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Life after Caring: The Post-Caring Experiences of Former Carers

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Summary

This qualitative study was informed by grounded theory and data were gathered primarily through semi-structured in-depth interviews with thirty-seven theoretically sampled former carers. They were all white British, lived in the East Midlands and were predominately over sixty (68 per cent) and female (70 per cent). With the exception of one, all had cared for a close relative, 65 per cent having cared for a partner/spouse. Most of their dependants were older adults and each case the cessation of caring had coincided with the death of the dependant. The findings showed that post-caring life for the interviewees had an identifiable trajectory with three phases—the ‘post-caring void’, ‘closing down “the caring time”’ and ‘constructing life post-caring’. Each of these phases involved a distinct set of experiences. In addition, the study established that 70 per cent of those in the sample had cared more than once. Thus, two new concepts—‘the post-caring trajectory’ and the ‘serial carer’—were developed to reflect these findings. Suggestions are made about ways in which policy, practice and further research can be developed in order to ensure there is effective provision for those who have ceased caring.

Keywords: Caring, former carers, post-caring experiences, post-caring trajectory, serial caring

Introduction

During the past three decades, community care policies across the European Union have increasingly assumed that dependant people will
be cared for in the community by family members and significant others; some of the most significant pieces of legislation in the UK have been the 1990 National Health Service and Community Care Act, the 1995 Carers Recognition and Services Act and the 2004 Carers (Equal Opportunities) Act. Examples of similar policies have also emerged in countries such as Germany, Greece, Sweden, Denmark and Italy. For instance, during the 1990s, the emphasis in German social assistance law moved from care in institutions to community-based care. The European Union itself has supported care in community projects through the European Social Fund (Chamberlayne and King, 2000; Means et al., 2003).

Even if they are not formally recognized as ‘carers’, more people have consequently taken on the role of ‘carer’. These developments are also linked to the emergence of another group in society—those who have been carers. Whilst there is evidence that the concept of a ‘former carer’ has been recognized since the late 1980s, a review of relevant literature revealed that only a limited amount has been published about former carers. Thus, there is still a relative dearth of research and knowledge about the simultaneously increasing numbers of people in this newly recognized group in society.

The findings presented and discussed in this article form part of a study which aimed to extend the knowledge that has been slowly emerging in the published literature about former carers over the past twenty years. A qualitative, interpretive approach was used in order to explore the subjective meaning of the post-caring experience. The research was based on grounded theory and data were gathered primarily through semi-structured in-depth interviews with thirty-seven theoretically sampled former carers.

One of the most significant findings was that there were identifiable phases in the former carers’ post-caring lives. The literature review showed that there were some understandings about life at the beginning of the post-caring experience, such as the reduction in contact with formal services (Means et al., 2003) and the nature of the activities that are carried out (Brown and Stetz, 1999). Examples of the latter were changes made to the home as a result of the cared-for person dying (such as the removal of adaptations and specialist equipment), sorting out financial matters and ‘tying up loose ends’ from caring. Other studies produced insights into the emotional turmoil experienced in these early stages; Jenkinson (2004) referred to this as the ‘void’ and it involved emotions such as bitterness, guilt, regret, loneliness and loss of confidence, esteem, purpose and identity. For those of an employable age, there was also a sense that they had lost skills and employment experience. Many of these feelings were caused by the negative impact of caring on former carers’ post-caring social lives, employment opportunities and financial situations (Lewis and Meredith, 1988; McLaughlin and Ritchie, 1994; Jenkinson, 2004; Nurock and Wojciechowska, 2007). Several studies had briefly addressed bereavement and grieving during the initial stages of post-caring
life (Lewis and Meredith, 1988; Askham et al., 1992; Mullan, 1992; Taraborelli, 1993; Bodnar and Kiecolt-Glaser, 1994; White, 1994; Quee, 1995; Nolan et al., 1996; Schulz et al., 1997; Brown and Stetz, 1999).

