Crisis development in Community Dementia Care: A Case Study Analysis
ABSTRACT

- The researcher aims to investigate and analyse to what extent dementia care within the community is being experienced by the person with dementia, their next of kin/caregivers and, the healthcare professionals also involved in their care.
  - Health Care triad
- Research will be conducted in 2 phases and will incorporate both case study and discourse analysis in both.
- As well as analysing the experience of dementia care being experienced, the research will analyse why a ‘crisis’ can developed in the community in dementia care
- A crisis in dementia care in the community usually instigates the need for the person with Dementia to be assessed as a matter of urgency by either community healthcare professionals (GP’s, Public Health Nurses, or Psychiatry for the Elderly teams) or through Accident and Emergency Depts.
- A crisis may have a two tailed pattern of development: that of carer burden and stress secondary to the changes in the behaviour and dependency levels of the person with dementia, and that of fragmented services and lack of community care structures for persons with dementia and their next of kin or family members.
approx 40,000 people in Ireland with dementia (Alzheimer's Society 2009)

broad agreement in the literature and social policy that people with dementia should remain in their own homes for as long as it is appropriate.

family care accounts for 76% of the overall responsibility of care, only 6% of government spending is directed to community services (Dementia Manifesto 2007)

- Carer burden, both formal (Nursing and care assistant staff) and informal (spouse/children/other non paid carer) is noted in the literature to be the cause of stress and burnout
  - Which according to the literature can be one of the causes of a crisis
Crisis admissions to acute secondary care are common from both the community and long term care (LTC) settings and can lead to a negative impact on wellbeing for the person with dementia, their carer and a heavy burden on the secondary health care system.

- Estimates of those suffering with a cognitive impairment or dementia in Long Term Care LTC facilities are stated to be as high as 70% according to O Shea (2008).

- Care should start with early diagnosis and be stepped up seamlessly (Dementia Strategy UK 2009)

- It is argued that care should be driven by the voice of service users (A Vision for Change, An Action Plan for Dementia, Adams and Manthorpe 2003, Ingram et al 2002). However even with over ten years of government documents and policies arguing the case for seamless care it is not the norm.
It is only through analysing the crisis from the perspective of the person with dementia, their informal and/or formal carers through a Health Care Triad that needs and knowledge gaps regarding dementia care in the community will be identified.

Little research in the literature examining the person with dementias’ experiences with their formal care and encounters with their family members (Keady and Gilliard 1999).

- dementia progresses → person is considered a passive recipient of their care

Poor understanding of the experience of dementia leads to inappropriate care of the person with dementia which can lead to crisis development which in turn can precipitate long term care placement for persons with dementia (International Geriatric Association)

- Often no voice or choice
- Nursing claims that holism and individual care are pivotal attributes underpinning nursing practice
  - Vulnerable (elderly) populations experience needs that are neither acknowledged nor integrated into interventions or care plans (Wilson & Neville 2008)

- Carer burden and burnout - the carers experience (Adams 2002)
Methodology Rationale

- Case study can be described as organising the “how” and “why” questions are investigated (Yin 2003)
- Discourse Analysis: This study investigates how linguistic and structural discourses about a person with dementia, particularly those that have a crisis, may be treated or viewed without a voice due to their diagnosis of dementia or possible involvement with Psychiatry
- Discourse is the medium for transmitting power/knowledge (Irving 2002)
- Health Care Triad: Power is not hierarchical – works on minute levels through the interplay of knowledge and power – those with dementia particularly as it advances seen as passive recipients of care – no voice
  - Language is used for a variety of functions and its use has a variety of consequences – the same phenomenon can be described in a number of ways.
  - Discourse analysis helps to understand, expose and investigate any social inequality (Van Dijk 2002)
  - Power is not always exercised in obvious ways
Motivation

- Experiential
- Referrals - from GPs and NH settings increasingly done because of a crisis or behavioural issue – not always diagnosed with a dementia at time of assessment
- General lack of input from any services even if diagnosis of dementia made
- Those living alone only referred when crisis developed
- Personal interest due to working between medicine and psychiatry for the elderly
  - Discourse from different healthcare professionals and family members different and labelled when psychiatry was involved
PHASE 1:

- Will look at community Dementia care provision within the general Dementia population in a particular geographical area (North Dublin).
- Recruitment will be through the Memory Clinic in Beaumont Hospital –
  - Cases will be divided into the 3 general stages of dementia

PHASE 2:

