care home admission:

"The lack of support from the HSE means we have to think about nursing home care"
[Family A, Participant 2; Daughter]

Indeed, many carers pointed out that even basic physical/personal care needs are sometimes not adequately met through current State provision of homecare.

"We needed home-help for mum and dad, but the local district nurse said that will take a while to set up and you won't get all the hours that you actually need. She was right on both counts."

[Family A, Participant 3; Daughter]

"They already seem to think that evening home help isn't needed, so I don't see them paying for the level of support we would need to keep dad at home."

[Family A, Participant 2; Daughter]

Furthermore, several families included here reported losing homecare hours since the beginning of the COVID-19 pandemic:

"Since COVID, were not even getting half of the home-help hours we should be getting. We had 16 or so hours before COVID and we don't even have 8 now."

[Family E, Participant 10; Daughter]

Another frustrating aspect for families is the fragmentation that exists in the health system, which makes it difficult to identify and access services and supports in a timely manner.

"What we find is the Public Health Nurse does this, but not another thing, and someone else does this, and 'we don't know who does that, but it's not me'. That's the way it is, dealing with the HSE."

[Family A, Participant 4, Granddaughter]

Many family carers called for a single liaison, such as a local dementia adviser, to be available to all carers, to help them navigate the health and social care system as, and when needed. Just three of the ten families reported having met with a dementia adviser in this study.

"It would be handy if there was one person we could go to and say this is the person you deal with, and they get you the support or direct you to it."

[Family B, Participant 5; Daughter]

Other problems, which have long-preceded, but have been exacerbated by the COVID-19 pandemic, relate to poor continuity of care, especially in the public health system, e.g., vacant consultant positions, substantial periods without specialist medical review, dropped correspondence, etc.

"So [the consultant] left, and we were completely without a consultant for over 18 months. And we had to find a private consultant to take her on in a clinic in Dublin."

[Family E, Participant 11; Daughter]

"He had a consultation, and a lady was supposed to call me back about dementia services, but I never heard from her."

[Family G, Participant 14; Daughter]

Families struggle with such fragmentation because it can lead to unmanaged symptoms and significant emotional distress.

“We were chasing things to help her sleep, things to stop her pacing – to no avail. Our thing is, we’re thinking is she pacing because she’s in pain, or upset, you know?”

[Family E, Participant 10; Daughter]

All family carers interviewed for this study pointed out that the single largest gap in need nationally, is for home-based social care, which can also provide respite for the carer, if they are temporarily relieved of their duties. This need is prominent enough that families that can afford private social care are willing to pay out-of-pocket for this form of support.

“Then it became obvious we needed more full-time care for her. I had to put a private arrangement in place with a local woman because there was nothing available to us. What she needed most was a companion. And we did get someone to come in, but we had to source and pay for that ourselves.”

[Family E, Participant 9; Husband]

The preference for additional community- and home-based respite options was clear amongst interviewees, many of whom have found traditional respite options, particularly residential respite in care homes or community hospitals, to have poor availability, capacity and acceptability. Low acceptability for people with dementia was a prominent barrier to using respite services.

Daughter: *“He was offered a place in [day service] but didn’t want to go. I think we’ll start talking about that again”*

Person with dementia: *“No, I don’t think so.”*

Daughter: *“Well, we will see...”*

[Family G, Participants 14 & 15]

Carers of people with early onset dementia noted that this group tend to have different needs and priorities than older adults with dementia, and so traditional respite options were even less acceptable to them.

“A lot of the other supports like day centres and all that, mam would have been too young to go there, she was 57/58 when she was diagnosed. That kind of environment, the idea of it, freaked her out.”

[Family E, Participant 11; Daughter]

Moreover, even where respite and other social services are available to families, some still don’t have the capacity to cater to the needs of people with dementia and therefore they are not eligible to attend.

“There is only one day service local to us and it’s not open to people who have dementia.”

[Family D, Participant 8; Husband]

This is especially the case when the person with dementia presents with behavioural and non-cognitive symptoms. One family here noted that it is not just respite services that don’t have dementia care capacity; even personal care (Home Support Service) services can be withheld where behavioural symptoms occur.

"We had home-help services coming in until COVID-19 hit. Then the decision was made to stop all outside people coming in. In retrospect, cancelling the home-help wasn't a good choice because we never got it back. We were told that because of her behaviour issues, she would now need additional home help staff, and even at that, they would find it hard to handle her. So, it seems the health service can't help us that way anymore."

[Family E, Participant 9; Husband]

Furthermore, two families indicated that even in the hospital setting, dementia care capacity is sometimes poor, and family carers taken for granted. One daughter outlined how she felt the system had taken advantage of her during an already stressful time.

