Group support during caring and post-caring: The role of carers groups

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Abstract: This article discusses the findings about the role of face-to-face carers groups which emerged from a qualitative, interpretive study of 37 former carers' experiences. The study was informed by grounded theory and semi-structured in-depth interviews were used as the main method of data collection. The advantages and disadvantages of carers groups during caring and post-caring that were identified are presented. These include the nature of the support they provided for their members, their limitations and ways in which they can be developed in order to meet the needs of carers and former carers. The concepts of social integration and social support are used to supplement the interviewees' explanations of the beneficial effects of carers groups. Following the discussions, suggestions are made about further research into increasing the effectiveness of carers groups' in meeting the needs of those who are caring and their previously unrecognized role in meeting post-caring needs.

Keywords: carers; former carers; carers groups; caring; post-caring; group support

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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 or significant others. 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 relevent 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 was gathered primarily through semi-structured in-depth interviews with thirtyseven theoretically sampled former carers.

Despite the focus on former carers, the study increased the understanding of many different aspects of both carers' and former carers' lives. One of these was their experiences of face-to-face carers groups during caring and post-caring. It is these experiences that are discussed in this article.

The findings did not enable an analysis of issues such as carer group sessions, groupwork, group processes, communication and interaction, or the stages of group development. Nor was it possible to use any of the established classification systems for carers groups, such as, whether they were 'an off-shoot of a service facility' facilitated or attended by professional workers, or a 'self help group run by and for carers' (Twigg et al., 1990, p.18). Indeed, for the purposes of this research, carers groups were defined as those groups that the interviewees themselves referred to as such. However, this study did identify how these groups were sources of friendship and social activities, the nature of the support they provided and the extent Mary Larkin

to which they were valued by the former carers interviewed in the study.

The article starts by reviewing the literature on users' experiences of carers groups during caring and post-caring. This is followed by an outline of the way that the study was carried out. The results of the qualitative and quantitative analyses about the advantages and disadvantages of carers groups during caring and post-caring are then presented. These findings are discussed and suggestions made about further research into increasing the effectiveness of carers groups' in meeting the needs of carers and former carers. Unless stated otherwise, all references to carers groups mean face-to-face carers groups.

Literature review

With reference to caring itself, research to date has produced insights into users' experiences of face-to-face carers groups during caring; in the 1980s and 1990s studies of carers groups were mainly from a professional perspective and highlighted the different aims, functions, activities and organizational features of carers groups, issues affecting them, and attempts to ensure consistency in standards. They also identified some of the benefits carers derived from these groups; one of these was the provision of support, such as social, emotional, informational and mutual peer support. Other perceived benefits centred around the opportunities these groups afforded their members to express feelings, meet others with similar problems, share experiences and to develop their self-identities as carers (Glosser and Wexler, 1985; Hinrischsen et al 1985: Fielding, 1990: Tinker et al, 1994: Twigg et al, 1990: Twigg and Atkin, 1994: Barnes, 1997). The latter was found to increase their assertiveness when trying to obtain appropriate support for their dependants. (Twigg and Atkin, 1994).

This earlier work also included the extent to which carers groups' links with professionals affected the level of support they provided for their members (Smith and Cantley, 1985; Wilson, 1988, 1995). Mitchell (1996), using the classification system for carers groups devised by Twigg et al (1990), showed that the six carers groups he studied varied in terms of the emotional, informational and mutual peer support they provided according to the organization of the group. For example,

groups which were 'off-shoots of service facilities' attached to day centres offered less emotional support than 'free-standing groups' that were not attached to a service facility (Mitchell, 1996).

From the late 1990s, there has been change in the direction of the literature on carers groups. This has been attributed in part to the increase in the of number of mutual aid/ self help groups, and the growing emphasis on service user involvement which means that researchers carrying out studies into carers groups now include service users themselves. As a result, there have been many studies into carers' experiences of a wide range of both generic carer support groups and groups for carers of specific types of dependants. The latter include substance misusers and those suffering from Alzheimer's, dementia, mental health problems, strokes, and visual impairments. These studies have not only confirmed some of the benefits of the carers groups for users, such as informational and emotional support, but also identified a broader range of benefits. Examples of these are the establishment of valued relationships with peers, increased ability to cope with stigma and stress, decrease in psychological and psychosomatic symptoms in lonely carers, and improved quality of life (Thorgrimsen et al, 2003; Cimarolli, 2004; O'Grady, 2004; Munns-Giddings and McVicar, 2006; Droes et al, 2006, Logsdon et al; 2006; Reed and Davis, 2006; Schure et al, 2006; Anfilogoff, 2007).

