



## Open Research Online

### Citation

Larkin, Mary (2015). Unbecoming a carer. In: British Medical Sociology Association, 2015, British Medical Sociology Association.

### URL

<https://oro.open.ac.uk/44443/>

### License

(CC-BY-NC-ND 4.0)Creative Commons: Attribution-Noncommercial-No Derivative Works 4.0

### Policy

This document has been downloaded from Open Research Online, The Open University's repository of research publications. This version is being made available in accordance with Open Research Online policies available from [Open Research Online \(ORO\) Policies](#)

### Versions

If this document is identified as the Author Accepted Manuscript it is the version after peer review but before type setting, copy editing or publisher branding

# 'Unbecoming' a carer; Conceptualising 'former carers'

Dr Mary Larkin,  
The Open University

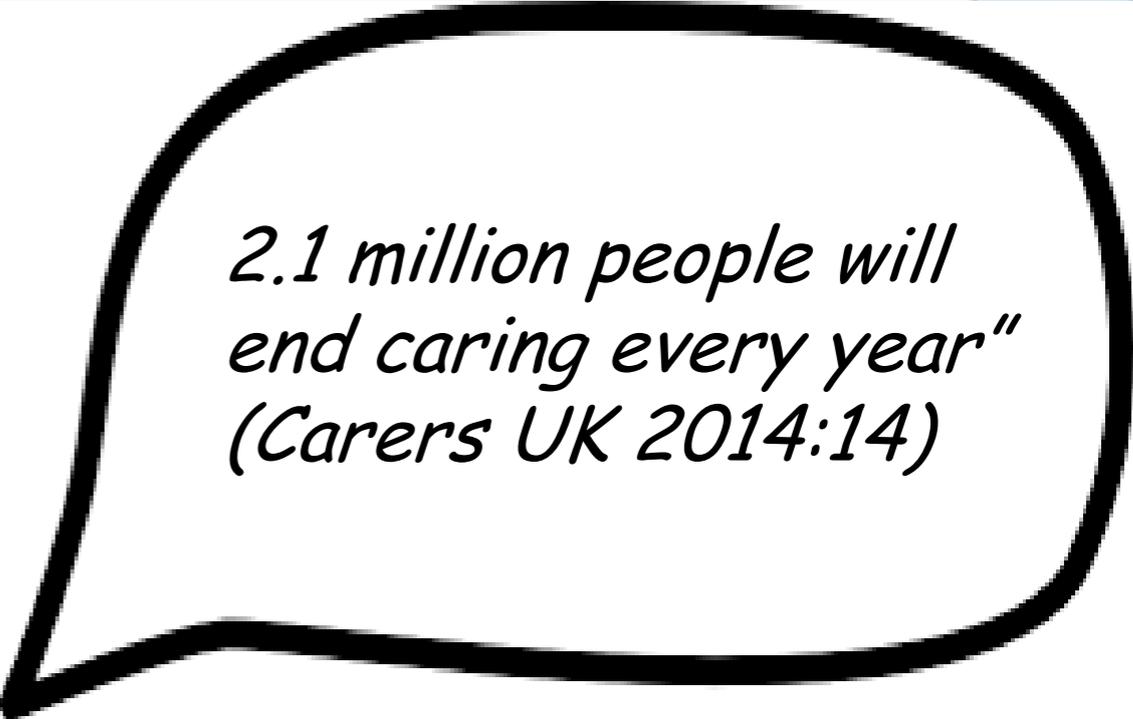
---

Email: [mary.larkin@open.ac.uk](mailto:mary.larkin@open.ac.uk)

# Introduction

---

- the growing number of family carers also means that there are an increasing number of former carers
- recognition of their status is gathering momentum
- this recognition underpinned a systematic literature review conducted in 2014/15 with the aim of drawing together what is known about former carers and the nature of that knowledge



*2.1 million people will end caring every year"  
(Carers UK 2014:14)*

# Outline

---

1. LITERATURE REVIEW
2. LITERATURE REVIEW THEMES
3. EXISTING RESEARCH ABOUT FORMER CARERS:  
STRENGTHS
4. EXISTING RESEARCH ABOUT FORMER CARERS:  
WEAKNESSES
5. WAYS FORWARD

