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Being a former carer: impacts on health and wellbeing

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Introduction

Much care for older, ill and disabled people is provided by informal unpaid carers usually in the context of familial relationships. Such care can involve providing support with aspects of daily living including shopping, transport to medical appointments as well as physical and personal care. Those who receive informal care may be living with multiple health conditions that give rise to complex needs such that carers might also provide assistance with managing medication and contact with health and social care professionals (Hammond et al, 2013). The variation in the extent to which carers carry out these different tasks and the amount of time they spend doing them illustrates the potentially multi-faceted nature of the caregiving experience.

Since the emergence in the 1980s of the concept of 'carer', research about carers and their experiences has expanded and informal caregiving is now recognised as increasingly important, particularly in the context of scarce health and social care resources (Mosher et al, 2013). Caregiving is a dynamic process that varies over time and intensity but is often characterised as exhausting both physically and emotionally (Caserta et al, 2013). The detrimental effects of caregiving are well documented with family carers reporting poor health, high levels of depression, stress and anxiety and social isolation as a result of their role (Pinquart and Sorenson, 2003; Hanratty et al, 2007; Hoffman et al, 2012). Some commentators such as Roth et al (2015) and Ott et al (2007), however, comment that most caregivers report some benefits from caregiving and many report little or no caregiving-related strain so there is a more mixed cost/benefit caregiving picture than is often presented. Also to note is the increasingly large group of carers who are older members of the population living with their own health concerns (Ahn et al, 2012).

Whilst much of the literature on informal caregiving is empirical, a number of analytical frameworks have been developed drawing on different theoretical traditions including those from an influential body of feminist and psycho-social scholarship (see Gilligan, 1982). More recently, caregiving has been the subject of enhanced analysis with a plethora of characterising features emerging. Duration and intensity of caregiving are factors that help shape what Lindgren (1993) and Aneshensel et al (1995) term the 'caregiving career' that they theorise as having three stages - the encounter stage, the enduring stage and the exit stage. These stages comprise role acquisition, role enactment and role disengagement – this last stage being due to care home admission, death of the care recipient or their recovery and regained independence. Whilst the first two stages have been the subject of considerable discussion in the literature, the transition to becoming a former carer (role disengagement), merits further attention, particularly because of growing evidence of difficult adjustment and lack of support for carers when caregiving ends (Butterworth et al, 2010; Carter, 2005; Crespo, 2013; Jenkins et al, 2009; Kenny et al, 2014; Thomas et al, 2015).

Though less is known about the experiences of former carers, the work of Larkin (2009) offers some insight into what, for many carers, is a difficult transition to a non-caregiving life. Larkin (2009) develops a stages approach to the caregiving career specifically applying this to the end of caregiving. She argues that former carers'

post-caregiving lives are made up of phases and that the beginning of the post caregiving experience is often characterised by a reduction of contact with formal services. There may also be spatial changes in the home with the removal of equipment and medication. Larkin (2009) describes this initial phase as the 'wind down period' because it involves changes to routines and the daily pattern of life. This period might also entail 'closure tasks' such as making funeral arrangements and sorting out financial and legal issues. Later stages focus on constructing a post-caring life with former carers undertaking new activities such as voluntary and paid work.

Decisions carers make concerning work (be it paid or voluntary) both in the active and post-caregiving phases are shaped by a complex interplay of factors that include carers' health, financial considerations, work-related issues and matters related to the care recipient (Aldridge and Hughes, 2016; Brimblecombe et al, 2016). Whatever the particular context of these decisions, work is understood to contribute to an individual's identity and wellbeing and for some people is an essential feature of how they see themselves in the world (Watts, 2015). Part-time work is the principal means by which many people manage the dual responsibilities of paid work and providing care with this mainly the case for women with childcare commitments (Wattis and James, 2013). It has also been found to provide women with a respite from caregiving (Masuy, 2009). However, for many providing care for older, disabled or frail family members even the option of part-time work may not be feasible because, although work can be 'contained', caregiving often cannot be. In the post-caregiving phase, a focus on re-entering the paid workforce might not be realistic, particularly following a long period of caregiving due to poor health and labour market barriers in the form of requirements for up to date knowledge and skills.

This article reports preliminary findings from a prospective qualitative study carried out in the UK that explored the experiences of former carers. Data revealed that the impacts on the health and wellbeing of carers during the post-caregiving phase were shaped by a number of influences including the levels of support available and the nature of the loss. The sections that follow outline the context for the study, its methodology and thematic discussion of the findings with a concluding section that draws together key points.