Other studies have focused on the beneficial effects of groups for carers who share particular characteristics, such as their ethnic origin; Hepworth (2005) in his study of Asian carers found that carers groups 'offered opportunities for socializing, talking to others in a similar situation as well as acting as an information resource and a point of referral' (Hepworth 2005, p.350). Chien et al (2006) in their study of mutual support groups for Chinese carers of patients with schizophrenia in Hong Kong found that these groups empowered members, produced positive personal changes and provided informational support.

In addition to the research on face-to-face carers groups, there have been recent studies on telephone-based support groups for carers (Winter and Gitin, 2006) and computer-mediated support groups for carers (Han and Belcher, 2001; Coulson et al, 2004; Blackburn et al 2005). Telephone-based support groups were found to ease depression amongst older carers. Whilst the studies on computer-mediated support

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groups found that they provide carers with emotional and informational support, they do also have disadvantages. For instance, they tend to be used less by lower socioeconomic groups and users commented on the lack of physical contact and proximity.

As noted above, all the aforementioned studies refer to carers groups to during caring. Although Mitchell (1996) and Munns-Giddings and McVicar (2006) found a very small minority of those attending the face-to-face carers groups in their study 'were no longer providing care, their dependants having died or moved to residential care' (Mitchell, 1996:117), there are no known studies into the role of carers groups *post-caring*. Therefore, the findings discussed in this paper not only contribute to the existing literature on carers groups during caring but also address a gap in the literature on users' experiences of these groups when they have ceased caring.

The study

The study was submitted as a doctoral thesis. Thus, ethical approval was obtained through the official procedures of the awarding University. It was based on the approach to grounded theory originally developed by Glaser and Strauss (1967) and involved the use of the guidelines and procedures 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. Consequently, data collection and analysis is both ongoing and concurrent, and the analysis of new data entails systematic checking against existing data as well as directing further data collection. It also means that the interpretation of 'data' is very broad and can include observations, other studies, documents, interviews and media material. These elements, together with some of Strauss and Corbin's key procedures are referred to in the following account of how the study was carried out and the data analysed. The account is structured so that it clearly shows both the relationship between data collection and analysis in the approach to grounded theory adopted and the nature of the sequential analysis and sampling in this study.

Preparatory phase

The literature review was followed by a preparatory phase which comprised two focus groups and four pilot interviews. It was conducted to develop, refine and confirm outstanding issues from the literature review. These included the adoption of an approach informed by grounded theory, the use of semi-structured in-depth interviews as the main data collection method in conjunction with other data collection techniques, and the suitability of both the interview schedule and the interview technique developed from the literature review. In addition, an operational definition of a former carer was finalised. 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 successful resolution of these issues meant that the main part of the study was able to proceed.

Main study

After this preparatory stage, a sample of former carers, identified through direct contact or indirect contact through intermediaries, was established. The former carers who were sampled through direct contact were those who made themselves known to the researcher when they heard of the research, for instance, following presentations made by the researcher. Examples of intermediaries were Community Nurses, co-coordinators of carers' organizations such as Crossroads, 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 Mary Larkin

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 44 but a further outcome of the theoretical sampling process was that it was reduced to 37 (this is discussed in more detail below). Of the sample 11 were male and 26 were female. There was a much higher proportion of older former carers than younger ones; only 12 were under 60 years of age whereas 25 were over 60. Their age groups ranged from 30 to 80+ with the modal being those in the 60-69 age group. The average length of time spent caring was nine years. The average time since caring had ceased for the whole group was two and half years; at the time of their interviews, significantly more had ceased caring less than three years ago compared to those who had ceased more than three years prior to the interview. Four had undertaken paid work throughout the whole of their caring experience and 11 worked post-caring. All paid work was on a part-time basis. With reference to the characteristics of their dependants, many were their partner; 24 had cared for a partner (23 of these had been a spouse), compared to 10 who had cared for a parent, 2 had cared for in-laws (a sister-in-law and a father-in-law) and one for a neighbour. The interviewees and their dependants were given pseudonyms, and any place names were also fictionalised.

Data was gathered primarily through semi-structured in-depth interviews with these 37 theoretically sampled former carers. Other sources of data were obtained from key informants working for carers' organisations and carers centres, academics and District Nurses. The research diary that the researcher kept throughout the course of the study was also an invaluable source of data.

The approach to the length of the interviews was flexible and each interview was transcribed by the researcher very soon after it had taken place. 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). A copy of the interview schedule was used unobtrusively as an 'aide memoire' during each interview. The emphasis was not on using it prescriptively, but on eliciting meaning from the interviewees' perspective.