# 1. Literature Review

---

- the Centre for Reviews & Dissemination guidelines for undertaking literature reviews was used
- it involved a comprehensive search of relevant databases including - Social Policy and Research, Scopus, PsychINFO, ASSIA, MEDLINE & CINAHL Plus + additional studies & grey literature was identified via hand searches
- Key terms were broad to maximise inclusion: former carer/caregiver + ex + past + bereaved + post
- Literature from 1985 (GHS ex carers question for first time) to 2015: English language only
- Search yielded 160 items: analysed using critical appraisal skills programme in relation to rigour, methodology, credibility, relevance & findings: narrative synthesis tools & techniques was adopted to capture the breadth of the review

## 2. Literature Review themes

---

6 themes were identified:

- the concept of former carer
- the legacies of caring
- influences on the legacies of caring
- conceptualising post-caring
- post-caring and the lifecourse
- support services for former carers

# The concept of a former carer

---



Considerable terminological variation:

- 'carer' is a contested term: many carers do not 'own' the label
- 7 possible routes into becoming a former carer

When the cared-for person:

1. dies
2. is admitted to a hospital
3. is admitted to a hospice
4. is admitted to long term care (i.e. permanently admitted to a nursing or residential care home or continuing care in hospital)
5. recovers from their health problem (e.g. substance users)
6. goes into remission (e.g. for cancer patients)

OR as in the case of some young carers:

7. the carer moves on from the caring role (e.g. grows up and/leaves home)

# The 'legacies of caring'

---

- There are a number of *post-caring legacies* that can adversely affect carers lives for many years, including:
  - financial hardship caused by depleted savings & increased care related costs may be worsened by the loss of carer-related benefits
  - long-term caring has a well-established link with increased risk of a range of negative physical and psychological health outcomes - these may persist post-caring & include back problems, high blood pressure, isolation & depression
- *Influences on 'legacies of caring'* include:
  - long term health problems pre-dating caring
  - a poor relationship with the cared for person pre dating *and* embedded in the care relationship
  - whether the carer adopts a 'new' post caring role
  - whether the carer has experienced losses before they become a former carer e.g. 'quasi-bereavement' linked to dementia care (Larkin and Milne, submitted)

# Conceptualising post caring

---

- number of theoretical models incorporating post-caring experiences
- long-standing model conceptualises caring as a continuum - post-caring is seen as integral to the "overall caregiving career" (Orzeck and Silverman, 2008)
- Brown and Stetz's (1999) study of carers of people with life-threatening illnesses refers to the 'labor of caregiving' -comprises 4 phases including a phase entitled 'taking the next step' post-bereavement
- Research in the 1990's about dementia care took a similar path: an influential model identifies 8 temporal stages including a 'final stage' relating to care home admission referred to as 'a new beginning' (Nolan *et al*, 1996)
- Larkin's work on bereaved carers developed the concept of a specific post-caring trajectory comprising 3 phases each containing a distinct sets of experiences: the 'post-caring void', 'closing down the caring time' & 'constructing life post-caring' (2009)
- Cronin *et al* (2015) conceptualise post-caring life as a time of being 'between worlds' during which former carers experience three interrelated transitions - referred to as 'loss of the caring world', 'living in loss' and 'moving on'

# Post-caring and the lifecourse

- the experience of caring shapes post-caring experiences; it profoundly impacts on carers' identity & sense of self
- many former carers adopt a 'new' caring role - as a paid worker, a volunteer or as a carer for another relative
- reasons for this are complex but appear to include a mixture of having a particular care-related skill set, no longer possessing skills for other kinds of work, & continuing to have a sense of carer-related identity
- often former carers feel they have "little control over their resumption of the role of carer; somebody who was closely related to them had needed care" (Larkin, 2009:1039)
- concepts such as "serial carer" (Larkin 2009) have been used to describe this group reflecting the sequential nature of caregiving roles

• **BUT** remains a profoundly under-researched issue

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

# Support services for former carers



- some policy and practice acknowledgement of the importance of support services for former carers
- services include: psycho-social support, financial advice, support groups, counselling, & employment advice; specialist services include those for specific groups of carers e.g. bereaved carers
- a small number of studies have identified the value of: community-based support groups for former carers (Larkin, 2008); peer support (Greenwood *et al.* 2013); support groups for care home residents' relatives; & bereaved carers
- Local authorities have a limited obligation to offer support to people who are no longer 'actively caring'
- recent developments suggest that former carers' support needs are beginning to have a more visible public profile

