Resilience in later life: Myth and metaphor or real and measurable?

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Reflecting on the role of personal career events

“I want to keep going as long as I can. I’d like to be able to until I’m 90 years old. Keep your nose to the grindstone. Don’t swim till it hurts, swim until your tired. It takes some time so be patient.”

“I’ve surprised myself that I’ve carried on being physically active. The years slip by and you don’t notice it. I ignore my birthdays. Age is just a number if you’d like it to be.”

(Interview with the Daily Post, December 2011)
In pictures: Photographer 'in awe' of older athletes

Myths of ageing - frailty vs super functioning
Health in later life

• In developed nations there has been an ‘epidemiologic transition’, reflecting the decline of infectious and acute diseases and a growth in chronic and degenerative diseases and co-morbidity (World Health Organisation, WHO; 2011).

• Fifty-two million EU citizens aged 55-74 report having a long-standing illness or health problem. This is about half of all people in this age group (Harbers & Achterberg, 2012).
“Someone in the world develops dementia every 3 seconds”

It is estimated almost 50 million people were living with dementia in 2017.

This number will almost double every 20 years, reaching 75 million in 2030 and 131.5 million in 2050.

・This finding has been interpreted as evidence of resilience in older age, and (along with the work of others) is increasingly becoming the focus of research into how good outcomes can be achieved, despite difficulty.

What is ‘resilience’?

- Consensus from research regarding difficulties in developing a single definition of resilience

- Prevalence of resilience – between 25% to 84% (Vanderbilt-Adriance & Shaw, 2008) – how can policy and practice respond?

- Our traditional scientific approach emphasizes precision and conceptual clarity as precondition for empirical studies
## Diversity in the use of the term ‘resilience’

**Criticism** – lack of clarity in the intended use of the term

<table>
<thead>
<tr>
<th>Resilience as...</th>
<th>Purpose</th>
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<tbody>
<tr>
<td>Goal</td>
<td>To determine what to aim at</td>
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<tr>
<td>Analytical tool</td>
<td>To understand the problem and find better solutions</td>
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<tr>
<td>Metaphor</td>
<td>To help break disciplinary or sectorial silos</td>
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<tr>
<td>Indicator</td>
<td>As a part of developmental objectives and sustainability</td>
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<tr>
<td>Heuristic</td>
<td>As a basis for modelling or describing a system</td>
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<tr>
<td>Buzzword</td>
<td>As a strategy (e.g. to publish or attract funds)</td>
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Source: Tanner, Bahadur and Moench (2017)

**Strength** – it can be explored in different populations, contexts and scientific disciplines
Multi-disciplinary perspectives on healthy ageing and the role of resilience across the life course

1) What is resilience?

2) How can we ‘measure’ resilience?

3) How do life-course experiences influence the development of resilience in later life?

4) How can we build resilience in people to enable them to manage difficulties?
What is resilience?

1) Deconstruct the concept of resilience
2) Develop a working definition of resilience
3) Improve theoretical understanding

- Project involved stakeholders and academics in discussion – multi-disciplinary & lifespan

- Literature review using systematic principles – searched academic journals, policy documents, internet – multi-disciplinary.

- Stakeholder input

- Applied concept analysis to clarify the definition of resilience – multi-disciplinary

Flow diagram of review process:

- Potentially relevant studies identified and screened for retrieval: 2,979
- Studies excluded; did not meet inclusion criteria: 2,456
- Unable to obtain: 40
- Duplicates removed: 167
- Full articles retrieved: 316
- Excluded; did not meet inclusion criteria: 45
- Included papers: 271
- Measurement scales identified: 17
- Excluded: 2
- Final number of measurement scales: 15 original validation papers, 4 subsequent refinements
Stakeholder/older people’s comments

