

“If we can get through this week” Experiences of Formal Dementia Home and Community Care in Ireland



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Access to timely formal care

The Actifcare Project (www.actifcare.eu)



Actifcare aims to analyse the pathways to care for people with dementia and their families, to better understand the reasons for inequalities in access to healthcare

This study explored

- Personal experiences
- Perceived barriers and facilitators to service access

From the perspectives of

- People with dementia
- Informal caregivers (variety of ages, relationships)
- Healthcare professionals (variety of disciplines)

Methodology



- Exploratory qualitative design
- Purposive sampling
- Tape-recorded focus groups
- Questioning route piloted in Germany
- Transcripts analysed using inductive content analysis
- Irish data are presented here

Focus Group	<i>N</i> (groups)	<i>n</i> (participants)
People with Dementia (P)	2	8
Informal Caregivers (C)	3	16
Healthcare Professionals (HCP)	3	18

Seven Recurring Themes



- Accessing Services / Service Availability
- Education and Awareness
- Capacity and Rights
- Best Practice

Shared perspectives

- Understanding Care Needs
- The Impact of a Dementia Diagnosis
- The Impact of Caring

Divergent views

Accessing Services / Availability



- Common triggers (Crisis/Concern/Diagnosis)
- What services are available/how to access them
 - ➔ Frustrations - HCPs lack of knowledge, delayed diagnosis, and not understanding care needs
- HCP are aware of their lack of knowledge
 - ➔ Systemic barriers - lack of clear pathways to services, poorly organised, badly integrated, lack of dementia-specific education in the health service
- Difficulties arise when services are refused
 - ➔ anxiety, fear, denial
 - ➔ lack of appropriate services (heterogenous group) – age, location, SES, needs, interests, personalities
- Lack of resources in the health system in Ireland

P

"I become an extra burden because I am in the middle of the country. So, do you want to rehouse me or buy me a horse?"

C

*"Most of us have to go looking for everything"
".. Won't get them on a Saturday or Sunday"*

*"It's incontinence or some crisis"
"And everything is really stretched, really stretched"
"Don't need 24/7 just 50 [hours]"*

HCP

Education and Awareness



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- Misconceptions and a general lack of knowledge of what dementia is
- Lack of knowledge of the formal dementia supports and services that are available
- Stigma around dementia and mental health services in general still exists in Ireland
- Result of misconceptions and stigma
 - ➔ Delayed diagnosis and delayed access to services
 - ➔ Lack of understanding of care needs and poor care management
 - ➔ Increasing isolation from the perspective of the person with dementia and their caregivers

P

“Would it have been a good idea to keep working or doing something?”

“There was this sense of me nearly needing to prove it all of the time”

C

“It’s a real learning curve”

“You don’t talk [about it]”

“Nobody ever approached us”

“...the stigma when we were based in a [Mental Health Hospital]”

“We, ourselves, aren’t too sure of the system”

Capacity and Rights



- People with dementia want to maintain control of their lives and remain independent for as long as possible
- All groups recognised these rights but, healthcare professionals highlighted times
 - ➔ When the capacity of the person to make decisions on their own behalf may be impaired
 - ➔ They faced a challenge in accurately assessing capacity
- Sometimes there can be conflict between the rights of the person with dementia and those of the informal caregiver

P

"I was a very active citizen, and then I was nothing"

"The more we can advocate for ourselves..."

