The health and wellbeing of former carers of older people

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Former carers

- Individuals for whom caregiving has come to an end
- 2 million people each year become former carer (Carers UK 2014)
- Increasing large section of the population
- May due to death, care home admission, recovery, change of caregiver
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Models of caregiving

- Demonstrate temporal and dynamic dimensions
- Role Disengagement. (Aneshensel et al, 1995)
- Resuming Life – Healing and Renewal (Pfeiffer 1999)
- New Horizons (Cavaye 2006)
- Post-Caregiving (Ume and Evans 2011)
- Integral part of caregiving - but overlooked by researchers
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Former Carers Study

- Small prospective study using social media
- Part 1: online web-based survey – www.formercarers.co.uk
- Part 2: in-depth qualitative interviews
- Co-produced with former carers
- Ethics approval from OU HREC committee
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Participants

- Respondents self-selected (35)
- 90% female and only 10% male
- Ages ranged from 37 – 72 years
- 67% caring for a parent
- 20% caring for a partner
- 9% had looked after a sibling
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Findings

End of caregiving as a result of:

- 72% - death
- 20% - admission to a care home
- 6% - recovery and independence regained

Support for this transition

- 60% had no support
- 12% had some or a little support
- 2% had a lot of support - mainly from family and friends
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Mental health and wellbeing

- 19% said that being a carer had not affected their mental health.
- “No, I have a good sense of humour and am fairly calm in nature”
- 48% - still suffered from stress
- 42% - depression and low mood
- 16% - anxiety
- 7% - unresolved anger about their experiences of being a carer
- loss of confidence
- loss of focus in their life
- low self esteem
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Mental health and wellbeing

● “Still stressed”

● “There was hardly a day went by when I was a carer that I didn’t think ‘when this is over I’ll be free to do whatever I want’. When it was finally over I felt I had lost all direction had no energy or enthusiasm to look for another.”

● “There is a sense of emptiness in my life and anger at some of the ways my father was treated during the last couple of years of his life”

● My life changed after the death of my sister. It took me at least 2 yrs to come to terms with her loss. I became very depressed

● I collapsed mentally and two and a half years later I am still trying to recover. I suffer from anxiety and mental fatigue but I am starting to get better lately. It has been a very confusing time for me because as a family we have all been quite robust in our mental faculties, and I looked after 52 employees. Now I find it difficult to deal with 4.
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Physical health and wellbeing

- 20% - said that being a carer had not affected their physical health
- 32% - still felt tired or exhausted, troubled sleeping – sleep patterns disrupted whilst a carer & never gone back to normal
- 16% - had musco-skeletal problems - back and shoulder pain, slipped discs, sciatica and prolapse
- 13% - had weight problems – some had lost whilst others had gained
- 10% - had problems with skin conditions such as rosacea, psoriasis and shingles
- 9% - reported digestive tract problems such as gastric reflux and ulcers
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Physical health and wellbeing

- “I still get tired very easily and have interrupted sleep patterns”
- “I spent so much time looking after someone else, I had no time to care for myself. I have gained 4 stone in weight ad have developed stress related psoriasis”
- “the physical impact on me are back and shoulder pain”
- “I got shingles while I was looking after both my parents, which still has repercussions on my health. I got rosacea and other problems that they said stemmed from my anxiety and the way it affected my digestion”
- “After I finished caring I was ill with a number of different problems such as ulcers, reflux disease, bladder problems and more. In the first year and half I had over 15 courses of antibiotics”
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Adapting to life after caregiving

- 63% - it has been fairy or very difficult to adapt
- 37% - it has been very or fairly easy to adapt

- “my mum moved into a care home 2 years ago now...the transition to having ‘guilt free’ time for me has been difficult to adjust to”

- “Mother was a dominant force in our life throughout our marriage and it took some adjusting when she was gone”

- “When it was finally over I felt I had lost all direction had no energy or enthusiasm to look for another.”

- “There is a sense of emptiness in my life and anger at some of the ways my father was treated during the last couple of years of his life”

- “I feel lost and can’t go into some shops that I used to take Annie to”
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Conclusions

- Former carers report poor mental and physical health and wellbeing
- For a few, health and wellbeing improves in the post-caregiving stage
- For the majority, poor health and wellbeing is a lasting legacy of caregiving
- Former carers felt unsupported and had difficulty adapting to the transition
- Essential that support is provided in the post-caregiving stage
- Policy and service providers should address the needs of former carers
- Former carers are an important but under-utilised resource
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References


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