Some of the longer-term aspects of post-caring life had also been identified in the existing literature. These included recognition that many former carers try to fill ‘the gap’ (Lewis and Meredith, 1988, p. 140) in their lives by undertaking new activities, such as voluntary and paid work (Lewis and Meredith, 1988; Hirst, 1999; Arksey, 2003). Lewis and Meredith (1988) also produced evidence that it was not uncommon for former carers to take on another caring role and, on the basis of their findings, developed the term ‘vocation carer’.

The lack of knowledge about phases in the post-caring life is not only due to the limited number of studies that exist, but can also be attributed to the absence of studies that have focused exclusively on exploring former carers’ experiences. There are only three studies which adopt the type of approach that would allow such an exploration. These are the qualitative studies by Lewis and Meredith (1988), McLaughlin and Ritchie (1994) and Brown and Stetz (1999). However, although they all used in-depth interviews with former carers, the insights into post-caring life they provide were constrained because their studies addressed other caring issues and a relatively small proportion of each study focused on former carers. For instance, despite the fact that Lewis and Meredith’s (1988) study explored the legacies of caring, much of the data related to the caring experience itself and not to post-caring. McLaughlin and Ritchie’s (1994) study of former carers was just a part of a larger national study of the effectiveness and targeting of social security help to carers. Most of the data in Brown and Stetz’s (1999) study were about the caring experience and only about a quarter of their article addressed the early stages of the post-caring experience. Moreover, apart from Lewis and Meredith’s (1988) study, which used forty-one former carers, the sample sizes in the other two were relatively small (ten and twenty-six, respectively).

Therefore, the adoption of an appropriate qualitative methodology in this study, together with the use of a substantive sample which comprised former carers only, facilitated the production of new findings about the transitions former carers experience in their post-caring lives. This article outlines the way that the study was carried out and presents and discusses the findings. It concludes with suggestions about ways in which the results can be used to inform both practice and further research.

The study

The study was submitted as a doctoral thesis. Thus, ethical approval was obtained through the official procedures of the awarding university and every stage was carried out solely by the author. It was based on the
approach to grounded theory originally developed by Glaser and Strauss (1967) and involved the use of the guidelines produced by Strauss and Corbin (1990, 1994, 1998). Central to this approach is the continuous interplay between data collection and analysis that takes place throughout the whole of the research process. Sampling is both sequential and theoretical in that it is driven by theoretically relevant concepts identified during the ongoing analysis of the data in order to explore them further. The concept of ‘theoretical saturation’ is used to denote the point at which no new information emerges from an analysis and marks its completion. The way that such grounded theory procedures were used is explained in the following account of how the study was carried out.

After the literature review, a preparatory phase, comprising two focus groups and four pilot interviews, was conducted to develop, refine and confirm outstanding issues. These included the suitability of the interview schedule and the interview technique developed from the literature review. In addition, as there are many situations that lead to a ‘carer’ becoming a ‘former carer’ and the definitions of a ‘former carer’ in the literature were therefore inconsistent, an operational definition of a former carer for the study was finalized. This was as follows:

A former carer is someone who does not necessarily identify themself as a former carer but who has experienced an episode of caring in the past that ended with the death of their dependant. This caring was not carried out on a professional basis, and excluding benefits, was unpaid.

The main part of the study then commenced with the establishment of a sample of former carers. These were identified through direct contact (those who made themselves known to the researcher when they heard of the research, for instance, following presentations made by the researcher) or indirect contact (through intermediaries such as community nurses, co-ordinators of carers’ organizations, carers and former carers group co-ordinators, carers forums and staff at carers centres). All of the former carers who expressed a willingness to participate in the research were asked, either by the researcher or an intermediary, to complete a questionnaire and return it in a SAE to the researcher. The questionnaire aimed primarily to establish important features of their caring and post-caring experiences and whether they met the criteria for the definition of a former carer being used in the study. It also invited former carers to give their contact details if they wished to be interviewed. Those who fulfilled the definitional requirements and had offered to be interviewed were selected for the sample.

