#### Dr Susan M Carr

Professor of Public Health Research,

Faculty of Health & Life sciences

Northumbria University, Newcastle upon Tyne, England

Associate Director of Fuse

sue.carr@northumbria.ac.uk

Dr Mark Parkinson, Northumbria University

Dr Anna Wolkowski, Dove House Hospice, Hull





# Exploring the potential for inequalities in family caregivers

IFNC14 Conference August 2019, Washington DC





### Dr Anna Wolkowski CEO, Dove House Hospice, Hull

Does Respite Care Address the Needs of Palliative Care Service Users and Carers? An Exploration of their Perspectives and Experience of Respite Care. (2012)

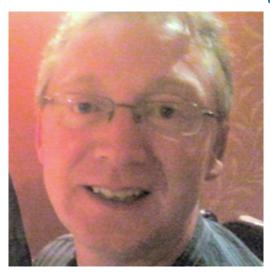






## Dr Mark Parkinson, Senior Research Assistant, Faculty of Health & Life Sciences Northumbria University

Positive adaptation to dementia: A Realist Evaluation of family carers' journey towards resilience. (2018)







#### **Translational paradigm:**

Participants' accounts privileged while cognisant of clinical & educational policy voices

#### Qualitative methodologies

Realist approaches

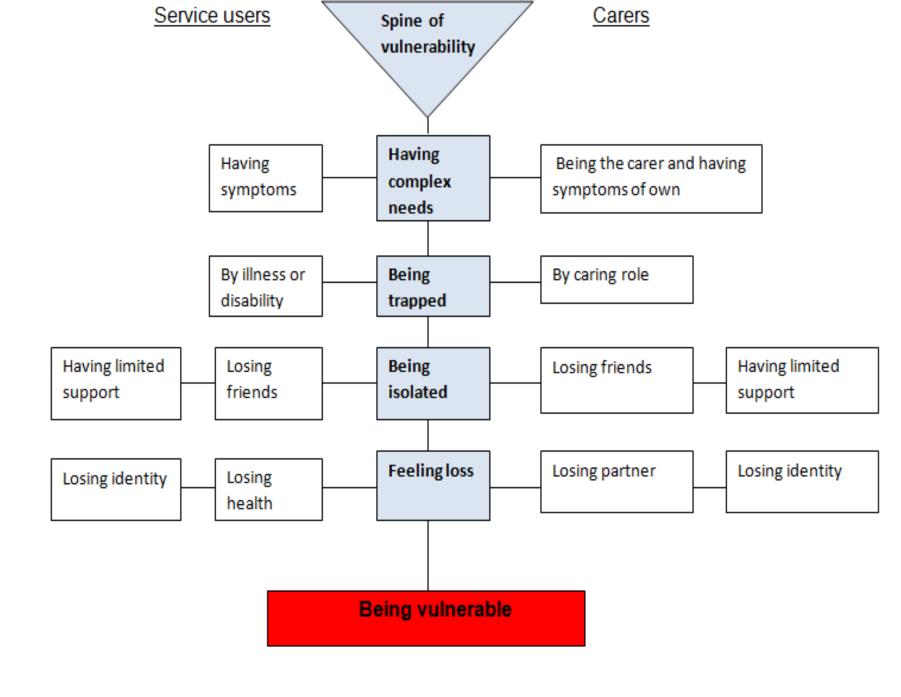
Constructive grounded theory

#### Sample

Care givers for family members with life limiting illnesses, principally cancers (n = 8) and dementia (n = 18)

#### **Data Collection activity**

**Interviews** 



#### Parkinson 2018

Carers compelled to develop strong sense of autonomy



Foster collaboration

Lack of service options available to carers



Alternatives to quasiinstitutional models

Practical focus to formal support



Opportunities to receive emotional support

Insufficient relational support

Opportunities to

promote social coping

Adoption of a shortterm perspective Support that is not contingent on long term planning

Lack of provider consensus



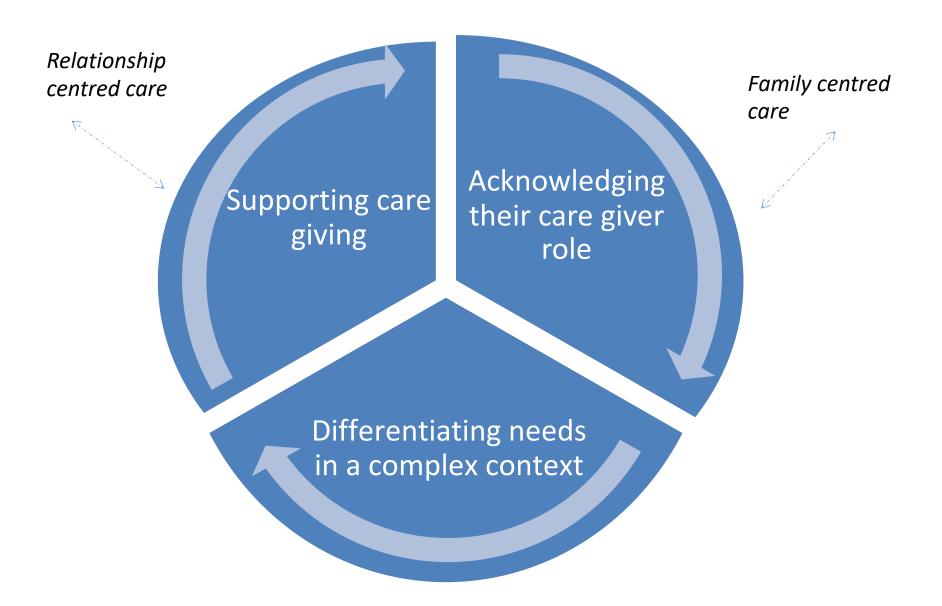
Promotion of bespoke support to develop adaptive strategies

Habituation towards coping autonomously



Strengthening bonds of trust between carer and providers

#### Triad needs framework



#### Returning to translational intent

We would really like to hear from you if:

- > our work generates any new thinking for you
- inspires you to re/ consider an aspect of your practice
- you adapt your practice/guidelines etc as a consequence
- you would like to discuss sth in more detail sue.carr@nothumbria.ac.uk



#### Related publications

Carr, SM, Lhussier, M & Forster, N. 2017. Lay health advisers: mapping the landscape. <u>J Healthcare Leadership.</u> 2017; 9: 59–67. Published online 2017 Jul 28.

doi: 10.2147/JHL.S134464

Wolkowski, A & Carr, SM. 2017. Does Respite Care Address the Needs of Palliative Care Service Users and Carers? An Exploration of Their Perspectives and Experience of Respite Care <u>Int J Palliat Nurs.</u> 2017 Apr 2;23(4):174-185. doi: 10.12968/ijpn.2017.23.4.174.

Parkinson, M, Carr, SM, Rushmer, R & Abley, C. 2016. *Investigating what works to support family carers of people with dementia: a rapid realist review Journal of Public Health* 2016; doi: 10.1093/pubmed/fdw100

Clarke, C, Wolkowski, A & Carr, S M.2010. Respite Care — What Does It Mean for Palliative Care Service Users and Carers? *International Journal of Palliative Nursing*, Vol. 18, No. 8, p. 388-392

Carr, S M. 2004. A framework for understanding clinical reasoning in community nursing *Journal of Clinical Nursing* 13, 850-857