- Crisis phase – following a crisis as detailed earlier
- Most will be recruited via psychiatry for the elderly
- Doesn’t matter at what stage their dementia is at
- Social settings as inclusion criteria
HEALTH CARE TRIAD MODEL: Adapted from Fortinsky et al (2002)

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<thead>
<tr>
<th></th>
<th>Carer (formal/informal)</th>
<th>Person with Dementia</th>
<th>Healthcare system</th>
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<tbody>
<tr>
<td>2</td>
<td>• Age</td>
<td>• Age</td>
<td>• Hospital case notes</td>
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<td></td>
<td>• Gender</td>
<td>• Gender</td>
<td>• Physicians involved in care</td>
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<td></td>
<td>• Ethnicity</td>
<td>• ethnicity</td>
<td>• Other health care professionals involved in care</td>
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<tr>
<td></td>
<td>• Relationship to PWD</td>
<td>• Stage of dementia</td>
<td>• Any other supports utilized</td>
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<td></td>
<td>• Employment status</td>
<td>• Behavioural and functional problems</td>
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<tr>
<td></td>
<td>• Level of health and well being</td>
<td>• Co – morbidities</td>
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<td></td>
<td>• Level of knowledge of dementia</td>
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<tr>
<td></td>
<td>• Number of years caring for PWD</td>
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RESEARCH QUESTIONS AND AIMS:

PHASE 1:

What is the experience of living with Dementia in the community from the perspective of someone with Dementia, their family members/next of kin and any Healthcare professionals involved in their care?

- How much might it differ between the different members of the HCT or the different stages of dementia – as stages progress will power be lost to the person with dementia?

What are the current barriers to seamless care in the community throughout the different phases of Dementia for persons with Dementia and their families/next of kin?

- Dementia care: priority? Genealogy. As they lose their voice = lose access to care/services. Different support systems - advocacy

What could enable continued living for people with dementia and their families from the perspective of the person with Dementia, their family members/next of kin, and any healthcare professionals involved in their care?

- How much might it differ according to severity of Dementia and within each HCT – when does the power interplay within the HCT alter/flu3ctuate and for what reasons?
What are the circumstances that impact on a crisis admission to acute care for a person with dementia in the community?
  - Discourses produce different meanings for different individuals

How can crisis development in community dementia care be avoided for persons with dementia?
  - How much might this differ within each HCT – conflicting ideas – Discourse analysis helps to understand the conditions behind a specific problem.
Data Collection:

- variety of sources:
  - HCT
  - Screening tools: Quantitative
  - Semi-structured interviews- Qualitative
  - case notes
CASE STUDY ANALYSIS

- An empirical inquiry that investigates a contemporary phenomenon within its real-life context; when the boundaries between phenomenon and context are not clearly evident; and in which multiple sources of evidence are used (Yin 2000)

Specific techniques
  - **Pattern matching** - helps to identify similarities if any throughout the research
  - **explanation building** - *explain* a phenomenon is to stipulate a presumed set of casual links about and within the case studies (Yin 2003). This approach will be used within the crisis patients in PHASE 2 of the research as it helps the researcher explore and compare details of a case study against another case study within similar phenomenon.
  - **cross-case synthesis** – singularly assessed – then comparisons within groups for any similarities
The way people speak is symptomatic of how people feel about certain situations and phenomenon and it in turn effects how other people then perceive the same situation or phenomenon.

Does not provide absolute answers to a problem – enables to understand the conditions behind a certain problem.

There is no one truth – many versions.

DA draws attention to systems of language as they relate to human beings and how they shape experiences of people (Heartfield 1996).

Power/Knowledge – people with dementia socially excluded from the decision making process within the HCT.

Power relations within mental health care – according to Foucault, power is something that is exercised rather then possessed – produces forms of knowledge and discourse (Barrett 1991)

• Medication
• MHA
Analysis:

- Each HCT = ‘case study’ - Categorisation. Examining. Pattern Matching
- Screening tools will aid quantifiable data within each HCT for cross analysis: MM, GDS, CSI
  - Then help with standardisation Between HCTs (or cases)
  - Further, between different phases of dementia (Mild, moderate, severe)

- Using Discourse Analysis – reading and rereading the transcriptions of the interviews and all written data and documents.

- Cross-case syntheses. This will be pertinent if one of the cases in PHASE 1 becomes a crisis or PHASE 2 case.
Complications:

- Difficulty in obtaining ethical permission from Acute General Setting
- Time constraints – took part time work to accommodate this
- Possible to recruit numbers within each phase?
Thank You

Any Questions or Comments

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