The size of the sample was eventually forty-four but a further outcome of the theoretical sampling process was that it was reduced to thirty-seven (this reduction is discussed in more detail below). All of those in the sample lived in the East Midlands and were white British. Eleven were male and twenty-six were female. There was a much higher proportion of older former carers
than younger ones; only twelve were under sixty years of age whereas twenty-five were over sixty. Their ages ranged from thirty to over eighty, with the modal being those in the sixty-to-sixty-nine age group. The average length of time spent caring was nine years. Four had undertaken paid work throughout the whole of their caring experience and eleven worked post-caring. All paid work was on a part-time basis.

With reference to the characteristics of their most recent dependants for whom they had cared, only one (a neighbour) had not been a close relative. Many had been their partner; twenty-four had cared for a partner (twenty-three of these had been a spouse), ten had cared for a parent and two had cared for in-laws (a sister-in-law and a father-in-law). Although some of the former carers had started to care when their dependents were much younger (for instance, five had cared for between fourteen and thirty-two years), the dependants had been predominantly older adults and, in all cases, caring had ended upon their death. Where respondents had previous caring experiences (see the discussion of the concept of the ‘serial carer’), these were more likely to have involved a younger adult, such as a sibling or a first partner/spouse. The average time since caring had ceased for the whole group was two-and-a-half years.

Data were gathered primarily through semi-structured in-depth interviews with these thirty-seven theoretically sampled former carers. Other sources of data were obtained from key informants working for carers’ organizations and carers centres, academics and District Nurses. These key informants were approached when particular issues and themes arose during the research and were selected because of their knowledge and/or expertise. In order to ensure validity and reduce the potential for error, a number of key informants were interviewed about the same issues and the data were cross-checked from these interviews (Bryman, 1995). The research diary that the researcher kept throughout the course of the study was also an invaluable source of data.

All of the interviews took place in the interviewees’ homes and were conducted over a period of fifteen months. On average, they lasted an hour and a half and each one was transcribed by the researcher very soon after it had taken place. The interviewees and their dependants were given pseudonyms, and any place names were also fictionalized. In accordance with the use of grounded theory, amendments were regularly made to the interview schedule and technique in the light of the ongoing review of the literature, relevant sources of data and data analysis (Glaser and Strauss, 1967; Smith and Biley, 1997).

The interviews started with the first six former carers who had offered to be interviewed. Four key themes emerged from the preliminary analysis of these transcripts. The information on the questionnaires was used to create ‘batches’ of interviewees to enable the exploration of each of these themes. A further four ‘batches’ were created using the questionnaire information in order to explore the themes that emerged from the initial four
‘batches’. The questionnaires were also used to ensure that variables other than those which had already been explored were not introduced into the ‘batches’. The ‘batches’ contained between three and six former carers. Batch size was determined by the number of interviews it took to reach the point where new information about each ‘type’ of former carer was no longer emerging, and thus saturation had been achieved. It transpired that seven of those in the sample did not need to be interviewed, as saturation was reached for their ‘type’ through interviews with other former carers. Consequently, as mentioned above, a total of thirty-seven former carers were interviewed.

This concurrent preliminary analysis and theoretical structuring of the sample was then followed by other stages in the grounded theory data analysis process, such as microanalysis and theoretical coding, to produce concepts, sub-categories and core categories. Relevant literature and data produced through the use of the other data collection techniques were scrutinized and compared to the findings that were emerging. As a result, all the data were analysed several times.

**Findings**

The core categories that emerged related to both caring and post-caring experiences. With reference to the latter, further integration of the categories led to the development of two new concepts—‘the post-caring trajectory’ and the ‘serial carer’. These are discussed below; quotations from the interview transcripts and the results of any quantitative analysis of the findings are used to support and illustrate the findings.

