The health and wellbeing of former carers of older people

Conference or Workshop Item

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Health and Wellbeing of Former Carers of Older People

Dr Joyce Cavaye
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Health and wellbeing of former carers

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”
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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