"When the eye thing happened last year, I had to stay in hospital 24/7. They kept saying there was no aide available to be with her. I think because I was there, they just thought, she's there, she will do it. For two whole days and nights I stayed there. I didn't get any sleep. They were the ones who insisted, 'she has dementia, someone has to be here with her all the time'. But they meant me. They knew I wouldn't leave her."

[Family C, Participant 7; Daughter]

Finally, it is worth noting that COVID-19 has played a significant role in patterns of access to health and social care, since March 2020. While some families have had some limited contact with their public health nurse and/or GP, other families reported having not had input from a healthcare professional since before the pandemic began.

"She hasn't been seen by a specialist in over 2 years, since before COVID."

[Family H, Participant 16; Daughter]

"We've had no contact with the dementia adviser since before COVID, and outside of the public health nurse once, we didn't hear from anyone in the HSE since COVID."

[Family C, Participant 7; Daughter]

Financial Factors

A key concern for interviewees was how little value the government appears to place on the care work undertaken by family carers of people with dementia. One important issue relates to failure to compensate carers appropriately and fairly for their time and work.

"Informal carers need to be properly recognized money-wise for what we do."

[Family B, Participant 5; Daughter]

Some interviewees reported that nobody in their family is willing to be designated as the official primary carer, either because they don't want to commit to assuming the most responsibility, and/or they can't afford to leave full-time employment to be the primary carer. This means some families forego applying for the Carer's Allowance.

"We don't get the Carer's Allowance because no one wanted to be the official carer on paper. So we pay for most things ourselves. We are not wealthy people, which is why none of us can afford to take on the official carer role."

[Family I, Participant 18]

Some of the costs that are absorbed by families include personal care materials and medications. A few interviewees pointed out that even though dementia is an economically burdensome condition for families, it doesn't qualify for the Long-term Illness scheme.

"Dementia doesn't fall under the long-term illness scheme so the medications costs aren't covered. I personally cannot understand why not."
[Family E, Participant 10; Daughter]

Another significant cost shouldered by families relates to purchasing materials needed for care, e.g., continence wear (and subsequent disposal of same):

"We get a delivery every two months. Even in the beginning that delivery was never enough for mum. All you get is the bare minimum continence wear. So not only are you providing care with no support, you are also having to fork out for extra continence wear. All these little things keep adding up. It's expensive, and I'm a one-income household."
[Family C, Participant 7; Daughter]

"The other thing is she's incontinent now as well... The PHN came to do an evaluation and told us what we could buy in the store. But the packs are €10 or so, and on a bad day she could go through a whole packet. It's just another expensive thing we pay for."
[Family B, Participant 5; Daughter]

An additional factor, noted by a handful of interviewees, is how money can become a point of contention in families, especially if the person with dementia doesn't recognise their own need for care. Speaking about the prospect of privately purchasing in-home care for her mother, one daughter explained:

"We don't have that money to pay privately. And we never got her finances in order because she wasn't going to give us control over that... She's adamant she can control everything herself. She won't pay for care because she thinks she doesn't need it. She says there is nothing wrong with her and we should mind our own business."
[Family C, Participant 7; Daughter]

Some interviewees who were in a more financially secure position, and able to pay out-of-pocket for the materials and services needed to provide dementia care at home, acknowledged the strain this must put on families with lower incomes and/or those who are surviving just on the Carer's Allowance.

"We're lucky dad has a good job, but I don't see how some people, especially those who had to stop working, how do they get by? You could see how people might have to make a choice between buying medication and buying groceries."
[Family E, Participant 10; Daughter]

One family that needs, but cannot afford, more in-home care agreed that nursing home admission is likely imminent, not because they want this, but because they are left with no other viable option.

"It would be fantastic if we could have a professional come help us out to take some pressure off me and [sister], but you know that's not really an option for us financially. We're not left with any options, only to go the nursing home route."
[Family G, Participant 14; Daughter]

Several interviewees insisted that Government should commit to redirecting funds that would otherwise be used for residential care, toward community and home-based care. One woman elaborated on this, suggesting that alleviating the pressure on the family, may strengthen family relationships, and ultimately, create a far more sustainable situation.

"If the HSE were to provide you with the funds they would be spending on residential care, so you could get in-home care, you would know she had someone there with her and was safe. That would be the ideal scenario. I think if that were the situation, some of the family would call more often... The pressure would be off to care, we could just be family."

[Family C, Participant 7; Daughter]

Interviewees across most families noted that the economics of caring is not just about the direct costs of caring; the opportunity costs of caring must also be factored in. Many of the participants included here reported forgoing opportunities for employment and career progression, both at home and abroad, either to be the primary carer, or to be near home to support the primary carer:

"I was offered an opportunity abroad that was very attractive to me, but I knew that it really wouldn't have been feasible for my home life to make it work."