**The post-caring trajectory**

The study established that post-caring life for those interviewed had an identifiable trajectory with three phases, each of which involved a distinct set of experiences. These were the ‘post-caring void’, ‘closing down “the caring time”’ and ‘constructing life post-caring’. As the cessation of caring coincided with the death of a close relative for all but one of the former carers interviewed, bereavement influenced this trajectory. In the exploration of the three phases that follows, the findings about the interviewees’ lives when caring that emerged from the study are used to identify those post-caring experiences that were associated with caring and its cessation. Hence, distinctions are made between those experiences that relate to post-caring life and those that are influenced by bereavement.
The ‘post-caring void’

The majority (thirty-two) of those interviewed reported experiencing a ‘void’ in their lives after caring ceased. Indeed, over half of them specifically referred to a ‘void’ of some description. For instance, Una used the word ‘void’ itself when she said ‘you have a great big void left’. Others used words to describe the sense of a void, such as ‘big hole’, ‘blank’, ‘ghastly space’, ‘vacuum’ and ‘there is nothing’.

This experience can in part be attributed to the death of the person who was their dependant. However, the interviewees identified different dimensions to this void that were clearly linked to the cessation of caring per se and are thus exclusive to post-caring life.

One dimension was a sense of a loss of purpose; many reported feeling ‘lost’ and ‘at a loss’ when caring ceased because their purpose in life had gone. Bob and Ted gave examples of this; Bob felt that caring for his wife had given him a ‘purpose’ which was now gone. Ted went one step further and said he felt that ‘all the reason for living had gone’. The findings about the interviewees’ caring experiences also indicated that this dimension of the void was distinctive to the end of caring; these showed that even if they had not defined themselves as a ‘carer’ when caring, they attached great significance to this role. As Clive explained, ‘it becomes part of your identity’. Consequently, the death of their dependant also meant the loss of this role. In addition, the average length of caring for the sample was nine years and the sense of loss of a role is more acute the longer the role incumbent has spent in it (Goffman, 1971; Quee, 1995). Thus, the loss of the role of carer would have been particularly acute for many of those interviewed and this contributed to the feelings of a loss of purpose they expressed.

Another dimension to this void caused by the cessation of caring was the experience of disequilibrium; Claude described how he felt ‘like an astronaut who has suddenly lost gravity. Now you are really sort of all at sea ... all at sea’. Doreen expressed similar feelings when she said she ‘fell apart’ when caring ceased and came to a ‘standstill’.

Several said they felt lonely during the post-caring void. Whilst such feelings occur during bereavement (Parkes, 1970, 1996; Hockey et al., 2001), some aspects of their loneliness were related specifically to life post-caring because they were associated with the caring experience and the fact that this had now ended. For instance, during caring, in both the public and private domain, those interviewed had been part of a social network of health and welfare professionals. Over a third (fourteen) talked about the way they lost this social network when they ceased caring. Particular reference was made to the way that members of this network no longer came to their homes to care for their dependant; Penny noted that ‘all of a sudden all the people disappear’ and Claude commented on how ‘the flow of people in and out of the house immediately stops’. This contact with
those who had been regular visitors during caring induced feelings of being alone; phrases such as ‘they are all gone’, ‘you are on your own and nobody comes in’ and ‘it was as if somebody had shut the door and nobody knew I was there’ were used.

Therefore, this initial phase in the trajectory involved specific emotional experiences, such as feelings of a loss of purpose, disequilibrium and loneliness. The second phase involved a different set of experiences.

‘Closing down “the caring time”’

The first few months of post-caring life were described as the ‘wind-down period’ because it involved winding down life as a carer. During this transitional period, routines changed and closure activities were undertaken.

With reference to changes in routines, many of these were related to the fact that those interviewed had cared for their dependant. They described how their daily routines had previously been dictated by their caring responsibilities; as Paula said, ‘my routine had revolved around Mum’. Just under a third (eleven) found themselves having to consciously change aspects of their routines; Claude now no longer qualified for the ‘orange badge’ he had used for eleven years when driving his disabled wife around. He said:

I had to physically stop myself from driving into an orange badge spot and physically go and pay for car parking whereas previously all you had to do was get out the wheelchair.

Sandy found it was ‘very difficult to get out of the routine of caring’ and talked about how, in the early days of post-caring life, she found that she ‘automatically started setting the tray in the morning’ for her husband’s breakfast before she ‘went out in the morning’.

