The legacies of caring

Conference or Workshop Item

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The legacies of caring

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INTRODUCTION

growth in the number of family carers =
growth in the number of ‘former carers’

Irish gov projects

although they receive limited attention from policy makers, or services. recognition of their profile and needs has recently started

Australian National Network of Carer Associations provides carer counselling services to former carers and former carers can also attend carer support groups

some attempts to quantify how many people become former carers

most of us will have caring responsibilities at one or more stages in our lives” (Department of Health, 2014:7)

https://www.carersuk.org/forum/support-and-advice/former-carers

a small but growing international body of research is developing
OUTLINE

• who is a former carer?

• former carers’ experiences

• the limitations of existing research

• ways forward
WHO IS A FORMER CARER?

Routes into former caring…..

When the cared-for person:

• dies

• is admitted to long-term care (i.e. permanently admitted to a nursing or residential care home or continuing care in hospital)

• is admitted to a hospital

• is admitted to a hospice

• recovers from their health problem (e.g. with substance misusers or those who have undergone major surgery)

• goes into remission (e.g. for cancer patients)
THE ‘LEGACIES OF CARING’

- financial legacy
- paid employment
- social isolation
- health and wellbeing
INFLUENCES ON THE ‘LEGACIES OF CARING’

● problematic caring experiences

● admission to a care home

● bereavement

● post-caring and more caring

● limited support
RESEARCH ABOUT FORMER CARERS: WEAKNESSES

- many weaknesses are methodology–related.
  - most studies are small scale
  - conducted by different bodies undermines the capacity of research to be additive;
  - minimal cross-fertilisation of ideas or expertise.
  - (often) limited geographically (e.g. one area)
  - focus on one particular group of former carers (e.g. those who have cared for a relative with dementia or cancer patients)
  - sample groups tend to be small
- few longitudinal studies
- limited funding available
- absence of a conceptual, theoretical or discipline-based lens of analysis
IMPLICATIONS

● opportunities to increase knowledge of carers post-caring experiences and identify ways of supporting them are constrained *and YET IMPORTANTLY*

● there will be a growing number of former carers who, because of their caring experiences, will suffer a range of complex financial, social, and emotional and health needs,

● more demands are being placed on former carers because of policy changes

● the legacies of caring may well increase
WAYS FORWARD…..

● more research but need to rethink former carer research

● central to this rethink is addressing some of these weaknesses e.g.

  ➢ need more funding opportunities to be made available
  ➢ more joined up approach to research into former carers
  ➢ more longitudinal studies
  ➢ more studies that engage with former carer generated perspectives to capture their distinctive needs
  ➢ absence of a conceptual, theoretical or discipline-based analysis. Eg sociological analyses based on concepts such as liminality and Social identity theory
THE CASE FOR FOCUSING ON FORMER CARERS in research policy and practice

- lessening post-caring ‘legacies of caring’ and the factors which exacerbate them for this growing group is a matter of social justice

- social and economic rationale

- the growing demand for care and the predicted imbalance between ‘supply’ and ‘demand’