

“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)



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 first piloted in Germany
- Analysed using inductive content analysis
- Irish Data are presented here

Focus Group	N (groups)	N (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)
- Difficult to understand what services are available and how to access them
 - ⇒ Frustrations at HCP impeding access - lack of knowledge, delayed diagnosis, or not understanding care needs
 - ⇒ Systemic barriers (lack of clear pathways to services, poorly organised, badly integrated, lack of dementia-specific education in the health service)
- Lack of suitable services available
 - ⇒ Wrong place, wrong time, wrong type
 - ⇒ Lack of resources in the health system in Ireland
 - ⇒ We could do more with what is there

C

“Most of us have to go looking for everything”

“If you don’t know what you are looking for it is hard”

“.. Won’t get them on a Saturday or Sunday”

HCP

“And everything is really stretched, really stretched”

“Don’t need 24/7 just 50 [hours]”

Education and Awareness



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- Lack of knowledge (misconceptions) of dementia
 - ➔ Some GPs are slow to diagnose
 - ➔ Some families are afraid to bring up the topic
- Lack of knowledge of the formal dementia supports and services that are available
 - ➔ Clear need for information in year after diagnosis
 - ➔ Timely access to information
- Stigma around dementia and mental health services – it is improving but it can result in
 - ➔ Delayed diagnosis and delayed access to services
 - ➔ Lack of understanding of care needs resulting in poor care management
 - ➔ Increasing isolation for those living with dementia

P

“Would it have been a good idea to keep working or doing something?”
“The bit of literature you do get, is hand over your bank account”

C

“It’s a real learning curve”
“You don’t talk [about it]”
“Nobody ever approached us”

HCP

“the stigma when we were based in a [Mental Health Hospital]”
“We, ourselves, aren’t too sure of the system”

Capacity and Rights



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- ALL GROUPS recognised that people with dementia want to maintain control of their lives and remain independent for as long as possible
- But, the capacity of the person to make decisions on their own behalf may be or become impaired
 - ➔ Significant decision for HCP in Ireland given the all-or-nothing nature of capacity in the Irish legal system
- Sometimes there can be conflict between the rights of the person with dementia and those of the carer
 - ➔ Carers sometimes feel that their rights come second
 - ➔ Primary carer can advocate for advanced levels of care but other more distal family and HCPs fail to see the need
 - ➔ HCP themselves recognise this and they talked about the challenge in finding a care path suited to all

P

“I would prefer to do what I can for myself, while I can”

“I was a very active citizen and then I was nothing”

HCP

“They have a choice and they have the right to decide”

“[capacity issues] are very time consuming.. very difficult”

C

“I’m very worried because I don’t think [husband] will accept it”

Best Practice – What is good care?



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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
 - ➔ Good satisfaction at providing suitable care for the HCP
- In all cases, preferred services were
 - ➔ Timely and needs-driven
 - ➔ Person-centred, individualised, and age-appropriate
 - ➔ Community-based and home-based
 - ➔ Maintained independence, social integration, psychological well-being as well as physical health
 - ➔ Enable the person with dementia to live well at home for longer
 - ➔ Maximise quality of life not only for the person with dementia but also for their informal carer and family

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
 - ➔ Want regular assessments to capture changing needs over time, but this is often not the reality
 - ➔ Acknowledged that the main caregiver knows best
- But the reported experience of informal caregivers disputed these claims
 - ➔ HCP often disinterested in speaking to the carer or hearing what they had to say
- Likely due to a combination of factors including
 - ➔ Time available during healthcare visits
 - ➔ Known lack of suitable supports and services
 - ➔ the need to respect the rights of the person with dementia, even knowing that this causes a difficulty for the family caregiver

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
- Anxiety, fear and denial accompany a diagnosis
- The person with dementia
 - ➔ Must accept and adjust to the diagnosis and what it means to their independence, self-identity, their family, and their entwined futures
 - ➔ Deal with the ongoing emotional, cognitive and functional impact of the condition
- For HCP, it can be more difficult to understand the care needs of someone who is unaware of, or finds it difficult to articulate, their needs
- Not a separate theme for carers

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 do not want to be a burden on their families; they are very grateful for their support
- HCPs acknowledge the role and importance of informal caregivers but they
 - ➔ Argued that the healthcare system should not be the sole provider of care
 - ➔ Never elaborated on the concept of providing support aimed at the carers
- 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
 - ➔ Service availability in Ireland and the access pathways to these services
 - ➔ Respecting the rights of the person with dementia and their carers
- Unique perspectives of
 - ➔ 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 healthcare professionals, but for informal caregivers, it was subsumed into the overall impact of providing care for their loved ones



Conclusions



- Very clear gaps exist between the formal home- and community-based care available in Ireland and the care that is advocated for by our participants
- Ireland's first National Dementia Strategy was launched in December 2014 and five key priority areas were identified
 - ➔ Better awareness and understanding [of dementia]
 - ➔ Timely diagnosis and intervention
 - ➔ Integrated services, supports and care for people with dementia and their carers
 - ➔ Training and education
 - ➔ Leadership for Health Service employees
- These priorities align with the findings of our study
- Our results also support the need for an Assisted Decision Making Capacity Bill which has been on our legislative books since 2013

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Introduction

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Chapter 2 ▾

Chapter 3 ▾

Chapter 4 ▾

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Feedback

COURSE INTRODUCTION

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- Welcome
- Introduction to the module
- Why are you here?
- Our experts
- Meet Our Families
- Meet the carers
- Programme Outline
- For more information

General intro coping skills for carers



Coping Skills for families and carers

Introduction

Focusing on the person

Looking after yourself

Maintaining Relationships

Understanding Emotions

Supporting Daily Activities