[Family E, Participant 11; Daughter]

CONCLUSIONS AND IMPLICATIONS

This study aimed to explore the range of factors that influence sustainability in family caring for people with dementia in the community. We conducted in-depth interviews with 20 carers from 10 different families supporting someone with dementia, across every province in Ireland.

Four key themes were identified and are summarised in Table 2 below. The factors influencing sustainability across each of the four themes are divided into potential barriers and facilitators.

THEME	FACTORS INFLUENCING SUSTAINABILITY	
	Barriers	**Facilitators**
1. Cultural Norms & Narratives	Deficit views of dementia Stigma Duty of care presumed to lie with family	Strengths-based views of dementia Recognition of personhood Questioning the family as a neutral point of care provision
2. Family Relationships & Dynamics	Poor quality pre-morbid family relationships Changing roles within the family Conflicting perspectives on formal social care use Enmeshment dynamics	Primary carer has leadership and coordination skills Open, empathic communication Good listening skills and ability to perspective-take
3. Individual & Collective Capacity	Poor carer physical health Presence of behavioural/non-cognitive symptoms Poor carer mental health Other responsibilities (e.g., childcare, employment) Poor access to health and social care (especially community-based respite options) Poor dementia care capacity across health settings	Setting emotional boundaries Dementia care education for families Dementia-friendly communities & businesses Supportive social network Presence of other family members to relieve the primary carer Timely access to acceptable models of respite Peer support, Counselling
4. Financial Factors	High cost of care for families Hidden out-of-pocket costs	Family carers having supportive employers Financial advice Financial supports (but existing supports are inadequate)

IMPLICATIONS

We will now situate the findings specifically within the Irish context, to determine what they might mean for policy and practice, considering 1) shifting sociodemographics and cultural norms, 2) health system factors, 3) policy and legislation and 4) financial supports, as they relate to the sustainability of family-led, community-based dementia care.

1. Shifting Sociodemographics and Cultural Norms

When planning for future dementia care in Ireland, the shifting sociodemographic profile must be considered. The population-level need for family care is influenced, not just by the prevalence of disability and chronic illness, but also by labour market and other trends. What is often ignored in this conversation, is the role of women, in terms of both unpaid care work and participation in paid employment. As noted in chapter 1, the prevalence of dementia is growing rapidly, as the population ages. Family care is gendered, in that women are more likely to occupy care roles than men; according to the most recent census in Ireland, approximately 60% of carers are female (CSO, 2016). However, too often we ignore other parallel trends, e.g., how 1) growing female participation in paid employment, 2) increased geographical dispersal of extended family, and 3) increased average age of first-time mothers, are diminishing the availability and feasibility of family-provided care. This is a problem which needs to be tackled with urgency by senior policy- and decision-makers, especially given that dementia care costs €1.7bn annually, and that the person and their family bear almost half of this cost (Connolly et al., 2014). The State is therefore relying on a precarious situation, whereby under-valued family members are increasingly less likely to forgo paid work, to undertake a caring role.

One of the main problems facing the future of family care is the lack of incentive for either men or women to leave the paid labour market, in order to dedicate more of their time to family care, with minimal financial support. According to an ESRI report by Russell et al (2018), the care needs of a population are met through a combination of a) state, b) market and c) family provision. While state and market provision are regularly measured, Russell et al. (2018) point out that family-provided care is rarely quantified, in part because it doesn't involve direct financial exchanges. Folbre (2015) argues that by not representing unpaid care work in National Accounts of economic activity, the total care work that is done in many countries, including Ireland, remains unknown.

Some recognition of this issue in recent years has led to discussions about the need for a referendum regarding Article 41.2.1 of Bunreacht na hÉireann (the Irish Constitution). This refers to the contribution of women specifically, relating to the importance of their role 'in the home'; the purpose of this article originally was to support women, especially those with dependent family members, to remain at home, so they could focus on family care. However, Article 41.2.1 was born of a different time and cultural context, one which was more facilitative of traditional patriarchal structures and values. The legacy of this is that many family carers now feel pressure to participate in paid employment and unpaid family care work. This is in line with the findings of Family Carers Ireland's State of Caring (2020) survey, which reported that amongst carers who work full-time, 75% also provide 50+ hours of care per week. This pattern is supported by evidence; despite a narrowing gender gap in employment rates, gender differences in unpaid care work remain prominent (Blossfeld and Drobnic 2001; Bianchi et al., 2006; Gershuny, 2018). According to Gregory (2010), when family carers in employment take various forms of leave to care or exit the labour market early to assume a full-time care role for dependent relatives, their lifetime earnings and pension entitlements are significantly reduced, putting family carers, especially women, at an increased risk of poverty in their later years (discussed more later). In light of the felt lack of value expressed by family carers in this study, and the imminent dementia care crisis, it is crucial that we begin placing more value on the work of family carers. According to Russell et al (2018), the first step towards truly valuing care work is measuring it. There are many ways in which we could capture such data, one of which is to establish a National Carer's Registry. A key benefit of a Registry would be that data regarding the number of carers and their basic demographic characteristics (e.g., sex, age group), the diagnosis of the care recipient, and the time spent caring, would be available to inform the development of a more responsive health and social care system. A registry would also enable more efficient identification of family carers who are entitled to various financial supports, e.g., the carer's pension.