Such changes in routine involved changes in the sentient work caring had entailed. An example is the way that some found themselves still considering the dependant’s particular needs, such as the special food they required. Penny described how there were ‘certain things’ in the supermarket which she used to buy for her father and that it was ‘really strange walking past these things’ without buying them. Others found themselves thinking and behaving as if they were still ‘in role’. For instance, Clive talked about how he repeatedly thought he was ‘in charge’.

Routines in their social lives that had been established during caring also changed. For instance, family and friends who previously visited their dependant during caring because they were ill or disabled came round for ‘the first month or two months’ and then gradually, as Joan explained, ‘dropped off’. Three of the male carers commented on the way their wives’ friends continued to call in on them for a while after caring
ceased. Paddy gave a good example of this process when he described his experiences following caring for his housebound wife:

Mabel, she used to come in ... every other Wednesday, to have a cup of tea and biscuit with Bella and a natter. But you see when Bella passed away she came in once after that, you know, like you’re sitting there, and then that finished. ... and that stopped you see.

Other changes were caused by the fact that the end of caring for the former carers in this study also meant that they had been bereaved (Parkes, 1970, 1996; Hockey et al., 2001). Some of these were because they were coping with their own grief whilst others related to helping others around them deal with grieving over the loss of the dependant; Bob remembered how during ‘the first few weeks (of bereavement) I took too much alcoholic comfort and was smoking myself stupid’. Joyce had to focus her attention on her grandson, as he had taken his Grandad’s death ‘very bad’, and she had to try to keep talking about ‘his Grandad’ until he ‘settled down’.

Similarly, some activities in this period involve closure tasks, such as sorting out funeral arrangements, possessions, paperwork and financial and legal issues that are inevitable after any death. Pat provided some examples of these tasks when she said ‘the first two weeks you have such a lot to do paperwork to sort out and wills, and maybe making a new will for yourself which I did, but there is a lot to sort out’. Sandy talked about how she ‘bagged up’ her husband’s clothes on the Monday after he died and took them to a charity shop.

However, some closure tasks were more specifically related to the ‘winding’ down process of caring itself; four had to sort out benefits, such as Mobility Allowance and Attendance Allowance, to which they or their dependant had been entitled during caring. One of these was Joan, who described how she had received a letter a week after her husband died, asking her to return the ‘benefit books’ her husband had received when he required care. She had to go to the local benefit office to fill in various ‘claim forms’. Another such closure task talked about by six of the former carers was disposing of the equipment their dependant had required during caring. For example, Joyce explained that when she ceased caring for her husband, she had to do ‘a lot of ringing’ around different organizations to ask them to ‘come and collect everything back’. She also took ‘some of his stuff from the nurse that hadn’t been opened, that was still in boxes’ to the surgery.

The final type of closure activity associated with the end of caring was undertaking domestic tasks that had been left undone during caring because of lack of time, particularly in the later stages of caring; Jo caught up with household chores and said she wanted to ‘spring clean the house and get things all tidy’. Derek occupied himself ‘doing decorating of the house and things like that’.
As these transitions were made, life post-caring was gradually reconstructed in different ways. This process of reconstruction took place in the third phase of the post-caring experience.

‘Constructing life post-caring’

This involved getting ‘life together’ again, and ‘coming up to the surface’. Although factors such as being well integrated into a local community, good physical and mental health, and an adequate income all helped, it was families, interests, friends, paid employment and further caring activities that played the most important roles in the reconstruction of life post-caring. The contribution of each and the extent to which their roles relate to post-caring and post-bereavement life are discussed below.

Three-quarters (twenty-six) were more involved with various members of their families post-caring. This increased involvement helped them to rebuild their lives and establish new routines. For instance, Paddy described the regular contact he now had with his daughter: ‘... she’s just had her dinner here today. She comes in every Wednesday, every Monday and Wednesday for her dinner and I go round her house Sundays for dinner.’ Peggy’s sister had been inviting her ‘to her house for the weekend sometimes’ since she ceased caring.

