

‘I know what it is but how bad does it get’

Insights into the Lived Experience and Service Needs of People Living with Early-Stage Dementia

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Kings College London,
Postgraduate Conference in Gerontology
22nd of March 2009

Rationale

- Policy, practice, interventions under-developed
- Increasing numbers
- More people in early stages
- Lived experience never explored in Ireland
- Links the ‘personal’ (lived experience) to the ‘political’ (systematic context)
- Challenge stereotypes and stigma

Aims: To explore

- **Service provision**
- **Service access and interventions**
- **Including people living with dementia in research**
- Subjective meanings and experience
- Social implications
- Policy implications of this investigation

Dementia

- Umbrella term
- Alzheimer's disease most common form
- Not normal ageing but prevalence increases with age
- Memory, cognitive and sometimes behavioural and social changes
- 38,000 people in Ireland living with dementia (O'Shea, 2007)
- 52,265 people by 2026

Policy Context

- **Mixed welfare economy**
 - Public, private, voluntary (non-profit) & informal sectors (Fanning, 2006)
- **Community Care**
 - Policy directive to maintain people at home (Care for the Aged Report, 1968)
 - No historical basis (Convery, 2001)
 - Dependence on families and informal networks (Timonen et al, 2006)
 - Legislation underpinning medical care but not social care (Mangan, 2006)
- **Policy focus and funding towards long-term care** (O'Shea, 2006)

Dementia Policy

- An Action Plan for Dementia (O'Shea and O'Reilly, 1999)
 - Development of case management approach
 - Increased public awareness and socio-cultural & political change
 - Earlier diagnosis
 - Development of dementia services and information centre (DSIDC)
 - Develop appropriate psycho-social interventions
 - Expansion of community and hospital care
- Recommendations operationalised
 - Old-age psychiatry and geriatric medicine
 - Establishment of DSIDC

Dementia-specific services

- Older people's, mental health and disability services
- No dementia-specific care teams
- Alzheimer's Society of Ireland
 - home care for 2000 people
 - dementia-specific day centres
 - social clubs
 - pilot care/case manager in south Dublin
 - pilot advocacy programme in north Dublin

Research Methods

- Qualitative, in-depth interviews
 - 17 people living with dementia (x 2)
 - 13 care-partners
 - 6 policy experts
- Interpretive Phenomenological Analysis (Smith et al, 1997)
 - Theoretical foundation and procedural guide
 - Phenomenology and symbolic interactionism (Brocki & Weardon, 2006)
 - Reductionist
 - ‘Give voice’ (describing) and ‘make sense’ (interpretation)
- Ethical considerations
 - Including people with dementia in research
 - Role of researcher
 - Capacity and consent
- Process consent method (Dewing, 2007)

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FINDINGS

The sample (N=17)

- Community based
 - 4 live alone
 - Mean age 77 years
 - 8 women, 9 men
- Diagnosed between 2001 and 2006
 - early-stage Alzheimer's disease (n=12)
 - Vascular dementia (N=1)
 - mixed Alzheimer's disease and vascular dementia (N=4)
- Recruitment through Age-related Outpatient's Clinic at large urban based hospital

Service Use

Service	Number of Respondents
GP and Outpatients	17
Multiple services	2 Coordinated by care-partner and PHN
Home Help	6
Day centre	2
Contacted ASI	2
Social Worker	1
OT (home adaptations)	5
Rehabilitation (day hospital)	3

Reasons for not using services

- Did not perceive situation as critical

“I: Did you contact the Alzheimer’s Society? CP: No, I don’t think so. I: Would you ever think about contacting them? CP: Well maybe when she gets worse. We’re hoping she won’t get too bad” (Mr Curran, Care-partner, spouse)

- Never used social/formal support services before
- Did not know their entitlements
- Stigma attached to using formal supports

Referral Pathways

- No natural referral pathways
- Subjective, dependent on knowledge and inclination of service provider

“Interviewer: Is the information you’re getting then from friends or word of mouth? Care-partner: Oh they told me on the phone her own mother got it, she was out of -----, I don’t know why she was talking to me, but she told me herself her mother was waiting and she got it [house adaptations] done herself. Interviewer: This was a service provider? Care-partner: Yeah. She said, I said ‘ah no’, she said ‘forget that’, it could have been when Seamus was up at one of the clinics now Emer, could have been after that, we’re thinking of getting it done, says she ‘my mother got it done herself because I believe there’s a waiting list of two years’” (Mrs Barry, Care-partner, spouse)

Disclosure of diagnosis

- Six respondents told their diagnosis
- Eleven told in softer terms of having a memory problem
- No national guidelines for practitioners
- No follow-up system and little opportunity to ask questions

“Well what I said to you first was you know, you know get the [enduring] power of whatever and get onto the driver, them things and all, he (the doctor) was on about them things and then other things and all sorts of things and then when I asked him, ‘well right what’s it going to be for me’? And I actually said to Maggie (his wife) you know ‘he sounds like a fella who’s touting for you know the, ah feck.... the insurance and all that sort of thing, or the insurance people are telling him anybody comes in with that tell them, you know”

**(Mr Murphy, male, 70 years,
Alzheimer’s disease, lives with spouse)**

Conclusion: Deficits of the system

- Heavily medicalised model of health and social care
- No guidelines on disclosure
- No systematic approach to addressing dementia
- High dependence on informal care
- No legislation underpinning social care

Conclusion

Relationship with broader health and social care system poor due to:

- Lack of currency needed to engage (absence of physical ill-health)
- Lack of incentive due to medical model
- Lack of disclosure and knowledge of entitlements

- Respondents able to express themselves and give insight
- Systematic change:
 - Recognise people with dementia can contribute; they are the experts
 - Move away from service observations of person's decline
 - Moving towards model of citizenship
 - Encourage and engage



THANK YOU