In addition, while views on dementia are slowly changing, the experiences of family carers here indicate that we have much more work to do regarding creating non-stigmatising public awareness and narratives of dementia. Public awareness initiatives and media depictions of dementia must carefully consider the implicit messages that are being communicated to the public. This includes ensuring that dementia is not characterised solely by deficit, loss, and disability, in a way that implies denigration of personhood. Depictions should emphasize the importance of how the environment and interpersonal interactions and relationships can support personhood and dignity and can offset some of the limitations associated with the dementia condition. The 'Understand Together' campaign has been one such positive national awareness campaign, led by the HSE's Health and Wellbeing division, in partnership with the Alzheimer Society of Ireland and Atlantic Philanthropies.

The above point is not to suggest that awareness campaigns and/or media publications should omit or airbrush the challenges that people with dementia and their families face; instead, it is about not demonizing dementia as a condition, or 'othering' people who live with it. There is a great deal of literature analysing media narratives of dementia, demonstrating how dementia is often implicitly framed as akin to zombiehood and other dehumanized states (see Behuniak, 2011; and Aquilina & Hughes, 2006). Those involved in creating content for media have a professional responsibility to report dementia in a balanced, unsensational manner. Media reporting guidelines may play a crucial role in reshaping dementia constructions and narratives, especially in news media. The Alzheimer Society of Ireland have created Dementia Friendly Language guidelines which are helpful in this respect. The Alzheimer Society in the UK have also published detailed guidelines on media reporting of dementia, as have other dementia organisations worldwide (e.g., Dementia Australia). It is important that those who shape national and international narratives on dementia are made aware of existing reporting guidelines, and that editors and curators of content enforce them.

2. Health System Factors

The Irish health system is unusual within the European context in how it is characterized by two tiers, i.e., public, and private (OECD, 2017). The inequity associated with this system is well-noted (Burke et al. 2018), and the findings here indicate that this structure adversely impacts patterns of access to formal health and social care for families dealing with dementia. Those with more personal resources and/or who can afford private health insurance gain more rapid access to assessment, treatment and/or care than those in the public system, irrespective of need.

A second characteristic of the Irish health system which was reflected in the present findings is a long history of under-resourcing community care. This shows up in many of the findings here from the family carer perspective, in terms of poor availability and access to homecare support, respite and day services, lack of financial supports for materials and medications relating to the dementia condition, etc. This is supported by the Connolly et al (2014) finding that formal health and social care services contribute to just 9% of the total cost of dementia care in Ireland. In the 'Paying the Price' survey of family carers by FCI, almost half (49%) said that formal health services and supports were not available to support them in their role. The 2021 Budget pledged to create 16,000 additional posts across the healthcare sector, however it is not yet clear which areas of the health system might benefit from this. Perhaps the most urgent need currently, based on the present findings, is to address the shortage of formal homecare workers. As participants in this study explain, getting approval for the amount of homecare hours needed is increasingly difficult, and even where home support hours have been approved, the service sometimes can't commence because a homecare worker isn't available locally (FCI, 2021). Policy decisions that have influenced this pattern of under-resourcing are discussed further below.

The most obvious unmet formal service need reported by family carers in this study is for community- and home-based respite care. In Ireland, just two models of respite are available in the case of dementia, i.e., residential respite in institutional settings and adult day services. Similar to the lack of national data on the contribution of family carers to the total amount of care provided, there is also an absence of data pertaining to total respite service provision for dementia in Ireland. However, in 2018, a national mapping study of dementia-specific services was conducted by the Alzheimer Society of Ireland in collaboration with the HSE's National Dementia Office. The authors concluded that day service provision is weak and fragmented, and that capacity varies greatly across Ireland's nine CHO regions, ranging from 106-350 day service places (ASI, 2018). This is in line with the 'Paying the Price' survey finding that almost three-quarters (74%) of older adults requiring substantial care (i.e., 100+ hours/week) had no access to home support services that permit the family carer to leave the home. In a recent evaluation of Government's commitment to supporting family carers, FCI (2021) underlined the 'continued under-resourcing of appropriate respite care, across the life course'.