Context

It is estimated that the UK has 6.5 million carers of whom, almost 2 million become former carers each year (Carers UK, 2014). At the same time, another 2.1 million individuals take on a caregiving role for the first time and become 'silent sufferers' (Trudeau-Hern and Daneshpour, 2012: 534) providing increasing amounts of unpaid care (Carers UK, 2014). Additionally, because of an ageing population and a reduction in the availability of formal service provision, the numbers of active carers in the UK are projected to rise. Thus, the number of former carers will also rise.

In recent years UK policy has formalised the role of carers in providing unpaid care and support by the introduction of new rights and entitlements. For example, the Care Act 2014, which came into force in April 2015, provides carers with a new legal entitlement to support. While this legislation is underpinned by the concepts of wellbeing and empowerment, it is directed only at active carers who are conceptualised as being an important and essential resource. The needs of former carers are consistently overlooked by policymakers despite the evidence that the end of caregiving is a challenging period.

As policy seeks to increase the level of informal care provision, there is an increasing risk that former carers will face uncertainty and social exclusion in the post-caregiving period. Conceptualised by former carers as 'being caught between worlds' (Cronin et al, 2015:93), this period is one which is difficult to adjust to and move on from. Yet in the context of poor health and high unemployment, there may be few opportunities for former carers to return to the labour market or forge new careers. Thus it is imperative that formal health and social care providers fulfil their legal and moral duty to provide former carers with support.

Methodology

The aim of the study was to explore the experiences of former carers. Design of the research study included the important initial phase of a literature review. Drawing on an international body of literature, the intention of the review was to explore current knowledge about the wellbeing and experiences of carers in the post-caregiving period. Findings from the review suggest that former carers experience high levels of psychological distress and that caregiving has a profound and long lasting impact on their lives (Cavaye and Watts, 2016). Findings from the literature review were used to inform the design of the second part of the study which is the focus of this article.

Study sample

The study was promoted by carer support groups and social media with data being gathered between March and December 2015. Some carers support groups acted as gatekeepers by inviting former carers to take part in the study. Potential participants were encouraged to access the questionnaire which was available online. Thus the sample was a self-selecting one and this may be the reason that twenty four participants started but did not complete the questionnaire.

A total of 103 carers responded to calls for participants but data was only collected from 79 former carers who completed the entire questionnaire. To be eligible for the study, participants' role as a carer had to have ended more than 6 months before but less than 5 years. This timeframe ensured that participants were not recently bereaved and thus were at lesser risk of being distressed by the questions asked. It also ensured that the caregiving experience was not so far in the distant past, that memories of it were impaired.

The participant profile had the following features: 90% were female and 10% male with ages ranging from 37-72 years. This gender profile is not representative of the general carer population in the UK.

Data Collection

The main empirical phase of the former carers' research project involved the use of a structured questionnaire which was co-produced with three former carers who, reflecting on their own experience, made suggestions about relevant topics to be included. The questionnaire was structured with three sections focusing on: the care recipient and experiences of caregiving, the impact of caregiving and the changes that had taken place since the end of the caregiving role. Each section comprised a mix of open and closed questions with space for 'free comment' and including the option of participating in a follow-up interview – a planned series of semi-structured interviews comprising the third and currently uncompleted stage of the study. As suggested by Bryman (2004: 133), the questionnaire was constructed in simple language and was made relatively short to reduce the risk of 'respondent fatigue'. Being homogeneous in nature, a questionnaire does not have the problem of

interviewers asking questions in a different order or in different ways that Phellas et al (2012) argue can result in data distortion. Data was thematically analysed drawing on principles outlined by Braun and Clarke (2006) with descriptive statistics used to summarise basic features of the sample.

Ethical considerations

Usual consent procedures were followed with a particular focus on ethical aspects. The need for consent was outlined and assumed to have been given by the completion of the questionnaire. Given findings from the literature review relating to carer distress, the importance of embedding sound ethical principles within the conduct of the study was given a high priority. Participants could be seen as a potentially vulnerable research population. Although willing participants, the sensitive nature of the topic was perceived to be risk-laden in terms of giving rise to difficult emotions and even disclosure of attitudes which would normally be kept private. Whilst all social research has its consequences and implications, those involved in research connected to sensitive areas of human experience such as death, trauma and illness might have more to lose by taking part (Liamputtong, 2007). Protection of participant anonymity in any reporting of the study, the opportunity for further contact and information about possible sources of support, particularly access to bereavement services, were some of the ethical components of the research.

Results

Data show that the end of caregiving for the majority of participants in the study was due mainly to the death of the person being cared for with admission to a care home being the next reason. A few participants were no longer required to be a carer because their relative had recovered their health and independence.

