Unbecoming a carer

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‘Unbecoming’ a carer; Conceptualising ‘former carers’

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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

<table>
<thead>
<tr>
<th>When the cared-for person:</th>
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<tr>
<td>1. dies</td>
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<td>2. is admitted to a hospital</td>
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<tr>
<td>3. is admitted to a hospice</td>
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<tr>
<td>4. is admitted to long term care (i.e. permanently admitted to a nursing or residential care home or continuing care in hospital)</td>
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<tr>
<td>5. recovers from their health problem (e.g. substance users)</td>
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<tr>
<td>6. goes into remission (e.g. for cancer patients)</td>
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**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
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':

2. ignores some less well-recognised groups which contributes to the invisibility of such groups inside the former carers arena

3. *methodological issues*: most studies are small, focus on one group in one area, take a 'snapshot': additive capacity is limited & short term purview

4. *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

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*
Larkin, M. and Milne, A. *Knowledge Generation and 'Former Carers': a review and critique of existing research* (submitted), *Sociology of Health and Illnes*