A qualitative study by O' Shea et al. (2019) explored multiple stakeholders' perspectives (N=35) on accessing respite services in the context of dementia in Ireland. The study reported on factors which influence patterns of respite access for dementia, including, 1) respite service acceptability, 2) the family's abilities to navigate the fragmented health and social care system, and 3) the state's failure to recognize the respite needs of family carers. All three themes are consistent with the present findings. Additionally, it is worth noting that institutional models of respite tend to have the lowest acceptability for families supporting someone with dementia (O' Shea et al., 2019). Each of the families in the present study indicated that in order to facilitate sustainability, effective models of community- and home-based respite must be made widely available to family carers. The Programme for Government has committed to developing a 'Carer's Guarantee' proposal that will provide a core basket of services to carers across the country, regardless of where they live. Despite €2 million being dedicated to this in Budget 2021, just €100,000 of it had been allocated by November 2021. Unfortunately, no concrete progress has been made in relation to developing such a proposal, as of January 2022. FCI's submission to the Department of Health, regarding the development of the Statutory Homecare Scheme, clearly outlined that any home support package must include regular, flexible, and appropriate respite, where needed.

A further factor influencing sustainability relates to the inadequate supply of psychosocial supports, including formal counselling and psychotherapy, and psychoeducational interventions, both for people with dementia and family carers. Appropriately resourcing such supports would bolster the resilience of primary carers and improve relational dynamics within families engaged in dementia care. Only a minority of family carers included in this study reported accessing any psychosocial supports, and those that did paid out-of-pocket or through private health insurance, demonstrating a stark inequity between those with and without means. Previous research has found that 30-40% of family carers experience clinical depression or anxiety (Brennan et al., 2017; Lafferty et al., 2014). In addition, a recent survey of 566 family carers of people with dementia found that 16% of family carers of people with dementia were suicidal (O'Dwyer et al., 2016). In light of the present findings about primary carers' internal resources, and how family dynamics can have a significant influence on sustainability, it is important that we validate and roll-out interventions which can support a positive psychology and constructive interpersonal patterns of communication amongst family members.

Ireland's updated national mental health strategy, 'Sharing the Vision' was published in 2020 (DoH, 2020), and €38m was allocated to its implementation in the 2021 Budget. The strategy indicates that people requiring specialist Mental Health Services for Older People (MHSOP) should receive that service regardless of their past or current mental health history. It also specifically states that people with early onset dementia should have access to MHSOP (p. 60), which is important given those with early onset dementia can have especially poor access to formal services. There is no specific mention of provisions or actions regarding family carers in 'Sharing the Vision', despite family carers being a particularly vulnerable and notoriously under-supported group in society.

Finally, as most families in this study outlined, one of the biggest access barriers across health services for dementia is the absence of a dedicated key worker or point of contact, within the health system, to help families source appropriate services in a timely manner. This is a known gap in need and is addressed in most relevant policies relating to family carers and dementia care. In response to this gap in need, the Alzheimer Society of Ireland created the 'Dementia Adviser' service, an individualised information, advice and signposting service for people with dementia and their carers. The service is currently funded by the HSE and operationalized by ASI. As of February 2022, there were 29 dementia adviser posts across Ireland, with one covering every county. This role is indispensable to families trying to understand dementia and navigate the health system in the post-diagnostic period. However, while many dementia advisers do have clinical backgrounds, the role does not have an official clinical remit. According to an evaluation of the service (Coffey et al., 2018), which was largely positive, this means that integration with existing services and supports is more difficult, and many health and social care professionals involved in dementia care are not fully aware of the role, or its scope. Work is ongoing to develop awareness of the role amongst health and social care professionals who encounter people and families, in the context of dementia.

One more initiative that is relevant to supporting family carers is the development of the interRAI Family Carer Needs Assessment. The Carer Needs Assessment Development (CNAD) Working Group was commenced, which included a Family Carer Reference Group, to ensure adequate representation of the perspectives of family carers. The purpose of the CNAD Working Group was to design, develop and pilot a new assessment tool, which comprehensively assesses the unmet needs of family carers of older people, and support them to make contingency plans in the case that they are not available, or unable to continue the caring role. The group produced the interRAI Family Carer Needs Assessment approximately five years ago, in 2017. The following year, Government funding from Dormant Accounts was secured to pilot the new tool. Community Healthcare West was chosen as the site for this pilot, but the roll-out is yet to commence.

