‘Understanding resilience and its role in family caregiving for a person with dementia’

Centre for Economic and Social Research on Dementia (CESRD), ILAS, NUI Galway

10th February 2017

Presenter: Dr Attracta Lafferty
Overview

- Background
- Research team, collaborators, advisory group, project staff
- Dementia caregiving
- Resilience in dementia caregiving
- 3-year HRB project: *Towards resilience in family caregiving for people with dementia*
  - Aim and objectives
  - Research design
  - Brief overview of 3 work packages
  - Progress to date – work package 1
Towards resilience in family caregiving for people with dementia
Research Team

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• **Mr. Liam O'Sullivan**, Executive Director and **Ms. Zoe Hughes**, Policy & Research Officer, Care Alliance Ireland
Project Collaborators

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- **Dr. Deirdre O'Donnell**, Lecturer in Health Systems, UCD School of Nursing, Midwifery and Health Systems
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- **Mr. Diarmaid O’Sullivan**, Campaigns and Research Manager, Family Carers Ireland
• **Prof. Murna Downs**, Head of School of Dementia Studies, Faculty of Health Studies, University of Bradford

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- **Ms Sandra McCarthy**, Research Assistant, Care Alliance Ireland
Irish Policy

National Carers’ Strategy (2012)

• Emphasises the importance of carers being ‘valued and supported to manage their caring responsibilities with confidence

• Carers need to be ‘empowered to have a life of their own outside of caring’ (DoH 2012).

Irish National Dementia Strategy (2014)

• Acknowledges that family caregivers provide the majority of care for people with dementia

• Highlights that dementia places great demands on family caregivers and can adversely affect carers’ well-being, social and economic circumstances and relationships (DoH 2014).

• Stresses the importance of promoting dementia-friendly communities to support carers and people with dementia
A Carer is a person who:

‘provides regular unpaid personal help for a friend or family member with a long-term illness, health problem of disability (including problems due to old age). Personal help includes help with basic tasks such as feeding and dressing’

(CSO 2011; 2016)

• 4.1% of the Irish population identify themselves as an unpaid carer (aged 15 years and older) (CSO 2011)
• The majority of carers are female (61%) (CSO 2011)
• 52% are aged between 40 to 59 years (CSO 2011)
• One in five provide full-time care (i.e. 43 hours or more) (CSO 2011)
• 80% of primary caregivers to people aged 50 years and older are themselves aged 50 years and over (Kamiya et al. 2012)
• Approximately 55,000 people are living with dementia in Ireland.

• As a result of an ageing population, this number is expected to double by 2031 (Pierce, Cahill and O’Shea 2011).

• It is estimated that approximately 23,000 older people with dementia live at home in the community, many of whom are unaware that they even have the disease (Cahill, O’Shea and Pierce 2012).

• For every one person diagnosed, three other family members are significantly affected (DoH 2014; Cahill, O’Shea and Pierce 2012).
• There will be an increased reliance on family carers to provide care in the community.

• While up to 90% of people with dementia have significant behavioural disturbances (BPSD) that challenge carers (Sadavoy et al. 2008), many carers have no preparation for the role (Arskey et al., 2004).

• Dementia caregiving can result in:
  • Carer burden (Sörensen et al. 2006)
  • Symptoms of depression (Sörensen et al. 2006).
  • High levels of psychological distress (O’Shea 2000).
  • Poor carer health (Etters et al. 2008).
  • Early nursing home placements for people with dementia (Etters et al. 2008).
  • Conflict in the caregiving relationship (Lafferty et al. 2014; Cooper et al. 2009; Yan and Kwok 2011)
However, while many carers experience challenges with caring for a person with dementia, not all carers experience burden, depression and other psychosocial effects of caregiving.

Such carers may be considered ‘resilient’ and are able to recover from, resist, or adapt to the physical and psychological demands of caring (Herrman et al. 2011).

Carer resilience can predict lower levels of depression in spousal carers of people with dementia (O’Rourke et al. 2010).

Carer resilience is considered an important factor in suicide prevention (Johnson et al. 2011).

On the whole, there has been a general shift towards exploring psychological resources that empower people to cope.
What is Resilience?
Resilience in adults can be operationally defined as:

‘the process of effectively negotiating, adapting to, or managing significant sources of stress or trauma. Assets and resources within the individual, their life and environment facilitate this capacity for adaptation and ‘bouncing back’ in the face of adversity’

(Windle 2011)
Carer Resilience in Dementia

Figure 1: Model of factors influencing resilience (Cherry et al. 2013)
Towards resilience in family caregiving for people with dementia

3-year HRB project

Overall Aim
To promote resilience in family carers of people with dementia using participatory action research to develop an innovative Enhancing Carers’ Resilience (EnCaRe) programme.

