SUSTAINCARE: SUPPORTING FAMILY CARERS OF PEOPLE WITH DEMENTIA

DR EMMA O' SHEA
CENTRE FOR GERONTOLOGY & REHABILITATION
UNIVERSITY COLLEGE CORK

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ABOUT THE PROJECT

- Funded by the Irish Research Council
- Partnership with Family Carers Ireland
- 9-month duration
- Aim: To understand the factors that influence the sustainability of family caregiving in the context of dementia

UCC
University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

Centre for Gerontology and Rehabilitation
An tIonad Seaneolaíochta agus Athshlánaithe

Family Carers Ireland
No one should have to care alone

IRISH RESEARCH COUNCIL
An Chomhairle um Thaighde in Éirinn

BACKGROUND

- Families provide the bulk of dementia care in Ireland
- Over 60% of the 55000 people with dementia (PWD) in Ireland are living in the community
- Most rely on support from family and other informal carers, to avoid institutionalisation
- Almost half (48%) of the cost of dementia care is attributable to the opportunity cost of care provided by family (Connolly et al., 2014).

EMPHASIS ON THE FAMILY

- Typically dementia care research focuses on the primary carer(s) and the person with dementia
- But - care dyads don’t exist within a vacuum
- They are mostly (though not always) part of a wider family network, and part of a local community, etc.
- Take a holistic view of factors supporting resilience in families supporting someone with dementia

METHODS

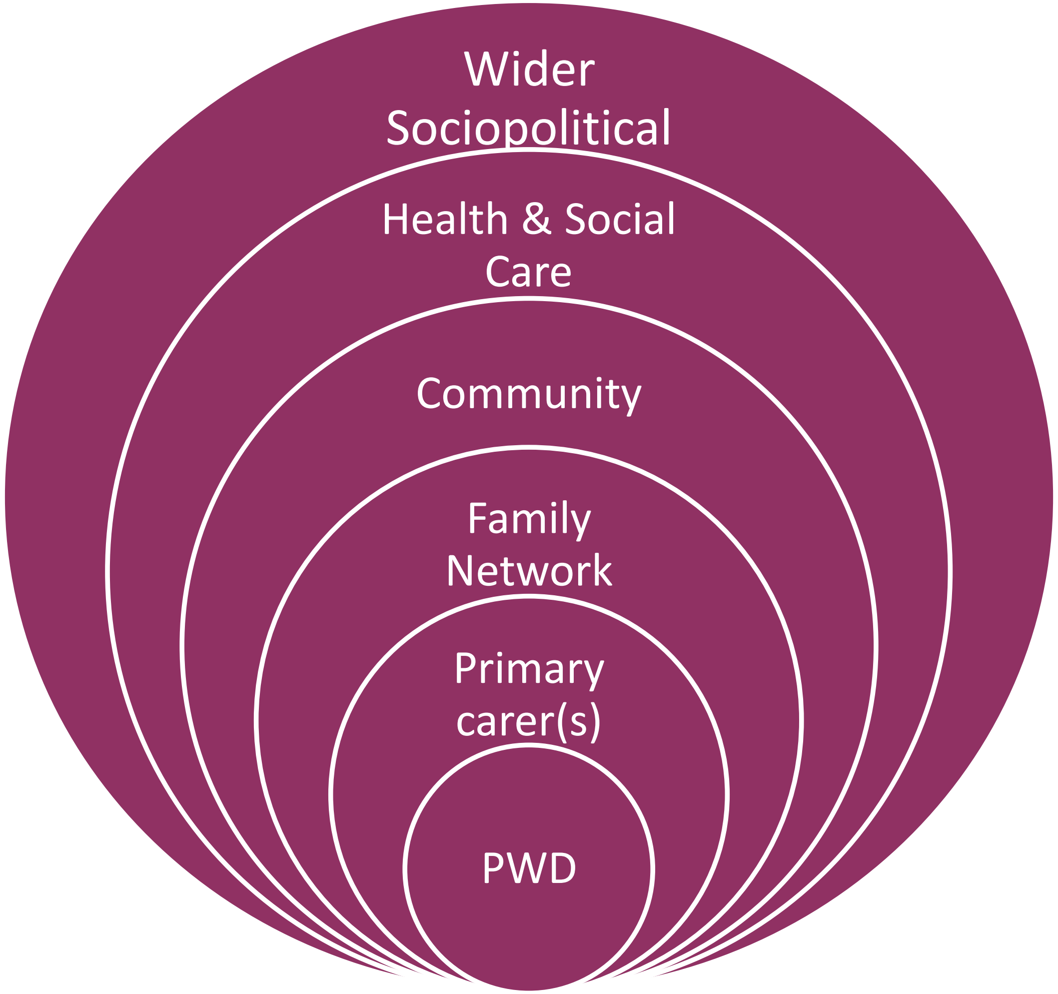
- 20 qualitative interviews, across 10 family units (by phone/virtual)
- Purpose sampling - variation
- Family story → Interview/focus group
- Interview schedule tailored to each family
- Duration 42-84 minutes
- The data were subjected to Thematic Analysis (as per Braun & Clarke, 2006)