3. Policy & Legislation

The National Carer's Strategy was first published in 2012, outlining cross-departmental actions to be undertaken by Government, which were intended to improve the wellbeing and quality of life of family carers. In 2020, the Government, acknowledging poor implementation of the Strategy actions, committed to developing an updated National Carer's Strategy in the Programme for Government (p.76). Unfortunately, as of January 2022, preparatory work for this is still not underway, despite Government having pledged it as a priority for 2021. It is crucial that an updated Carers' Strategy and action plan is developed in 2022, in collaboration with representative stakeholder groups and organisations, and that ring-fenced funding is allocated for its delivery.

Another relevant policy is the first Irish National Dementia Strategy (NDS). This was published by the Department of Health in 2014 and outlined 35 key actions to improve dementia care in Ireland, across six action areas: Better Awareness and Understanding; Timely Diagnosis and Intervention; Integrated services, Supports and Care; Training and Education; Research and Information Systems; and Leadership. To facilitate implementation, an investment of €12.5 million was made by Atlantic Philanthropies, and an additional €15 million was committed from the Department of Health and the HSE. In May 2018, a review of the NDS implementation process was conducted, chaired by the Department of Health. Progress was noted in 17 of the 35 action areas, which was facilitated by the establishment of the HSE's National Dementia Office in 2015. The remaining 18 action areas had not yet been fulfilled, though some preliminary work had been conducted on 17 of these outstanding areas. In 2019, an external evaluation report of the NDS implementation was published by IPSOS and University College Cork. The authors designate the roll-out of Dementia Intensive Homecare Packages (IHCP) as one of the most important outcomes of the strategy. In light of the dearth of community and home-based supports for dementia, as experienced by family carers in this study, this initiative should be continued and expanded on. The Alzheimer Society of Ireland has been vocal about calling on the Government to make extra funding available for further implementation of the National Dementia Strategy (ASI, 2018).

EU Directive on Work-Life Balance for Parents and Carers

In line with experiences regarding supportive employment environments, the State of Caring (2020) survey found that 52% of employed family carers said more flexibility in their work hours would help them to continue participating in the paid labour market. One-in-five working family carers reported that allowances for working from home would play another important role in sustainability, and the COVID-19 pandemic has shifted patterns of working in some sectors, in line with this. The European Union Directive on Work Life Balance for Parents and Carers, legislates for i) the introduction of a minimum of five days of leave each year for family carers who are also in paid employment and (ii) the right to flexible working to facilitate them in their care role. This directive has been entered into European law, and is expected to be transposed into Irish law in August 2022. In terms of practical initiatives and awareness raising, FCI provide the 'Caring Employers' programme; this aims to deliver education and advice on fostering inclusive work environments, which are understanding of the needs of employees with family care responsibilities. Importantly, it also educates companies and services on the evidence that not considering the flexibility needs of family carers can have negative impacts on businesses. Another way in which companies could be incentivized to provide a more carer-friendly work environment, would be to introduce a tax break for companies that incur expenses through establishing such policies and practices.

Statutory Homecare Scheme

The 2012 Primary Care Strategy advocated a shift from hospital to community- and home-based care. Many other policy and strategy documents have echoed the need to build formal care capacity in the community, including but not limited to, the National Carer's Strategy (2012), the National Dementia Strategy (2014), the National Positive Ageing Strategy (2013), and of course, the SláinteCare reform policy. SláinteCare is Ireland's current national health and social care reform policy, planning a shift from our two-tier public-private system, toward a new model of coordinated universal health and social care, with an emphasis on primary and community-based care.

It is in line with this health system reform proposal, that the Statutory Home Care Scheme is currently being developed. It is important that such a scheme is developed using a whole-of-Government approach, characterized by cross-party and -departmental collaboration. The reason for this is that people with dementia and family carers, like all other citizens, have rights and needs that extend beyond healthcare, e.g., in relation to housing, education, rural and community development, social protection, transport, etc. It is also important that any statutory scheme does not have too narrow a focus, e.g., sole focus on personal/physical care, sole focus on older adults, etc.. Homecare packages should be tailored to the needs of each recipient family, based on the Single Assessment Tool (SAT; including the Carer Needs Assessment, when finalised) and should include, as appropriate, a range of home-based supports, including assistive technology, aids and applications, respite, personal care, meaningful and engaging activities, housing grants to adapt environment based on needs, etc. Of note, originally the SAT was intended for an older adult population; it is important that those with early onset dementia, under 65 years, should also be included.

Critics have pointed out that while many national policies clearly communicate an intention to develop community health and social care capacity, resource allocation decisions are inconsistent with this. In 2018 the Government published the Health Service Capacity Review. The review showed that €408m was allocated for homecare in 2018, while more than double that (€962m) was allocated to the Nursing Home Support Scheme. This also represented a €22m increase in funding for long-term residential care compared to the previous year. The experiences of family carers in this study demonstrate that while plans for the roll-out of the homecare scheme are still in flux, nursing home admission remains the only feasible option for many families of people with dementia on the margins of care. This is because the 'Fair Deal' residential care scheme is still the only established pathway to ensuring safe, consistent, and affordable care for the person with dementia. This situation leads to excess stress and burden for family carers who are already struggling considerably, especially when it is the stated preference of the person with dementia, and/or other family members, that they remain at home.