Although such increased involvement could be expected post-bereavement, particularly in the case of the loss of a spouse/partner, there was evidence that the nature of these family relationships was linked to the caring experience. For instance, Clive explained that his relationship with his children was affected when he was caring for his wife. This was because she had wanted their children to ‘get on with their lives’ and ‘did not want them to feel they had to support her with her multiple sclerosis’. He felt that since he ceased caring for her, he had a ‘different sort of relationship’ with them and they had ‘been very close, closer’. Another three talked about spending time and energy rebuilding family relationships that had suffered during caring. Paula provided a good example of this; she felt that whilst she was caring for her mother, she had neglected her son. Once caring ceased, she said ‘Jason came first again’ and she worked hard at creating ‘normality’ for him, such as having his friends round and taking him on outings.

The amount of time spent on interests expanded post-caring for the majority (thirty-three) of those interviewed. These included sports activities, adult education classes, theatre-going, walking, gardening and taking holidays. One or two were fulfilling life-long ambitions, such as studying for a degree and travelling. Others had become involved with their local communities or joined groups such as social, environmental and art groups. Eight were now undertaking voluntary work associated with caring. This included work with disabled groups, volunteering at hospitals.
and hospices, membership of carers groups and former carers groups, and attending and helping out at a carers centre. Five were involved in campaigning for carers; four of these were on carers forums and one had become a Trustee of a national charity for carers.

Furthermore, eighteen of the interviewees had become involved with carers groups, carers centres and undertaken voluntary work associated with caring for people with illnesses and disabilities whilst caring. These all continued their involvement post-caring. Other social activities associated with caring also still featured in some of the former carers’ lives; eight maintained part of the caring social networks that had existed in their private domains, for example, by keeping in regular contact with the carers who helped to care for their dependants.

Where these interests and activities entailed regular attendance at groups, classes and meetings, this also helped to create routine in post-caring daily life. Moreover, they were a means of ‘opening the door’ to further activities, and, in Christopher’s words, helped them to ‘meet new people’ and make ‘new friends’. The increase in free time also meant that six had been able to resume former friendships. However, over half (twenty-one) said there had been no change in their friends post-caring and another three said that some friendships had lapsed since caring ceased.

Once again, an expansion of time spent on interests is predictable after the death of a spouse/partner or co-resident relative. However, three-quarters (twenty-nine) of those interviewed felt their lives when caring were restricted and half felt that they could not live their own lives; the way that they could not pursue interests and activities when caring was identified as a major restriction. Hence, the extent to which they pursued these post-caring was likely to be due to the fact that their opportunities to do so had been limited during their lives as carers. In addition, caring strongly influenced many of the post-caring activities undertaken. One example was the way that eight had taken up caring-related interests. This can be attributed to the general increase in awareness of health and social care issues that had occurred as a result of caring reported by over half (twenty) of those interviewed. Joseph was one of those whose increased awareness had stimulated him into undertaking voluntary work associated with caring; he explained that whilst caring for his mother, he had developed an interest in Alzheimer’s and, as a result, he now goes ‘to the home where she lived and sees the residents, they don’t get a lot. I’m on quite a few committees, and belong to a carers group’. Further examples of links between caring and post-caring activities were the continued involvement of so many with carers groups, carers centres and voluntary work associated with caring for people with illnesses and disabilities, and the post-caring maintenance of social networks that had developed during caring (as discussed above).

With reference to paid employment, most of those in the third of the sample who were of working age when caring ceased undertook paid
work post-caring. Once more, the influence of caring was apparent; half changed their job post-caring in order to undertake paid employment associated with caring. For instance, Paula was counselling at a carers centre, and Ethel had worked as a paid carer for a carers agency.

However, it was the way that post-caring involved further caring activities where the relationship with caring was strongest; half did caring tasks for friends and neighbours such as ‘a bit of washing and ironing’. There was no obvious explanation as to why this group undertook these tasks but three said they felt that they wanted to continue ‘to look after people’. More significantly, for many of them, post-caring life involved or had involved being a carer yet again; over half (twenty) had undertaken their most recent unpaid caring role following the cessation of a previous episode of caring. Another six were now caring once more and two of these had also cared prior to their most recent unpaid caring role.

