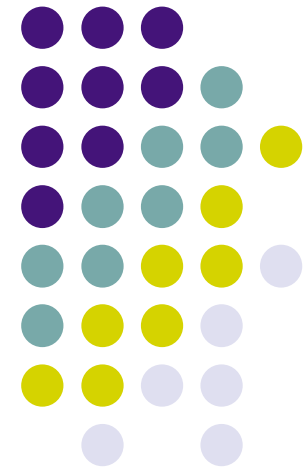


Learning from the Person with Dementia

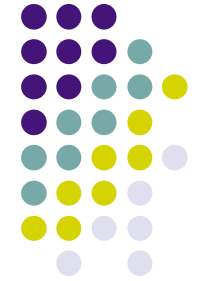
Emer Begley PhD

Supervisors: Dr Virpi Timonen and Dr Suzanne Cahill

Dementia Services Information and Development Centre
Spring Synapse Seminar
Thursday 29th of April 2010



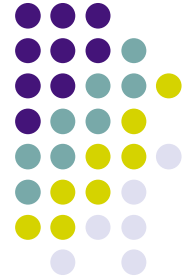
Broad Aim



To investigate the lived experience and service needs of community-dwelling people living with early-stage dementia.

Rationale:

A consideration and understanding of the experience of dementia can shed light on appropriate and effective ways to respond.



Specific research questions



How do people living with dementia cope with the onset of the illness?



How do people living with dementia conceptualise the symptoms of the illness?



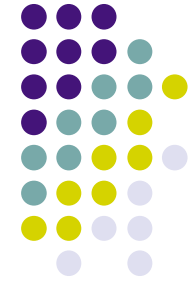
What are the implications of this investigation to policy and service development?



Consultation and research

- Lack of involvement of people living with dementia in research, policy and service development (van der Roest et al, 2007; Cotrell and Shulz, 1993).
- Despite international psychosocial research with the person living with dementia as the main informant, in Ireland there is a limited body of research (Cahill et al, 2008; Cahill et al, 2006).
- Recent international movements/developments – Scottish Dementia Working Group (SDWG)), Dementia Advocacy Support Network International (DASNI).

Literature: the experience of dementia



Individual/personal level

- Awareness
- Identity
- Views of self
- Coping strategies
- Management techniques

Interaction with the social world

- Stigma
- Social engagement
- Participation
- Activities
- Withdrawal
- Relationship with others
- Changing roles



The literature (ii)

Steeman et al (2006) *Living with Early-Stage Dementia: A review of qualitative studies*.
Journal of Advanced Nursing 54(6): 722-738

Systematic Review from early 1990's to mid 2000's

- 33 articles
- 26 separate studies
- 21 research samples

Findings:

- the importance of autonomy for the person
- struggle between self-protection and self-adjustment
- others ability to cope affects the person's coping
- dementia integrated into daily life
- cognitive change affects person's sense of identity, their membership in society and their feelings of security and autonomy
- Over-time dementia can become less threatening



The Research

Qualitative, in-depth interviews

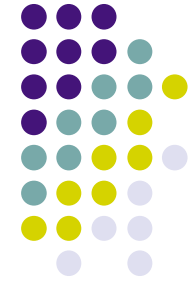
- Person with dementia (N=17)
 - eight women, nine men
 - mean age of 77 years
 - majority living with others (four respondents lived alone)
- Care-partner (N=13)
 - eight females, five males
 - 11 were married to person with dementia
 - one care-partner in paid employment (part-time)
- Policy experts (N=6)
 - Department of Health and Children, HSE x2,
 - NCAOP, NUI Galway, ASI.



Ethical Considerations

- Including people with dementia in research
- Ethical approval given from recruitment site
- Role of researcher
 - Reflexivity
- Consent
 - Capacity to consent
 - Process consent method (Dewing, 2007)

