

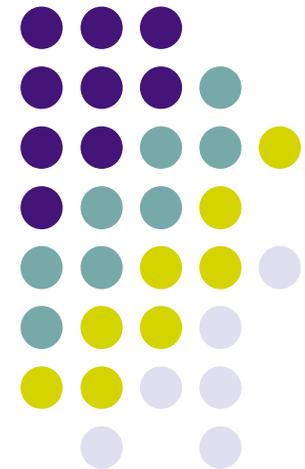
# Learning from the Person with Dementia

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Emer Begley PhD

Supervisors: Dr Virpi Timonen and Dr Suzanne Cahill

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# 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:

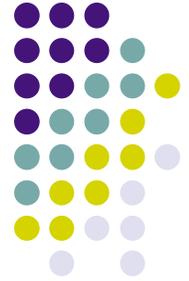
- the importance of autonomy for the person
- struggle between self-protection and self-adjustment
- others ability to cope affects the person's coping
- dementia integrated into daily life
- cognitive change affects person's sense of identity, their membership in society and their feelings of security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

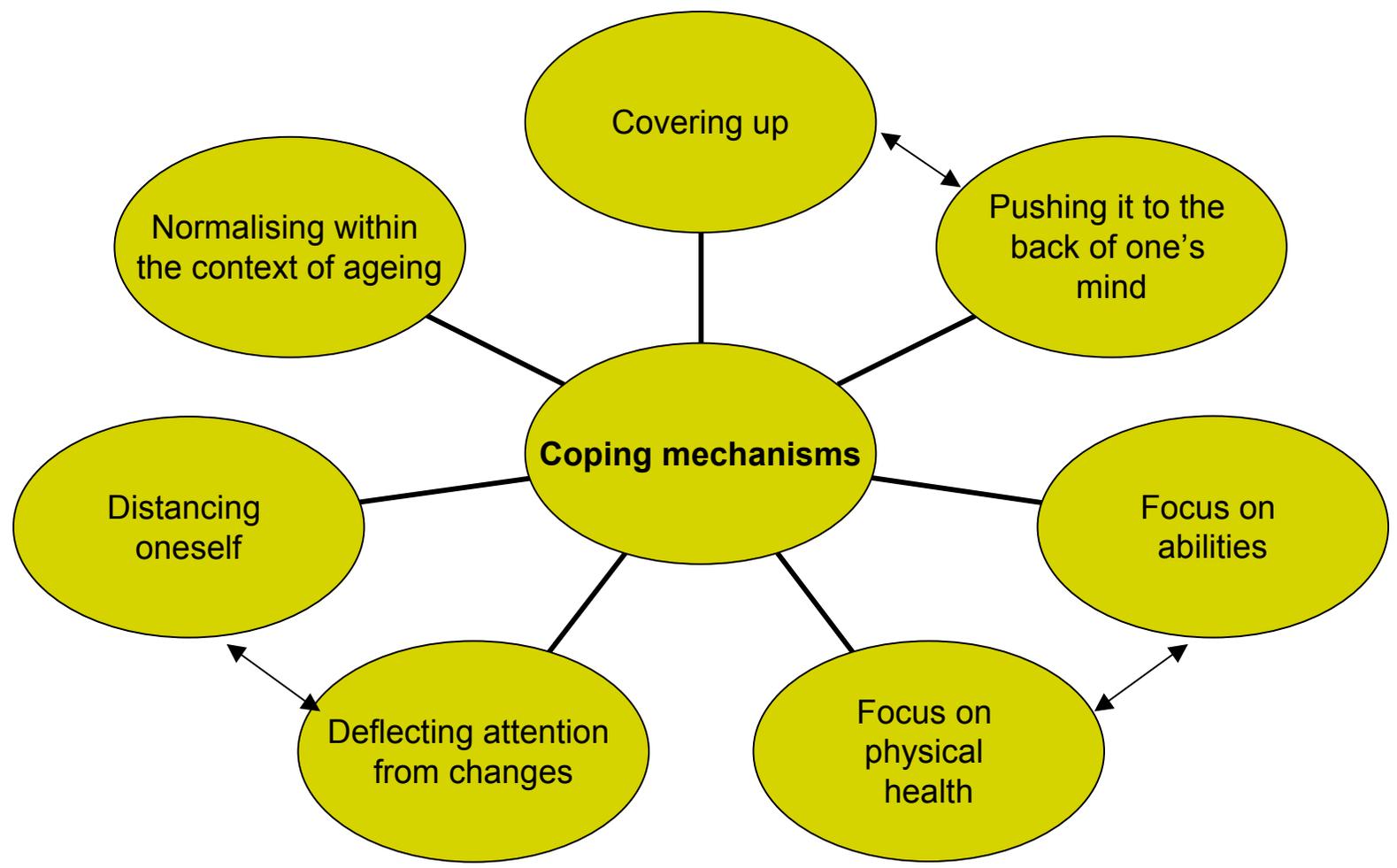
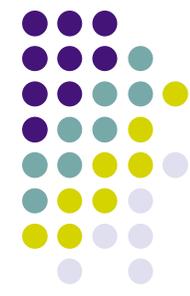
# Interpretive Phenomenological Analysis (IPA)



- 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**

[socialinclusion@ageaction.ie](mailto:socialinclusion@ageaction.ie)