"I'm very worried because I don't think [husband] will accept it"

C

"They have a choice and they have the right to decide"

"[capacity issues] are very time consuming.. very difficult"

HCP

Best Practice



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- Positive impact of good care merged in all groups
 - ➔ Good quality of life for the person with dementia and for the informal caregiver
 - ➔ High satisfaction at providing suitable care for the HCP
- People with dementia and informal carers outlined the services and supports they want to see while HCPs made recommendations regarding approaches that they thought would work best
- In all cases, preferred services were
 - ➔ Timely, person-centred, age-appropriate, individualised
 - ➔ Community- and home-based
 - ➔ Maintained independence, social integration, and general health and well-being
 - ➔ Such that the person with dementia could live at home well for longer

P

"We are not for day centres"

"It would be nice to be involved in something socially"

C

"How are you doing" once a week ... a contact, a normal process"

HCP

"Everyone [working in the HSE] would want individualised services, but it is not there to give"

Understanding Care Needs



- Key concern for healthcare professionals
 - ➔ Regular assessments to capture changing needs
 - ➔ Importance of obtaining adequate collateral from primary caregivers
- But informal caregivers reported that HCPs were often disinterested in speaking to them or hearing what they had to say
- This discordance is likely the result of a combination of factors including
 - ➔ Length of typical healthcare visits (too short)
 - ➔ Known lack of suitable supports and services
 - ➔ the need to respect the rights of the person with dementia

HCP

"We have to be very careful that we don't disable people"

"..getting collateral from family members .. Try and get a clear picture"

C

"But he contradicted me all along. He said 'There's nothing wrong with your husband'"

"It's the one-size-fits-all approach"

The Impact of Dementia



- The inherent difficulties of dementia as a condition complicate the provision of care
- People with dementia and HCPs commented on the anxiety, fear and denial that accompany a diagnosis
- The person with dementia must
 - ➔ Accept and adjust to the diagnosis and what it means to their independence, self-identity, and their family
 - ➔ Deal with the ongoing emotional, cognitive and functional impact of the condition
- The nature of dementia makes difficult for HCPs to identify the care needs of someone who is unaware of, or finds it difficult to articulate these needs
- Not a separate theme for carers but many similar difficulties arose in their accounts of accessing services and supports

P

"I was beating myself up over the fact that I couldn't follow a recipe"

"It's very hard to put anything in place because how soon, how quick am I going to go?"

"The person with dementia is usually the most resistant to accepting services"

"Experience has taught us, eventually it will come to a crisis"

HCP

The Impact of Caring

- People with dementia and healthcare professionals acknowledge the role and importance of informal caregivers, but
 - ➔ People with dementia worry about burdening families
 - ➔ And only 1 HCP mentioned carer support groups and this was in the context of not having something similar for people with dementia
- The idea of *“Caring for the Carer”* only emerged in the caregiver groups
 - ➔ Carers want to care, but the nature and extent of dementia care, particularly as the condition progresses, is burdensome, stressful, and can only successfully be achieved when the carer themselves is supported.

P

“I felt I couldn’t be keeping them out of their houses”

C

“When I’m not there she gets it”
“You kind of park your family and your husband”
“Even when you are prepared .. It’s not easy”
“I used to go to a support group, but then I had to get someone to cover that [mind husband]”

Shared and Unique Perspectives



- Shared perspectives arose from
 - ➔ Our common understanding of dementia as a condition
 - ➔ Service availability in Ireland and the access pathways to these services
 - ➔ Respecting the rights of the person with dementia and their caregivers
- Unique perspectives
 - ➔ HCP relating to the barriers and facilitators they face when trying to provide formal dementia care in Ireland
 - ➔ Informal caregivers relating to the amount, nature, and burden of providing significant amounts of support without adequate support of their own
- Impact of having dementia was central to the narratives of people with dementia and HCPs although this was subsumed into the overall impact of providing care for informal caregivers

Conclusions



- Very clear gaps exist between the formal community- and home-based care that is available in Ireland and the care that is advocated for by our participants
- Ireland has had an Assisted Decision Making Capacity Bill on the legislative books since 2013 – still unknown when and if this will be enacted into law
- Ireland launched the first Irish National Dementia Strategy in December 2014 and selected five key priorities
 - ➔ Better awareness and understanding, timely diagnosis and intervention, and integrated services, supports and care for people with dementia and their carers
 - ➔ Training and education and Leadership for Health Service employees
 - ➔ As yet, no implementation plan has been published and it is difficult to see how these items will be addressed in the short-term.

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