The majority (68%) of participants had been caring for a parent, 19% for a partner, 8% for a sibling, 3% had looked after a grandparent and 2% had cared for a child with learning disabilities.

A wide time-span of years spent caring was represented in the study with 31% being a carer for less than 3 years, 38% for between 3 to 10 years, 23% being a carer for more than 10 years and 6% for more than 20 years. In terms of the time commitment, 17% of participants reported spending under 20 hours a week devoted to caregiving while 31% said they spent between 20 – 50 hours a week. The majority (52%) reported that they devoted more than 50 hours a week providing care. These figures show that the majority of former carers in this study were at the heavy end of caregiving and some of them, for a considerable length of time.

Two major themes emerged from the data and these are now presented below. The first theme is the health and wellbeing of carers in the post-caregiving period and the second relates to issues of support – both personal and professional.

Health and wellbeing post-caregiving

A key theme of this study was the psychological impact of the transition to post-caregiving with a majority (80%) of participants reporting continued feelings of stress, anxiety, depression and low mood. For some who had been carers for longer than a year, this was accompanied by a loss of confidence and a loss of focus in their life; some also reported reduced self-esteem. The quotes below highlight these negative impacts.

"I am 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."

"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."

Complex emotional reactions in the post-caregiving period were reported. For example, a small proportion of respondents (7%) commented on their unresolved anger about their experiences of being a carer. Others reflected upon and worried about whether the care they had provided had been enough.

"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 lonely, guilty, angry and pretty stupid in general now."

"It was a very emotional time knowing that whatever I did, he was going to die. I just hoped that I was doing enough for him"

Over time, carers had become isolated as a result of their caregiving role and experienced a loss of friendships and social activity. These feelings did not dissipate in the post-caregiving period with feelings of isolation compounding the grief and distress experienced and hindered them from moving on with their lives.

Alongside the psychological impacts experienced in the post-caregiving phase, some participants continued to suffer physical health problems. 32% of participants reported still feeling tired or exhausted and had trouble sleeping; 16% had musco-skeletal problems; 13% had weight problems; 10% had problems with skin conditions and 9% reported digestive tract problems. These health issues had developed during the active phase of caregiving but were not immediately resolved in the post-caregiving period. The nature and extent of these physical health issues are drawn out in the comments below.

"I still get tired very easily and have an interrupted sleep pattern"

"I spent so much time looking after someone else, I had no time to care for myself. I have gained 4 stone in weight and have developed stress related psoriasis"

"The physical impacts 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”.

Not all respondents had experienced negative effects on their health in the post-caregiving phase, with some commenting on how they had managed to remain resilient and positive. The comments below illustrate caregiver resilience and are drawn from answers to the question asking whether being a carer had affected their mental health.

“No, I have a good sense of humour and am fairly calm in nature”.

“No, nothing permanent but I’m sure there were times when I felt down”.

“Not really. I was a bereaved carer and felt appropriately low in mood. Also when one person you care for dies, you may have to go straight back to caring for another and this gives no time to grieve”.

Resilience was associated with the nature of the caregiving relationship and carers’ ability to be flexible and gain some satisfaction from their role.

Financial wellbeing

Wellbeing of carers in the post-caregiving period was for some connected to their financial situation that had radically altered during their caregiving career. For the majority of participants, becoming a carer had been accompanied by either a reduction of paid work or giving up their job completely in order to cope with the competing and increasing demands of caregiving. Those who were providing care for a terminally ill relative were least likely to give up their jobs completely. The knowledge that the caregiving role was likely to be time limited enabled them to take leave or continue on reduced hours for the duration of their role. This was experienced by some as challenging, both emotionally and practically – earning money took time away from caregiving and caregiving took time away from paid work resulting in financial strain (Olson, 2015). Comments from participants below highlight some of the financial penalties arising from aligning work to caregiving.

“Gave up a well paid teaching job 4 years ago. Loss of income, loss of pension, now cannot live on the income I have so going back to work at age 6”.

“My husband needed me as a full time carer. I was working part time as a registered nurse and resigned from my post. I was not told at the time that I could have taken extended leave. This would have been unpaid leave so would still have impacted on my income”.

“I ran a business but had to give up due to the circumstances surrounding my Mother's condition so couldn't work and consequently used my savings. I felt I could not claim Carers Allowance because she was my Mum. I learned later that I would have qualified for other financial assistance but only after Mum had passed. Of course it also means my pension contributions are less than they would have been which means my pension will be significantly reduced”.

“I left work and moved house to look after my Father. My loss of earnings would be about £250000 gross. I have no pension. I am dependent upon my husband's pension”.