PARTICIPANT CHARACTERISTICS

PP	Family Unit	Relationship to PwD	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

FINDINGS

SIX SUPERORDINATE STRATA INFLUENCING SUSTAINABILITY



Wider Sociopolitical

Health & Social Care

Community

Family Network

Primary carer(s)

PWD

FOUR CONCEPTUAL THEMES

- Cultural Narratives
- Roles & Relationships
- Individual & Collective Capacity
- Contextual Factors

CULTURAL NARRATIVES

1. Dementia

- Deficit
- Personhood

“All I had to go off is what I’d seen on TV or read, and those depictions of dementia are so, so bleak.”

2. Duty of Care

- Familialism → Gender
- AIP

“The attitude is ‘you shouldn’t be thinking of putting her in a home’. But it’s not in her best interest to be in this house.”

ROLES AND RELATIONSHIPS (1)

1. Changing Roles

- Autonomy for PWD
- Becoming the ‘carer’

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

2. Positive psychology

- Gratitude
- Optimism
- Empathy

“I know you have taken so much of that role of keeping structure and routine for her. I know it’s not easy. When I see everything that you have taken on - we are all grateful [Brother, to his sister]

ROLES & RELATIONSHIPS (2)

3. Damaging Dynamics

- Disengagement
- Enmeshment

"On some days I feel like no good deed goes unpunished. She could be off with me, but [son] will take her out and she will be an angel around him!"

4. Resentment

- Opportunity cost of caring
- Lack of appreciation

"In the last few weeks I see [family members] have gone on holidays, out for dinner and you know I can't do any of that. They don't spare a thought for what's going on, on the other side of the road"

INDIVIDUAL AND COLLECTIVE CAPACITY (1)

1. **Primary Carer:**

- Knowledge & Skills
- Leadership & Coordination

"I do my best, but we are not always equipped. Some days I think, 'am I making this worse?' Or days when I'm grouchy I might say something snappy and then the guilt sets in."

2. Carer's Health

- Mental
- Physical

"I have my own health issues and chronic pain. He needs help with showering, dressing, all those things. There are days that I'm just not able to give him what he needs."

INDIVIDUAL AND COLLECTIVE CAPACITY (2)

3. Non-cognitive symptoms

- Behavioural issues
- Intensify carer stress

> "Its not just mam its affecting [sleep issues]. Dad is awake too and he's going to burn himself out. His own health has gone downhill. He has heart problems and the stress isn't helping."

4. Wider Social Network

- Friends
- Neighbours

> "I feel lucky - as well as my daughters, I have local people and neighbours who come in."

INDIVIDUAL AND COLLECTIVE CAPACITY (3)

5. Formal support

- Coordinator
- Acceptability
- Poor capacity

"We definitely need more outside care coming in to relieve dad."

6. Dementia-Friendly Communities

"I do think there has to be more consideration for people with dementia at appointments. With her eye appointments, one day we were sitting there from one to 5pm…It's very stressful."

CONTEXTUAL FACTORS (1)

1. Dementia Type & Stage

“As mam got sicker, in some ways it was easier for us.”

2. Other Responsibilities/ Circumstances

“I’m one person, with a full-time job and my husband is not very well at all, so I just can’t do it anymore”

CONTEXTUAL FACTORS (2)

3. Financial Supports

"Dementia doesn't fall under the LTI scheme so costs aren't covered. We're lucky dad has a good job. I don't see how some families get by"

4. Funding Model(s)

"If the HSE were to provide you with the funds they would be spending on residential care, so you could purchase homecare, the pressure would be off to care, we could just be family".

CONTEXTUAL FACTORS [COVID-19]

1. Isolation

"The care situation did change during COVID. She had a very sharp decline because she wasn't interacting with people."

2. Mental Health

"I think about her mental health a lot, like her anxiety. We were very worried about her because everything about COVID made her very, very anxious."

3. Continuity of Care – in and outside the home

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

CONCLUDING THOUGHTS

- Note: These findings are preliminary - thematic categories may be restructured/renamed
- Responsibility – where should it lie when it comes to dementia care? For the person? For financing care?
- Capacity – forcing people into caring situations when they don't have the skills, knowledge and/or self-efficacy, the space, or a sufficient support network in terms of family, neighbours, friends, etc.
  - And waiting for crisis and/or burnout
- Lack of home-based social care options – but you can find a care home without problem
- We need to give families care options if we are going to propagate the 'ageing-in-place' dogma
- Next steps – think about policy implications and how government and the health and social care system can better support families that do wish to support their loved one at home
- Also must consider family-focused psychosocial interventions which could support resilience