- “Resilience is like a bouncing ball – a resilient person bounces back and keeps going”.
- “Resilience is the ability to overcome difficulties and move on”
- “Enhancing resilience may need good health, resources and a certain amount of risk taking.”
- “Resilience can be developed through exposure to a difficulty - you have to fight for everything – it gives you a different perspective”
- “Whether you become resilient may depend on how the difficulties currently being experienced are socially acceptable within your culture at that moment in time.”
- “Motivation is part of resilience – not feeling too old to try something new — People may not feel motivated because they conform to societal stereotyping, which can lead to social isolation, therefore it is important to be open to new ideas and experiences”
- “For disabled children, families/support networks are important.”
- “Health problems are a challenge to resilience”
- “Collective exposure to strife, e.g. wars may foster a collective sense of resilience – ‘everyone’s in it together’
- “The support structures available for church goers can be important when faced with adversity – the church community ‘will wrap round’”
Definition

‘Resilience is the process of negotiating, managing and adapting to 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. Across the life course, the experience of resilience will vary.’

Key requirements

• There must be a significant adversity/risk for a poor outcome

• The outcome is good or better than could be expected in the face of the challenges

• The person is able to resist, manage and adapt to the adversity (‘protective factors’, ‘resilience reserve’)
A resilience framework

**Antecedents and adversities**
- E.g. chronic disease; dementia; care-giver; bereavement

**Resilience reserve**
- **Protective Factors/assets/strengths for positive adaptation**
  - **Personal resources**
    - Biological (genetics), psychological resources (esteem, competence, control, efficacy, etc.); creativity; material resources
  - **Social resources**
    - Social support (family and friends); social participation
  - **Community/Society**
    - Neighborhood, social cohesion, health and social services, public policy

**Outcomes**
- Maintain or improve mental health, physical health and well-being
- Avoid, reduce or manage disability
- Alleviate loneliness and isolation

- Older Columbians living in poverty (Bennett, Reyes-Rodriguez, Altamar & Soulsby, 2016)
- Dementia caregiving (Donnellan, Bennett & Soulsby, 2014; Joling et al., 2016; Newman et al., 2018)
- Palliative care (Roper et al., 2018)
Resilience from the individual and the environment

Personal characteristics of resilience (e.g. positive attitude or purpose in life) were embedded in social and environmental contexts that could underpin or undermine resilience.
What does resilience mean when facing dementia?

Co-creating a resilience building framework for people living with dementia and their carers

Hannah Jelly PhD studentship

Health and Care Research Wales Social Care PhD studentship. £59,900.

The impact of multicomponent support groups for those living with rare dementias

ESRC-NIHR Dementia Research Initiative £4.5m
January 2019 for 5 years
What does it mean to be resilient when facing one of life's biggest challenges?

“I think it’s essential to have a sense of humour. When you are fighting, being able to realise that it’s actually not important and being able to laugh about it because you argue over the littlest and silliest things.” (Person with dementia)

“Breaks are important and retaining important hobbies” (Carer)

“Being able to cope and adapt. What works one day will not work another day and what works at one time doesn’t work another time.” (Carer)

“Relationships effect resilience. If you love someone enough you can adapt to cope with most things.” (Carer)

“But you can never bounce back the same as you were, it’s not possible when going through this to be the same” (Carer)
How can we measure resilience?
Resilience measurement scales

- 15 measures
- 6 x adults; 1 x children; 7 x youth; 1 x older adults
- Only 5 measures examined resilience across the multiple levels of functioning (as per the framework).
- Most focus on psychological resources/strengths
- Useful for measuring the outcome and the process (resources)

There are no validated measures of resilience for use with people living with dementia
Psychological resilience in later life is important for:

- Moderating the negative impact of ill-health on wellbeing (Windle, Woods & Markland, 2009)
- Reducing the impact of a new chronic condition on disability (Manning, Carr & Kail, 2014)
- Adjustment to multiple chronic conditions (Jason et al., 2015)
- Moderating the impact of daily stress on negative emotions (Ong et al., 2006)

“In old age the self remains resilient” (Baltes & Baltes, 1990)
Factors of Resilience in Informal Caregivers of People with Dementia from Integrative International Data Analysis

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Hein P.J. van Hout  Janet MacNeil Vrooomen  Peter M. van de Ven  
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Challenging care circumstances (high care demands):
- More severe dementia
- Limitations in basic self-care
- Behavioural (mood) problems
- Providing a substantial amount of care