"I lost 6 years pay. I worked only 1 -2 days per week but this largely went on fares and expenses. I put my pension lump sum and as much pension as possible into cash to pay my mortgage so I would not lose my home. Before I left work I had cut down my hours to care for my parents and this affected my pension as this was based on my last 2 years salary".

"I left my job, with a redundancy payment, to look after my wife full time. Stretching the redundancy with the help of carers' allowance for 4 years. Then took a part time job for 6 months, after which we had to move, as she was not able to continue at the same location which was affecting her mental health. Looked after her for a further 1 year, eventually able to take a full-time low paid job, with stressful moments. She copes well, now. During this 6/7 year period, I can calculate that my loss of earnings is in excess of £70,000 (but the result has been worth it)".

Carers who were in paid employment were clearly faced with complex and difficult choices connected to the competing demands of paid work and caregiving responsibilities. Reducing the amount of paid work or giving up employment altogether left the majority of carers with reduced or limited financial resources when their caregiving responsibilities ended.

A few former carers reported an improvement in their post-caregiving finances. This was mainly as a result of being able to gain paid employment, increasing the number of hours that they were able to work or getting a job with a higher salary than previously. In other instances, an improvement was due to an increase in welfare benefits or inheritance.

"I was working from 0-2 days per week as a carer. I am now working more so I am trying to get back on my feet financially - saving for the jobs on the house that I had no money to complete. I am no longer scared to open my letters."

"I went back to working with my husband and we also downsized so financially that is better."

"I have now found different work. Although still part-time, it is better paid."

"Yes, I'm a single parent now so receive widowed parents allowance."

"I'm living off my savings and my inherited savings from my mother."

In the post-caregiving period, the combination of loss of health and income left former carers in a vulnerable position. They were trying to cope with grief and bereavement but also multiple losses such as relationships, confidence and emotional stability. During a time at which additional support would have been welcomed, they were left to construct their post-caring lives drawing very much on their own resources.

The issue of support

One section of the questionnaire addressed issues connected to support for carers in the post-caregiving period. Specific questions about how easy or difficult it was to adapt to a post-caregiving life along with identifying sources of support were included as a way of exploring the place of support in helping with the transition to life after caring.

Whilst two thirds of participants reported that they had difficulty in adapting to the change, a third found it easy to adapt and some associated this with feelings of relief and release from caring responsibilities together with the prospect of rebuilding their former lives. Comments below illustrate this.

"It was a release and a relief to stop caring".

"It has been fairly easy to adapt because all responsibility for the ill person has gone".

"Looking after mother was so demanding (for me). It was a tremendous relief when she died. It took my husband and I a while to readjust to each other, and build up our social life again, and of course, I had to support my husband in coping with a loss of a mother who had been with him for 60 years!"

A majority of responses evidence a connection between lack of support and difficulty in adapting to life after caring. Some indicated difficulties in adjusting to a post-caring life despite benefiting from a high level of both practical and social support. There was a mix of informal and professional support provided with the roles of social worker, GP, bereavement counsellor and hospice workers highlighted by respondents.

The complex nature of trying to move forward as a former carer was drawn out by some respondents who expressed feelings of loss, emptiness and disconnection with those they had come to know through being a carer. One respondent suggested that having a mentor to support the transition from active to former carer would help to ameliorate the distress caused by a 'caring void'. Feelings of sadness, guilt and disorientation are all features of respondents' comments about this transition as reported below.

"It was tremendously difficult to go from caring 24 hours a day 7 days a week to nothing. I felt uncomfortably edgy, distraught at times. I honestly don't think anything could have helped, I think I just had to get through it".

"I felt very sad and guilty for some time. I was also quite tearful. I missed the family of carers who had helped me with my mother. Perhaps a friendly call from one of the care organisations to ask how things were going might have helped, or someone to talk to about my feelings. It is a mixed picture - some days I would be down, other days much better".

"It took me a long time to come to terms with the loss and I was also caring for both parents with dementia. It was hard resuming distant/ broken relationships. I needed to relearn how to relax and enjoy myself. I felt guilty about having time to do things for me. No one ever asked me how I was or offered help".

"Nothing can take away the pain of bereavement. There was a huge hole to fill".

"All the carers and social workers die with the person being cared for. If all those people we got to know well over years hadn't dropped away so suddenly it may have helped".

These comments illustrate a post-caregiving trajectory of uncertainty and multiple losses accompanied by complex emotions such as grief, loneliness, guilt and feelings

of abandonment. They also highlight the importance of relationships and support. The support network provided by formal service providers was withdrawn immediately death or relocation had taken place. Yet carers placed great value on these relationships and were shocked and surprised by their withdrawal, perceiving this as abandonment.