The exploration of the three phases in the post-caring trajectory has shown that many experiences were exclusive to post-caring life because their links with caring and its cessation enabled them to be distinguished from those experiences that related to bereavement. Therefore, although this trajectory was based on findings about bereaved former carers, the identification of distinctive features of post-caring life indicates that it is also relevant to non-bereaved former carers.

These phases in the trajectory were not experienced in a particular sequence and there was overlap between them. However, the ‘post-caring void’ and ‘closing down “the caring time”’ were transitory for all and did seem to be followed by the ‘constructing life post-caring’ phase. The extent to which this third phase was transitory was more complex; as explained above, it was transitory for six of the former carers after their last episode of caring and for twenty after previous caring experiences. This serial caring meant that the ‘constructing life post-caring’ phase had been transitory at least once for 70 per cent of the former carers interviewed.

Serial carer

The concept of the ‘serial carer’ was developed to reflect the phenomenon of serial caring that had emerged. The cyclical nature of caring and post-caring in serial carers’ lives in relation to the concept of the post-caring trajectory is represented diagrammatically in Figure 1.

As mentioned above, different patterns in serial caring were identified. Further analysis showed that there were three types of serial carer; one type had been through the above cycle twice. Some of these had cared prior to their most recent caring experience. Amongst these was Jo; she had cared for her grandmother in her ‘childhood’ and ‘teenage years’ before more recently caring for her mother. Another example was Doris,
who had spent ten years caring for her sister-in-law before then caring for her late husband for ‘two and a half years’. A second group were now caring again but had not cared before undertaking their last caring role. Hence, they had started the cycle for a second time. One of these was Peggy, who explained how her husband (Bill) had experienced ‘a couple of little heart attacks’ and developed ‘arthritis in his neck and spine and all sorts’ since she ceased caring for her mother. As a result, she had ‘reverted it all to Bill’.

The third type of serial carer had undertaken at least three caring roles and had therefore been through the caring and post-caring cycle more often than those discussed above. These serial carers made frequent reference to caring as a ‘lifestyle’; Jenny explained how she had cared for ‘Three people. Me mother first, me brother and then me partner’. Similarly, Brenda had cared for her mother and then her disabled sister before caring for her husband for eight years. She said, ‘you can’t stop caring really’.

Some indication of the possible effects of serial caring emerged. For instance, of the eighteen former carers in the sample who had experienced health problems post-caring, nearly all of these (sixteen) were serial carers. Only a tenth of the serial carers worked post-caring, whereas this figure was just under half for those in the rest of the sample.

In many cases, those interviewed felt they had not had a choice about their serial caring because of familial obligations to parents, siblings and partners and/or spouses. With reference to the six who were currently caring again, age was influential; a higher proportion of these former carers...
carers were under sixty compared with the rest of the sample (two-thirds compared with one-third of the whole sample). All of their new caring roles involved the care of a very close relative, such as a spouse, in-law, sibling or parent. In each case, it appeared that they had little control over their resumption of the role of carer; somebody who was closely related to them had needed care.

Discussion

As demonstrated above, this study produced two new concepts. One was the ‘post-caring trajectory’, which was used to denote the identifiable phases of the post-caring life that emerged from the findings. The other was that of the ‘serial carer’, which reflected the way that so many of those interviewed had cared more than once in their lives.

The findings confirmed the existing knowledge about the post-caring experience discussed in the Introduction. For instance, the way that there is a ‘void’ or ‘gap’ post-caring that involves specific emotions and activities. It also produced evidence to support Lewis and Meredith’s (1988) concept of a ‘vocation carer’. More importantly, though, the findings extended and deepened these understandings.

With reference to the ‘post-caring trajectory’, this is the first study to identify a trajectory in former carers’ lives comprising phases with distinct sets of experiences. The differentiation between post-caring and bereavement experiences that was made throughout the discussion of the phases in the post-caring trajectory highlights the experiences of both bereaved former carers and non-bereaved former carers. More specifically, this concept draws attention to transitions and emotions experienced in post-caring life, and the sorts of issues that former carers have to address. In addition, the findings about the ‘post-caring trajectory’ increase existing understanding of the process of reconstruction of life post-caring and the factors that shape this process.