The interviews started with the first 6 former carers who had offered to be interviewed. Four key themes emerged from the preliminary analysis of these transcripts. The information on the questionnaires (discussed above) was used to create 'batches' of interviewees to enable the exploration of each of these themes. The 'batches' contained between 3 and 6 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. 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'. It transpired that 7 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 37 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. This involved labelling raw data with indicators to denote shared characteristics, and the use of open, axial and selective coding. These procedures were often used simultaneously to produce concepts, subcategories 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 was analysed several times.

Results

The core categories that emerged related to both caring and postcaring experiences. A theoretical schema of the post-caring experience was developed through further integration of these categories. This represented both the caring and post-caring experience in order to reflect the way experiences during caring were found to contextualise life post-caring.

Included in the core categories and the theoretical schema were the respondents' experiences during and after caring of statutory and commercial organisations, the voluntary sector, family and friends, and the local community. Groups they referred to as 'carers groups' featured

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in their experiences of the voluntary sector. There was also one group solely for former carers. The data analysis enabled the identification of the level of satisfaction participants expressed about these groups, the nature of their involvement with them and the support they provided. Different types of support emerged from the data, which were then confirmed using data from the literature. As a result, Berkman et al's (2000) four subtypes of support were used to classify the examples of support. These are as follows:

Emotional support refers to love, sympathy, understanding and value. This is usually provided by a friend or confidante but can be provided by someone who is less intimate under prescribed circumstances.

Instrumental support is practical help with life's daily problems. It includes domestic chores (such as shopping, cooking, cleaning, childcare) and financial matters (link to support with the physical caring).

Appraisal support means help with decision making, dealing with feedback and agreeing courses of action.

Informational support is the provision of advice or information to meet particular needs.

The distinction between these subtypes is not always unequivocal. For instance, emotional, appraisal and informational forms of support can be hard to disaggregate. There are further problems in their use as analytical tools as there can be variation in the type, frequency, intensity and extent of support provided. Some social relationships provide several types of support while others are specialised and provide only one type. Nonetheless, despite such limitations, these subtypes proved to be the most useful in defining the support provided by carers groups.

Overall, those interviewed reported positive experiences of carers groups both during caring and post-caring; the local community gained a higher satisfaction rate during caring, while carers groups, the local community and family and friends received their highest satisfaction rate post-caring. Details of their experiences of carers groups are given below. The discussions of their experiences address three main issues - the role of carers groups during caring, the role of carers groups post-caring, and the limitations of carers groups for carers and former carers. The different types of support and examples of each type are included. Quotations from the interview transcripts and the results of any quantitative analysis are used to illustrate the findings, and to convey the meaning of the participants' experiences.

The role of carers groups during caring

Twenty had belonged to carers groups during caring. Of these, 18 showed that they valued their carers group and used expressions such as 'really good' and 'really a great help'. Some commented on the way that they had found new 'friends' in their groups and others clearly enjoyed the social activities their groups organised. Ted described some of these activities:

We had a walk round Oxford, all free of charge. In the Spring we went down to the south coast, free of charge again, no sorry, I had to pay for something. And then they hired a boat on the canal, you know a long boat, at Boxstone and we went up the river up the canal to a restaurant and we had a meal at the restaurant'

Many reported that their pre-caring friendships and social lives suffered as a result of caring; 49% reported they had lost some or all of their pre-caring friends, and just 70% said they could no longer continue with their pre-caring social lives. Thus the way that carers groups were sources of new friendships and social activities could have helped to redress these negative effects of caring.

Further analysis revealed that these groups also provided all four of Berkman et al.'s (2000) subtypes of support. *Emotional support* came through the friendships that developed. An example was given by Penny when she described how she shared the exhaustion she endured caring for her father and her father's antagonism to respite care with her carers group friends. They understood exactly how she felt and empowered her in their insistence that she 'must get a break".

Instrumental support included help from advocacy workers when fighting for suitable medical care for their dependants and practical support with caring. Paddy gave an example of practical support with caring; the 'group leader' of his carers group managed to resolve the problems he was experiencing in making arrangements for his wife while he had an operation in hospital. He relayed the story of how this happened:

... .he [the group leader] said, 'Don't worry about it. Can you get round here Wednesday, you know, about 2 o'clock and I'll get an Occupational Therapist from the hospital to talk to you'.... when I explained the situation she [the Occupational Therapist] started getting the ball rolling and she got Dot into Cedar House, a residential home for five weeks so it was a big relief.'

Examples of *appraisal support* were given by Madge and Penny; Madge found it 'helpful' to listen to the 'different approaches that others used' and to be able to 'talk and laugh about it'. Penny felt that her carers group had helped her to get things in perspective because she saw 'other people who were in a far worse position than me.' *Informational support* included advice about claiming benefits. Doreen illustrated this when she recalled how the 'wonderful, wonderful' lady at the carers centre 'got me extra money and then she got me income support'.