Caregiver resilience

High resilience: high care demands, good psychological well-being

Low resilience: high care demands, poor psychological well-being

<table>
<thead>
<tr>
<th>Care-giver demands</th>
<th>Prevalence of resilience</th>
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<tr>
<td>Severe dementia</td>
<td>43%</td>
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<tr>
<td>Limitations in basic self care</td>
<td>42%</td>
</tr>
<tr>
<td>High amount of care</td>
<td>41%</td>
</tr>
<tr>
<td>More than one care giver demand</td>
<td>39%</td>
</tr>
<tr>
<td>Behavioural/mood problems</td>
<td>35%</td>
</tr>
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Determinants of caregiver resilience

Across the integrated data, caregiver resilience was positively related to:

• Male caregiver
• Caring for a female
• Living apart from your relative
• Lower perceived burden
• A good quality relationship

Of the measures that couldn’t be integrated as not each sample used them, caregiver resilience was related to:

• A better sense of competence
• Greater mastery
• Fewer feelings of loneliness
• Fewer feelings of guilt
• Greater social support
Resilience and public health
Global interest in resilience and health

“In framing a public-health response that might strengthen an older person’s ability to navigate and adapt to the dynamics and losses they are likely to experience, we have drawn on the concept of resilience” (2015, p.27).

“It is important not just to consider approaches that ameliorate the losses associated with older age but also those that may reinforce recovery, adaptation and psychological growth” (2015, p.25).
the Healthy Ageing model conceptualizes resilience as the ability to maintain or improve a level of functional ability in the face of adversity (either through resistance, recovery or adaptation).

Priority areas for taking public health action
(Source: WHO, 2015, p.212)
Resilience and ‘responsibility’

To achieve the vision for longer, healthier and happier lives:

“We need people to take more responsibility, not only for their own health and wellbeing, but also for their family and for people they care for, perhaps even for their friends and neighbours.” (2018, p.7)

Neoliberalism - deregulation, minimalisation of the state, privatisation, the emergence of individual responsibility
Angie Hart,
Professor of Child Family and Community Health
University of Brighton, England

Co-production of resilience
Their work is carried out both with and as disadvantaged communities, and includes people who may be perceived as disadvantaged and marginalised at all stages of the research process.
‘Bouncing forward’ (Jeans et al., 2016) where future risk is potentially reduced through altering the conditions that created them in the first place.
Resilience in later life

Myth and metaphor or real and measurable?
How can we ensure resilient, supportive environments to enable all those affected by dementia, including family and professional carers, to function as best they can?
Cultural fear of dementia leads to stigma and exclusion

Provocative language in media e.g. ‘Tsunami’ ‘Epidemic’ ‘Burden’ (Zeilig, 2014)
The arts for social change
Engaging the public in conversations about living with dementia

Improve ‘dementia knowledge’
Exhibitions of artwork

“On it’s own it looks nothing, but together it is art”

Encourage the public to see dementia differently

“The group sucks you out of the abyss, lifted me out of depression”
Imagining Dementia Friendly Futures

What would we like the future to look like?
What are your dreams?
What would you like to change?

Drawing by a person living with dementia: imagining herself as a ballerina.
The role of the visual arts in the resilience of people living with dementia in care homes

Andrew Newman¹*, Anna Goulding², Bruce Davenport¹ and Gill Windle³

¹School of Arts and Cultures, Newcastle University, Newcastle upon Tyne, UK ²Institute of Health and Society

• Qualitative data analysis
• 48 people living with dementia and 37 staff and family carers
• Four care homes in the North East England
Visual arts intervention (12 weeks as 2 hours a week) leads to resilience processes for people living with dementia. These processes include:

- Enhanced relationships
- Creative expression
- Improved self-esteem
- Increased communication
Concluding thoughts

• How much adversity should we expect people to endure?

• What is the limit for resilience?

• How can we make sure that our efforts to build resilience don’t widen inequalities further?
Thank you
Diolch yn fawr

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