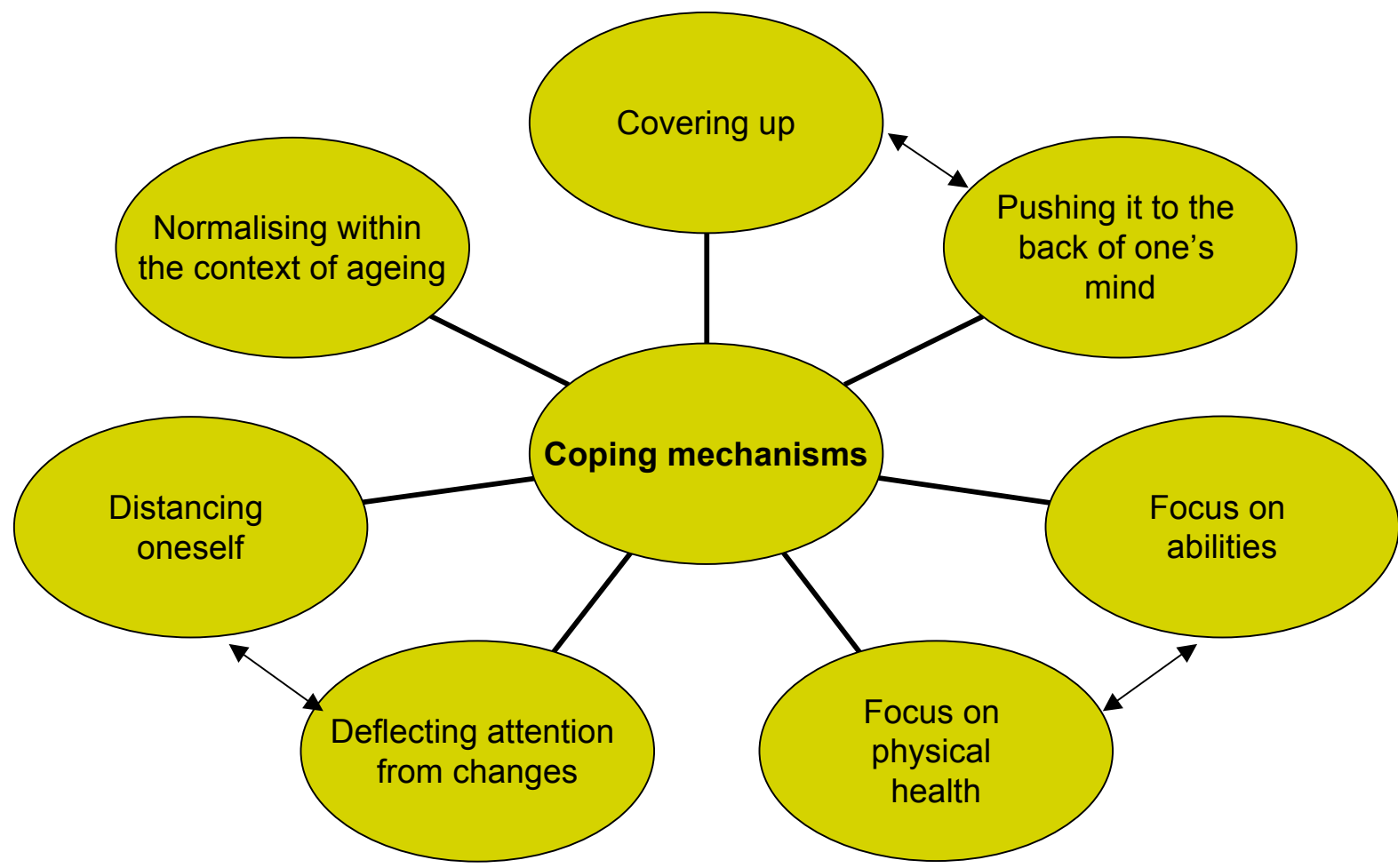
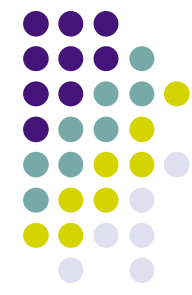
Interpretive Phenomenological Analysis (IPA)



- Theoretical foundation (Smith, 2004)
- Procedural guide
- Phenomenology and symbolic interactionism
- Analytical approach
 - ‘to give voice’ (describe)
 - ‘make sense’ (interpret)



Findings





Covering up

“Interviewer: And have you spoken to anyone about it (her forgetting)? Respondent: No, no, this is something that I would hide (places her hands on her chest)... You see, I’m trying to, I read before about it, I read a lot about it and it said you cover up and let me introduce things themselves and then you might click back, you know. So I cover up” (Mrs. Griffin, female, 75 years, Alzheimer’s disease, lives with spouse)



Normalising

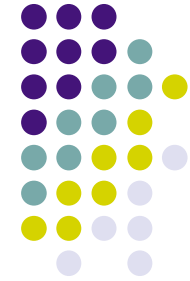
“Ah yeah, I would forget things, but when you get to this age you do forget things. Everyone forgets” (Mrs. Gannon, female, 62 years, Alzheimer’s disease, lives with spouse)



Implications of responses

- Covering up
 - assumption that people with dementia do not have any awareness
 - affects on autonomy and opportunity to make decisions
 - highlights stigma
- Distancing oneself
 - withdrawal from social activity and engagement
- Focus on physical health
 - lack of interventions to support the person with dementia
 - lack of knowledge of dementia
 - highlights personal priorities
- Normalising symptoms
 - people want to maintain sense of self and identity
 - highlights stigma

Conclusion



- Dominance of a medical model and focus on physical health;
 - Lack of psychosocial interventions to support the person following diagnosis;
- It should not be assumed that people with dementia lack awareness;
 - Using quantitative measures alone to assess awareness may be insufficient, need to explore this over time.;
- Lack of awareness and stigma around dementia can influence people seeking a diagnosis and the person seeking interventions to support their quality of life;
- Stigma related to dementia affects people's participation and engagement;
- Individual coping mechanisms represent a need for individualised responses and supports;



Thank You

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