The concept of the ‘serial carer’ is a further indication of the likelihood of the recurrence of episodes of caring during the life course. It also demonstrates how the so-called ‘reconstruction’ of life post-caring may only be partial in that it can involve recreating previous caring experiences with possible adverse consequences for individual lives.

The choice of methodology, sample size and the exclusive focus on former carers were clearly instrumental in the production of these original insights. Nonetheless, a critical reflection on the nature of the sample showed that some aspects of this were problematic. Despite the efforts to use a broad range of contacts, the achieved sample differed from the national profile of carers; some groups of former carers, such as those from an ethnic background who had been carers, were not represented in the sample. With the exception of one, all had cared for a close relative,
which meant that other types of caring relationships were not represented in the sample. Similarly, certain groups of former carers, such as those who are involved with carers groups, forums and organizations, were over-represented. Comparison with national figures showed that there was also a much higher proportion of older former carers than there is nationally; 66 per cent were over sixty compared with the national average of 25 per cent. The proportion of males to females was also unrepresentative of carers nationally; only 30 per cent of the sample were male and 70 per cent were female, whereas the national figures show that 42 per cent of carers are men and 58 per cent are women (Department of Health, 2006).

These biases in the sample obviously limit the generalizability of the findings in several ways. An example is the extent of serial caring; the numbers involved with, and receiving support from, carers groups, forums and organizations in this particular sample could have inflated the number of serial carers that emerged from the findings. Such involvement could indicate a stronger identification with the role of carer and consequently an increased likelihood of taking on more than one caring role.

However, this exploration of former carers’ lives has shown those who have ceased caring can face many challenges in their post-caring lives, including the resumption of caring. Recent policies that have aimed at improving carers’ lives have addressed some post-caring issues. For instance, the introduction of a second state pension for carers enables them to build up a second-tier pension whilst they are caring and contributes to their financial security post-caring. The findings suggest other ways in which provision could be developed effectively:

- **Adoption of a more holistic approach to carers’ needs:** The study indicates that the focus on carers’ needs during caring should be broader and include post-caring needs. One way forward is to use the resources available to carers as a result of the 2004 Carers (Equal Opportunities) Act, not only to support them during caring, but also to address their post-caring needs; when working with carers, social workers can encourage them to think about life post-caring and their requirements in order to achieve their goals when they have ceased caring. Some of the resources within their care package can then be allocated to helping them invest in their post-caring lives whilst caring. For example, they could use their vouchers/cash payments to obtain respite care/short-term break services for their dependant so they are free to spend time during caring maintaining their interests, developing their skills and undertaking any relevant education and training. A further suggestion is that local authorities redesign and extend carers’ assessments to identify serial carers and address needs that arise during caring and post-caring for this group.

- **Increased recognition of former carers by professionals:** Those working within health and social care who have had contact with carers during caring should not automatically close cases when caring ceases. Follow-up
visits could be introduced during which challenges former carers may face in their post-caring lives and sources of support, such as carers groups, discussed.

- **Use of voluntary provision:** Social workers working with those in the voluntary sector organizations who support carers, such as carers centres and carers groups, should encourage the provision of post-caring support that is responsive to the possible demands on former carers.

It is also clear from the findings that more research about former carers is required in order to ensure policy and practice improves the lives of this group of people who have given so much to dependent members of our society. Whilst the paucity of up-to-date research into this neglected area needs to be addressed, the two original concepts produced as a result of this study require additional exploration in particular; there is need for a more comprehensive understanding of the phases within the post-caring trajectory that can then be used to guide the future planning of post-caring support. Further research into the concept of the serial carer would contribute to greater recognition of the frequency of serial caring, its implications for the lives of those concerned, and enable more constructive ways of meeting serial carers’ needs to be devised.

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References