Objectives

1. Synthesise current evidence of resilience-enhancing and related psychosocial interventions and initiatives aimed at promoting positive outcomes for family carers

2. Measure and describe family carers’ experiences of caring for a person with dementia and their resilience in caregiving

3. Establish a network group comprising family carers of people with dementia and members of the research team and, through the network, develop and design an Enhancing Carers’ Resilience (EnCaRe) Programme

4. Conduct a feasibility study of the EnCaRe Programme through a demonstration project among a cohort of current family carers of people with dementia

5. Evaluate the EnCaRe Programme with reference to structure, process and outcome elements
A participatory action research framework based on the principle of collaborative inquiry with the aim of enabling and facilitating carers to develop an Enhancing Carers’ Resilience (EnCaRe) Programme for family caregivers of people with dementia.

**Research Design**

**Needs analysis**
Investigate caregiver experiences (literature reviews & survey)
Work package 1

**Action plan**
Establish carer network group to co-create an EnCaRe Programme
Work package 2

**Evaluate**
Conduct a feasibility study of the EnCaRe programme
Work package 3

**Introduce the EnCaRE Programme with family caregivers**
Work package 2

**Describe family caregivers' resilience**
Work package 1
Work package 1
• Synthesise current research of resilience in informal caregivers of people with dementia and highlight non-pharmacological interventions aimed at promoting positive outcomes for informal carers.

• Scholarly databases: Cochrane, PubMed, CINAHL, EMBASE, PsycInfo, ASSIA

• Search terms

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<th>String 1</th>
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<td>String 2</td>
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<td>String 3</td>
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<td>Final Search</td>
<td>(Dementia OR Alzheimer OR 'Vascular dementia' OR 'Lewy bodies' OR 'Frontotemporal dementia' OR Korsakoff OR 'memory loss' OR 'mild cognitive impairment') AND (Carer OR caregiver OR care-giver OR caregiving OR family OR relative OR kinship OR informal OR spousal OR spouse OR wife OR husband OR daughter OR son OR brother OR sister) AND (Resilience OR resiliency OR resilient OR protective factors OR burden OR ‘well-being’ OR wellbeing OR ‘well being’ OR health OR ‘self-efficacy’ OR management OR adapting OR interpersonal OR intrapersonal OR self-esteem OR ‘quality of life’ OR ‘sense of coherence’)(2006-2016)(English language)</td>
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Meta-analysis

- 27 intervention studies

- Carer burden
- Quality of life
- Carer outcomes
- General health
- Depression
Postage survey of family carers of people with dementia

- National cross-sectional survey of family carers in receipt of a carer’s allowance for care provided to a person with dementia
- Collaborating with Department of Social Protection, in sourcing a sample of family carers (3 mail-outs)
- 822 dementia carers in receipt of carers allowance for 825 care-recipients with dementia (March 2016)
- Data has been collected on:
  - Carer demographics
  - Carer resilience and carer burden
  - Caregiving activities
  - Perceived social support
  - Service utilisation
  - Care-recipient demographics
  - Dementia-related behavioural problems
  - Knowledge of dementia
Secondary analysis

- Pre-existing dataset of 2311 informal carers of older people
- 485 participants cared for a person with dementia
- Factors to be examined include:
  - Demographic profile of carers
  - Profile of care-recipients with dementia
  - Caregiving activities
  - Support and coping
  - Experience of being mistreated
  - Potentially harmful carer behaviours
Objective 3: **Establish a network group** comprising family carers of people with dementia and members of the research team and, through the network, develop and **design an Enhancing Carers’ Resilience (EnCaRe) Programme**

The EnCaRe Network group
- Up to six family carers of people with dementia
- Two research team members
- Bimonthly meetings
- Invite experts in the field to come in to present to the group

EnCaRe Programme
- Develop a grounded definition of ‘resilience’
- Informed by findings generated in work package 1 of the project
- A workable resilience-enhancing programme for peer family carers
- Grounded in carers’ own experiences and perspectives and designed by the Network
- Examples: training materials, peer support groups, online supports/forums, workshops, communication enhancing techniques etc.
Objective 4: **Conduct a feasibility study** of the EnCaRe Programme among family carers of people with dementia through a demonstration project among a cohort of family caregivers.

Objective 5: **Evaluate the EnCaRe Programme** with reference to structure, process and outcome elements.
References


Doeblcr, S. "The Health and Mental Health of Informal Caregivers in Rural and Urban Northern Ireland."


Thank You!

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A diamond is just a piece of charcoal that handled stress exceptionally well.

“One small crack does not mean that you are broken, it means that you were put to the test and you didn’t fall apart.”

— Linda Poindexter