The majority of support received in the post-caregiving period was from other family members. Very few carers were supported by bereavement services. Thus not only did carers have to cope with the loss of their close relative but also all the other relationships with individuals who had formed a large part of their caregiving world.

Discussion

This study sought to explore the experiences of former carers, an increasingly large group for whom caregiving has come to an end and about whom little is known. Participants had been at the heavy end of caring with the majority having devoted more than 50 hours a week to caregiving and another third spending between 20 – 50 hours a week. The duration of caregiving varied with a third being a carer for less than three years whilst another third had been a carer for more than 10 years.

Participants' reports of continuing poor physical health as a legacy of caregiving are similar findings to those of other researchers (Bastawrous et al, 2015). Similarly, poor mental health with depression, anxiety and low mood being reported has previously been associated with caregiving (Butterworth et al, 2010). Indeed, Keene and Procos (2008) argue that the duration of caregiving is the strongest predictor of depression in the post-caregiving period. Given how many participants had been a carer for more than three years, it is not surprising that this intensity and duration of caregiving impacted upon former carers' health and wellbeing. However, evidence of carer resilience was unexpected and merits further investigation.

The main reason for caregiving coming to end was the death of the cared for person. The second reason was the admission of the cared for person into a care home or other type of institutional care. Thus the reason for caregiving coming to an end may also be a factor contributing to poor health and wellbeing in the post-caregiving period. While it has been suggested that relinquishing care causes positive changes in carers' wellbeing (Bond et al, 2003) the evidence is ambiguous with others reporting that care home admission was a significant stressor for carers with feelings of loss and a sense of failure being reported (Dellasega and Nolan, 2007, Cronin et al, 2015).

The concept of wellbeing was for some respondents, closely connected to financial issues. Those who were living on a much reduced income due to restricted employment during years of caregiving, were facing a future of financial hardship with little or no savings and, in some cases, only a limited prospect of gaining employment. Impoverishment can thus be seen as another continuing feature of the post-caregiving life. Whether it is helpful to apply a temporal perspective to different features or phases of life after caregiving is a matter for further enquiry.

Former carers in this study expressed difficulty in adapting to a non-caregiving role. They were also disappointed at the lack of support they were offered in the post-caregiving period and particularly with the immediacy of the withdrawal of services and professionals. The issue of support for carers post-caregiving indicated that there was a connection between poor adaptation and receiving little or no support and this finding is supported by other studies (Grande and Ewing, 2009). Carers in other studies were also critical at the lack of support from health care professionals

and the immediate withdrawal of contact and services once the care recipient had died (Hasson et al, 2010; Di Giacoma et al, 2013).

Evidence from this study suggests that carers experience a variety of different trajectories in the post-caregiving period. In terms of health and wellbeing, the negative impact of caregiving extends beyond the immediate post-caregiving period with some reporting enduring problems two to three years later. Others seem to be more resilient and are better able to pick up the threads of their lives and take advantage of new opportunities for work or leisure.

Initial analysis of data from the study pointed to the utility of Larkin's (2009) theorisation of the post-caring life as a series of stages. However, a more in-depth analysis of respondents' narrative comments indicate that this holds only limited explanatory value for the current study, particularly in relation to findings concerned with physical and mental health. Focus on instrumental or 'closure' tasks in Larkin's (2009) model, as a feature of the initial post-caring phase, received limited attention with an emphasis on physical and mental health issues as an enduring 'stage' much to the fore. Although health and wellbeing did improve for some respondents in the post-caregiving stage, for the majority, poor health was a lasting legacy of caregiving.

Limitations

There were a number of limitations to this study. Firstly there was the recruitment process which relied on social media and carer support groups to direct participants to an online questionnaire. This means that former carers who did not have internet access were excluded. Another limitation was the self-selecting nature of respondents which means that the sample is unlikely to be representative of the general former carer population. Thus caution must be exercised in generalising the study's findings. Nonetheless, the study adds to our understanding of the experiences of former carers and how they negotiate the transition to a post-caregiving life.

Conclusion

This research adds to knowledge about the health and wellbeing of carers in the post-caregiving period. The main findings are that physical and mental health issues are a long term concern for former carers and that many are faced with financial losses that have a detrimental impact on their future wellbeing. Sources of support vary and, whilst not universally the case, carers with limited or no support in the post-caregiving period experience a more difficult adjustment.

Whilst the impact on the lives of carers of providing care has been recognised as part of support and policy initiatives, the needs of the growing number of former carers remain largely unacknowledged and unreported. Further research into the needs of this population is required to determine how former carers can be adequately supported to build positive lives in the aftermath of the transition to a post-caring identity.

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