In a submission to the Department of Health in 2018, FCI highlighted several significant concerns about the proposed Homecare Scheme, including: 1) the co-payment approach to financing, 2) restriction of remit to 'older people' only, and 3) the absence of a statutory definition regarding where the ultimate responsibility for care should be located, between State and Family. Given the financial pressures that many families living with dementia are under, it is important that other financing approaches are considered, along with co-payment, e.g., general taxation, social insurance, private insurance. An important finding of this study is that family carers of people with young-onset dementia are particularly disadvantaged when it comes to accessing support from formal health and social care services, because the person with dementia doesn't fall under the remit of Older Persons Services. The third concern, i.e., the failure to clearly define the boundaries of state versus family responsibilities in relation to homecare provision, is of particular importance based on the perspectives of family carers in this study. Unless the boundaries of responsibility are transparent and well-delineated, we will not have a reliably regulated or equitable homecare system. One significant challenge relating to the eventual national roll-out of the Scheme relates to how it can be feasibly implemented in more rural areas, especially given the widespread shortage of homecare workers across the country at present.

Assisted Decision-making legislation

The Assisted Decision-making Act was signed into law in December of 2015, replacing the Wardship system; however, it has still not been commenced in full, as of December 2021. The Act is an important and progressive piece of legislation, underpinned by a flexible, functional approach to capacity. This means, instead of a person being deemed categorically 'incapacitated' and losing their decision-making rights, the new legislation decrees that capacity should be determined on 1) an issue-, and 2) a time-specific basis. The Act places a legal responsibility on health service providers, clinicians, and other health professionals to include those appointed to participate in decision-making processes, in relevant discussions relating to the person's Advance Care Directive. There are three main decision-making support options, depending on the level of support needed by the person at that time. This will serve to assist adults with various levels of cognitive impairment to make decisions about their own finances, healthcare, personal welfare, property, etc. Notable features of the Act include: 1) tailored formal decision-making agreements, and 2) supervision of those appointed by the person, by the Director of the Decision Support Service, to ensure the person's will and preferences are being upheld, and their dignity supported.

Undoubtedly, the Act will influence family care relationships, particularly in the case of dementia. Family carers in this study noted the conflict that can arise within families, because they feel they need to make decisions on behalf of the person with dementia, in accordance with what they believe is in the persons' best interests. This speaks to how family carers struggle because they want to respect and support autonomy and independence in their family member with dementia, while also striving to minimize risk. Family carers here indicated that this very tension can be one of the most frustrating and upsetting day-to-day stressors for the person with dementia and/or family members, especially when the person with dementia still has awareness of their condition. Common examples of this tension in practice occurred about living arrangements, driving cessation, day care and respite attendance, etc. Current understanding of the Act amongst family carers is poor, with the State of Caring survey reporting that three-quarters (73%) are not aware of the Act, while a further 13% noted that they have heard of the Act but do not understand the implications. It is important before the Act is fully commenced, that healthcare providers and professionals implement it in a way that educates family carers on all facets of decision-making by providing, as necessary, e.g., information packs/online resources, education/training courses, a dedicated telephone helpline, and/or the support of a dedicated key worker, e.g., dementia adviser. In a recent press release (November, 2021), the Government committed to full commencement of the Act, by June 2022.

4. Financial Supports

The 2020 Programme for Government, 'Our Shared Future' acknowledges that family carers are 'the backbone of care provision in Ireland' and that they 'deserve support and recognition from Government' (p. 76). The findings of this study indicate that family carers continue to feel significantly under-valued and under-supported on many levels, especially financially. While family carers are understanding of the fact that the COVID-19 global pandemic disrupted many of Governments' planned commitments, some also indicate that the lack of appreciation and adequate financial support for family carers, including those of people with dementia, have long-preceded the pandemic.

In FCI's 'State of Caring' (2020) report, some stark findings were outlined in relation to the financial aspects of family care. Key findings include that: 79% of those in receipt of the Carer's Allowance find it difficult to make ends meet; and approximately 1-in-3 (29%) carers have a total household income of less than €20,000. Another finding, one which was strongly echoed in this study, is the expense associated with care-related materials, e.g., incontinence materials, and their disposal. Some other bleak findings in the report relating to family carers who struggle financially include: 21% report having to cut back on essentials such as food and heating in order to make ends meet; 25% cannot prepare for future care needs because they have no savings and live on a low income; and over one-third (36%) admitted forgoing or delaying a necessary visit to a healthcare professional, due to the costs that would be incurred.