*NHS England has said it will "include support for bereaved carers and relatives in its new ambitions for End of Life Care" (NHS England 2014:13) AND Carers UK has called for "public bodies & the voluntary sector to "plan for the fact that 2.1 million people will end caring every year*

### 3. Existing Research about Former Carers: Strengths

---

- current research does offer a picture of who (some) former carers are, how they 'became' former carer, the ongoing impact that caring has on their lives and health,
- alerts us to some of the complexities:
  - the challenges inherent in 'continuing to care' & adopting a new identity
  - the needs of former carers
  - the adoption of new/additional post care caring roles
- highlights the growing focus of policy & services on supporting former carers

## 4. Existing Research about Former Carers: Weaknesses



1

- there is considerable *terminological variation*; limited consensus about who is defined as a 'former carer':
- ignores some less well-recognised groups which contributes to the invisibility of such groups inside the former carers arena
- *methodological issues*: most studies are small, focus on one group in one area, take a 'snapshot': additive capacity is limited & short term purview
- *research funding* is limited

# Existing Research about Former Carers: Weaknesses 2



.....  
A number of fundamental *conceptual issues*:

- most evidence is drawn from work that embeds former carers in the care trajectory
- bifurcation of 'carer' & 'former carer': research struggles with more complex notions or types of formerality e.g. carer of care home resident & *then* a bereaved former carer
- static state: research is challenged to accommodate a shifting status e.g. from carer to former carer & back again
- most research is located inside the '*Gatherers & Evaluators*' paradigm: assesses who former carers are, how many & what carers do; what impact caring has had on health & well being; informed by a stress-burden model of caring; evaluates which services 'work' for carers; & adopts an atomized purview of the caregiving landscape (Milne & Larkin, 2015)
  - this is reflected in its limited engagement with theory, the nuanced nature of formerality or carer generated accounts of their lived experiences
  - fails to capture the actual and conceptual transition from one status to another, the process of *becoming* a former carer and/or *unbecoming* a carer or take account of concepts such as liminality, hybridity & biographical disruption.

# 5. Ways forward

---

- 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
- changing demographics mean that many of those suffering the effects of having been carers will be needed to care again
- this review points to a need to rethink former carer research and its conceptual, theoretical and paradigmatic underpinnings in order to:
  - extend understanding of a complex individual and relational experience
  - generate new knowledge
  - contribute to former carers' improved health and well-being
  - help address age and care related policy challenges

# Key references

- Carers UK (2014) *Need to know: Transitions in and out of caring: the information challenge*. London, Carers UK
- Department of Health (2014) *Carers Strategy: Second National Action Plan 2014 - 2016*. London: Department of Health
- Hatzidimitriadou, E., Milne, A et al., (submitted) 'Continuing Carers': Identity and Role Transition of Spouse Carers whose Partner is in Long Term Care, *Health Expectations*
- Henderson, J (2001) 'He's not my carer, he's my husband': personal and policy constructions of care in mental health. *Journal of Social Work Practice*, 15: 149-59
- Larkin, M. (2009) Life after Caring: Post-Caring Experiences, *British Journal of Social Work*, 39, 1026-1042
- Larkin, M & Milne, A. (2013) Carer Empowerment in the UK: A Reflection, *Social Policy & Society*, 13(1), 25-38
- Larkin, M. and Milne, A. Knowledge Generation and 'Former Carers': a review and critique of existing research (submitted), *Sociology of Health and Illness*
- Milne, A and Larkin, M (2015) Knowledge Generation about Caregiving in the UK: A Critical Review of Research Paradigms, *Special Issue of Health and Social Care in the Community*, Caring in the 21<sup>st</sup> Century, Papers from an ESRC Seminar Series, 23(1), 4-13
- NHS England (2014) *NHS England's Commitment to Carers*. Leeds: NHS England
- Seddon, D., et al, (2002) Carers experiences after a relative goes into nursing or residential care, *Quality in Ageing*, 3(3), p16-26