Carer resilience: ways forward for evidence-based policy and practice

Dr Mary Larkin,
The Open University
mary.larkin@open.ac.uk
INTRODUCTION

AIMS
To explore:

1. what we know about carer resilience

2. how we can take this agenda forward in order to develop evidence-based policy and practice

Introduce the CARER KNOWLEDGE EXCHANGE NETWORK (CAREN)
1. Evidence about carer resilience

2. What do we know about carer resilience?

3. The social ecology of resilience

4. Where to now?

5. Concluding comments
1. EVIDENCE ABOUT CARER RESILIENCE

CARER KNOWLEDGE EXCHANGE NETWORK (CAREN)

- www.open.ac.uk/caren

- a freely accessible knowledge exchange resource for all those across the globe who require any form of carer-related knowledge e.g. governments, carers, employers, policy makers, practitioners, researchers, NGOs and research funders around the world
Background to CAREN.....

- based on a unique scoping review of national and international carer-related knowledge (https://www.scie-socialcareonline.org.uk/seeing-the-wood-for-the-trees-carer-related-research-and-knowledge-a-scoping-review/r/a110f00000RCtCnAAL)

- DEMO - www.open.ac.uk/caren

Themes which are classified into four major categories:

- **Impact of Care**: the consequences and sequela of caring.
- **Carer Variables**: the characteristics and features of different types of carer and caring situations
- **Type of Care**: the nature of needs of the cared for person, and the features of the care situation.
- **Support and Carers**: The provision and impact of general and specific help and support
CAREN’s roles….

- a reliable and independent database for carer research and knowledge
- translation of research and evidence into evidence-based improvements in the quality and cost-effectiveness of both health and social care services and practice with carers
- a source of information about policy development and evidence for government departments and NGOs
- the facilitation of informed exchanges in relation to consultations and innovative practice
- help researchers reduce duplication of effort, quickly acquire knowledge about existing research
- an ‘international noticeboard’ for promoting conferences and events
2. WHAT DO WE KNOW ABOUT CARER RESILIENCE

Definitions…….

resilience
‘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 or “bouncing back” in the face of adversity’ (Windle, 2011, p. 163).

carer resilience
‘A resilient carer is someone who stays positive in the face of care demands and actively maintains and preserves their relationship and loved one’s former self. Resilient carers have access to and use services such as respite care and may actively engage with innovative schemes that aim to ‘give back’ to others in similar situations. Resilient carers are knowledgeable and well supported by family but especially friends, with whom they share this knowledge. Support group friends share emotional and practical advice and reassurance that may help the carer manage their role better. In doing so, carers may be more encouraged to pursue the positive aspects of caring which buffer the effect of burden on resilience” (Donnellan, Bennett, & Soulsby, 2015 p.938)
Benefits of building carer resilience

- Improvement in carer well-being (particularly in relation to depression)
- Increased likelihood of staying in work when caring
- Delayed institutionalisation of the person receiving care
Models of carer resilience – 1…..

Source: https://www.scie.org.uk/publications/windowsofopportunity/personalresources/carerresilience.asp
Carer Resilience models – 2.

Windle & Bennett, 2011.
Carer Resilience models – 3….

- Parkinson et al, 2017
Policies and initiatives……

- **Australia** – Integrated Carer Support Service

- **UK** – Carers Action Plan

**Examples of initiatives:**

- **Caring for the ‘Third Workforce’: Developing Resilience and Wellbeing with Carers** = a carer resilience project

- **Rotherham Carers Resilience Service**
  (http://www.yhscn.nhs.uk/media/PDFs/mhdn/Dementia/Dementia%20Research/Rotherham%20CCG%20launched%20a%20new%20Carers%20Resilience.pdf)
3. THE SOCIAL ECOLOGY OF RESILIENCE

- Carer resilience is a multidimensional construct which operates on individual, community and societal levels.

- This supports the need to examine resilience from an ecological perspective.

- The social ecology of carer resilience requires developing interventions which are not just targeted at individual carers and also address carers social environment.
4. WHERE TO NOW?

● utilise existing knowledge base effectively for ideas to build carer resilience

● share ideas about carer resilience and policies

● create an international interest group

● develop a comprehensive and robust research and evidence base which can inform policy and practice

● develop a clearer and fully operational definition of what carer resilience means

● develop ways of measuring outcomes of carer resilience interventions

● move towards ecological models of resilience
5. CONCLUDING COMMENTS

The case has been made for:
● acknowledging the centrality of both evidence and knowledge exchange between research, practice and policy stakeholders to the development of effective interventions

● being aware that the focus on carer resilience is not just seen as a cost containing way of improving outcomes for carers

● identifying ways of ensuring that future developments around the important policy area of carer resilience based on the social ecology of carer resilience can be underpinned by a robust evidence base

This is only the beginning of the journey!
References

- Donnellan, W., Bennett, K., & Soulsby, L. (2015). What are the factors that facilitate or hinder resilience in older spousal dementia carers? a qualitative study. *Aging and Mental Health*, 19(10), 932-939


QUESTIONS and SUGGESTIONS?