At present in Ireland, financial support for family carers of dependent adults consists principally of direct income supports, i.e., either the Carer's Benefit which pertains to pay-related social insurance contributions, or the means-tested 'Carer's Allowance' scheme and the annual Carer's Support Grant (formerly known as the 'respite grant'). Noting the low thresholds in the means-testing process for the Carer's Allowance, FCI made the following important reform submissions for Budget 2023:

- Commission an immediate independent review of Carer's Allowance including an examination of the abolition of the means-test.

In the interim:

- Increase the rate of Carer's Allowance to €325 per week.
- Increase the income disregard for Carer's Allowance to €1,500 (couple) and €750 (single) and thereafter adjust the means-test parameters over 3 years to ensure the effective abolition of the test for the population with a household income of less than €100k.
- Recognise the costs of caring in the allowable deductions for Carer's Allowance, including medical expenses, fuel, mortgage repayments and dependent children and assess income on net value.
- Include Carer's Allowance as qualifying payment for Fuel Allowance and increase excess to €140.

Between budgets 2021 and 2022, some progress was made in relation to direct income supports and income and capital disregard. There was an increase in the annual Carer's Support Grant, from €1,700 to €1,850. This demonstrates progress but falls short of the €2,000 that FCI have been advocating for in policy submissions to Government. Income disregard for the Carer's Allowance means-testing process was increased to €350 for single people, and €750 for couples, again demonstrating progress but falling short of FCI recommendations. The capital disregard for the Carer's Allowance was increased to €50,000, in line with FCI's recommendation. One disappointing decision is that the Carer's Allowance is not classified as a qualifying payment for obtaining the Fuel Allowance, despite the excess heating costs incurred as a result of providing full-time care in the home.

Other financial support issues relate to reforming the system of tax reliefs and credits, and pensions. Currently, the only tax relief available to a single person caring for an adult relative is the Dependent Relative Tax Credit, which amounts to €240. It is also a cause of frustration for many that single carers cannot avail of another form of tax relief, i.e., the Home Carer Tax Credit. This credit of €1,600 is only available to married couples or those who are jointly assessed for tax. This means that single carers of non-offspring, adult relatives are at a distinct financial disadvantage regarding tax relief, especially when you consider the more sizeable credit (€3300) applied to parents/guardians of children and adult offspring with a disability, through the Incapacitated Child Tax Credit. As mentioned earlier, regarding the State pension system, family carers are at a stark disadvantage. A 2021 report from the Commission on Pensions, which has been established to examine pension reform options (e.g., relating to qualifying age, contribution rates, total contributions, and eligibility requirements), made vital recommendations. These include introducing a 'Total Contributions' approach to pensions for long-term carers, which will serve to better reflect the contributions family carers make to society through their care work. This will involve the Exchequer applying credited contributions, to ensure that family carers are not at a systematic disadvantage, because of their care role. The recommendations are now being examined by the Cabinet Committee on Economic Recovery and Investment for consideration, and a response is expected within the first quarter of 2022.

FINAL CONCLUSIONS

This study has explored the constellation of factors that influence the sustainability of family-led dementia care in the community at many levels, i.e., individual, relational, community, health systems and sociopolitical. The findings indicate that while some progress has been made in recent years in relation to supporting family carers, there is still a long way to go to future-proof this situation, by better supporting and valuing family carers of people with dementia. The 'Understand Together' campaign has increased dementia awareness at population-level, however there is still much work to be done to change public perception and narratives of what it means to live with dementia; balanced, non-sensationalised media reporting is essential. It is clear than home- and community-embedded supports are greatly lacking, particularly outside of urban areas. Some families feel somewhat abandoned by the state, in the absence of having a point of contact for advice and signposting, timely access to acceptable respite, peer support, psychoeducational and counselling services, and/or appropriate recognition and monetary allowances/compensation for the care work that they do in the home. To complicate issues around sustainability further, some families have maladaptive relational dynamics (e.g., power struggles, enmeshment, disengagement behaviour) which can hamper sustainability, e.g., thwarting decision-making processes relating to the person with dementia and their care; and causing fatigue, frustration and even burnout for carer(s). Some families need a moderating presence to support constructive familial communication and decision-making, in a way that is empathy-driven, and person-centred. Given Ireland's ageing population and shifting norms pertaining to gender roles, the prevalence of dementia will continue to rise as the availability of potential and/or willing family carers diminishes. The need for the State to take greater responsibility for functionally, psychosocially, and economically supporting families to provide sustainable dementia care at home has never been so pressing. Building the necessary capacity in home care services, and within local communities is paramount.

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