

1. Background

Age-related illnesses such as dementia are becoming a greater policy concern in line with population ageing. Yet little is known of the service needs and uses of people recently diagnosed with dementia. This research links the 'personal' to the 'political' by placing the experiences of people living with early-stage dementia within the broader socio-economic and systematic context of the Irish health and social care system. The study was undertaken as part of a PhD through the Social Policy and Ageing Research Centre, Trinity College. Taking an Interpretive Phenomenological Analytical approach the person with dementia was placed at the centre of the research enquiry.

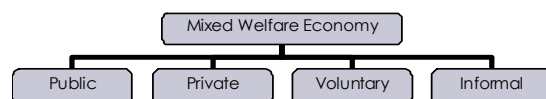
2. Aim

To explore the experiences of people with early-stage dementia and their care-partners in seeking and using health and social care services.

3. Characteristics of Dementia

- Umbrella term;
- Not inevitable part of ageing;
- Prevalence increases with age;
- 38,000 people in Ireland living with dementia;
- To increase to 52,265 people by 2026;
- Common symptoms:
 - memory loss,
 - spacial disorientation,
 - change in judgement,
 - misplacing items,
 - change in level of Interest,
 - change in personality,
 - change in ability to do everyday task,
 - change in mood.

4. Policy context



Community Care

- No historical basis;
- Policy directive to maintain people at home, yet no legislatively based community care services;
- Legislation underpinning medical care but not social care;
- Dependence on families and informal networks;
- Policy focus and funding towards long-term care;
- An Action Plan for Dementia, main policy document;
- 2009 New National Positive Ageing Strategy.

5. Research methods

- Qualitative, in-depth interviews
 - 17 people with dementia
 - 13 care-partners
 - 6 policy experts
- Theoretical foundation and procedural guide
 - Interpretive Phenomenological Analysis
 - Origins in phenomenology & symbolic interactionism
 - Analytical approach – to give voice' (describe) & 'make sense' (interpret)
- Ethical considerations
 - Including people with dementia in research
 - Role of researcher
 - Capacity & consent
- Process consent method (Dewing, 2007)

6. Findings 1: Service use

- ❖ Dementia seen as not critical enough to warrant intervention
- ❖ Never used social services before
- ❖ No knowledge of entitlements
- ❖ Stigma attached to some services
- ❖ No natural referral pathways
- ❖ Referral pathways dependent on knowledge and inclination of service providers
- ❖ Delays in accessing some services e.g. OT

Services	Used by respondents
GP & hospital outpatients	17
Home Help	6
Day centre	2
Contact ASI	2
Social Worker	1
OT (home adaptations)	5
Rehabilitation (day hospital)	3
Multiple services	2

7. Findings 2: Receiving a diagnosis

Alongside physical ill health, diagnosis constituted the 'currency' in which community-dwelling people with dementia could gain access to services under the current system.

- ❖ Six respondents received a diagnosis
- ❖ Eleven told they had a memory problem
- ❖ No national guidelines for practitioners
- ❖ No follow-up system

"[I] never discussed it with a doctor, you know" (Mrs Curran, female, 74 years, Alzheimer's disease)

8. Findings 3: Dementia-specific and psychosocial interventions

- ❖ Psychosocial interventions need to have meaning and/or be of interest to the person
- ❖ Gap in appropriate widespread interventions
- ❖ Negative response to existing interventions e.g. day centre

"Like a little meeting that you could go to, people have, that have this struggle. To have a chat like you know...." (Mrs Beattie, female, 67 years, Alzheimer's disease)

I went down and the chairs were along there (indicates chairs in a line up against the wall) and we sat in them chairs for I don't know, hours, doing nothing. And then I didn't go back. And she rang and said 'what, are you not coming?' And I said 'I can sit in my chair at home'. You know, I said to her 'we weren't doing anything' you know" (Mrs Doherty, female, 76 years, vascular dementia,)

9. Conclusion

- Respondent relationship with the system
 - Lack of incentive to engage
 - Lack of knowledge of service and entitlement
- Policy recommendations
 - Move towards a holistic/social model of dementia
 - Introduce comprehensive needs assessment
 - Formulate guidelines on disclosure
 - Assist informal carers and invest more in formal care
 - Introduce legislation to underpin social care



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