The two remaining former carers in this group of twenty had received support from carers groups, but felt that such groups were of limited value when caring. However, such views need to be considered in context. For instance, one of these was Sandy who was a District Nurse with previous experience of caring herself. She said, 'I did go, I did go once and ask them something but I don't think anybody could tell me anything I didn't already know.' Sandy's focus solely on informational support indicates that she may not have appreciated the full range of support provided by carers groups. Nonetheless, the nature of her background does highlight a reason why carers groups may not be universally appropriate.

The role of carers groups post-caring

With the exception of one person(Ted), all of those who had belonged to a carers group whilst caring continued to attend post-caring. As Ted explained, he left his carers group because he 'didn't want to be reminded of the past'. However, he did continue to meet informally with other carers he had met during caring. Another, Derek, had joined a carers group post–caring.

As during caring, these groups were a source of friendship. This was the case for those who continued their membership post-caring and were new members; Paddy talked about how his 'friends' in his carers group came to see him after caring ceased and said 'you're still coming'. Derek said 'he had established new friendships' through the carers group he had joined as a former carer. They also provided opportunities to participate in various social activities, such as the free trip 'at off-peak periods at Pontins or Butlins' that was organised by 'the Carers National Trust, [of which] Princess Anne is the head' that was on offer at Ted's carers group.

The analysis also showed that these groups were useful forms of emotional and appraisal support post-caring for different reasons. As explained already, they were a source of friendship that provided emotional support. In addition, some thought they were, as Doreen put it, 'a prop' and gave them an opportunity to reflect on their experience, and 'talk it over.' This indicated that attendance at such groups and centres also helped them deal with their experiences and were therefore a form of appraisal, as well as emotional support.

Brenda showed that such support could also meet other more complex post-caring needs, and this accounted for why former carers saw them as a valuable form of support post-caring. She felt that

.... carers groups are great because they don't mind you coming even if you've finished caring. They like you to keep coming. I mean I know all the people. They have fresh people but they are happy that we carry on going it makes you aware that there are still others that need support. A lot of them come, and people ask for help, or they have experiences, you know 'I've done that' or 'I've done this'. You can usually help somebody, we've all been in the same boat as well.

Brenda intimates here that in addition to being a source of friendship, attending a carers group post-caring gave her a sense of belonging, and because she was 'helping others' in the group, it gave her a role that allowed her to use her caring experience. Her attendance therefore seemed to help her address some of the post-caring needs that she was experiencing as a result of the cessation of caring. For instance, her new 'role' could have compensated in some ways for the loss of her role as carer.

The interviewees also made suggestions about the expansion of

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post-caring support groups; 22% felt that more emotional support could be provided through such groups. There were differences in the type of support groups proposed; 16% said that these should be set up specially, in Christopher's words, 'to support former carers'. 5% felt that continuing to belong to the same carers group that had been attended during caring can provide this sort of post-caring support. As Greg explained

.... if you can get involved in a [carers] group like that then you've got a contact for afterwards I think if carers could get together, can get together beforehand, then that association could probably continue afterwards.

Limitations of carers groups for carers and former carers

Notwithstanding the positive experiences of carers groups during and post-caring, as already indicated in the discussion of the findings about support from carers groups during caring, there was evidence that these groups have their limitations (for example, the fact that professional background and previous caring experience can influence the extent to which users find them useful).

The findings about the one group specifically for former carers also showed that such groups may be a more suitable form of group support post-caring than carers groups. This group owed its somewhat unique existence to the ad hoc way in which it had been formed; the excerpt from the transcript of its founding member (Julie) below illustrates this:

It was all by mistake. I'd been up to the carers centre, and just popped in, and Debbie who helped me at the hospital, she said 'Oh Julie, there are 2 or 3 people going out for a little car ride do you want to go along with them?' I said 'Oh I don't know about that'. She said 'Just go out with them for half an hour'. We went out to Barham Lodge, came back and Debbie said 'You know one of the ladies you went out here with, she's suggested that they get a little group up ... so that you can have a little social group. So how would you like to have a go at it?' I thought, well I said to her 'Tve got no experience of secretarial work or writing letters or anything''

Despite her lack of confidence, Julie did organize the former carers

group very effectively and the four interviewees who were members felt it was valuable form of support. They used expressions such as 'very good' to describe it. Social events were organized for members of this group. As Julie explained

.... we meet at the Empire Hotel for a toasted teacake and a cup of tea and coffee on a regular basis, usually about every couple of months. There are usually about sixteen turning up there. Go on a Summer outing, I book the coach tickets.

Through these events, *emotional* and *appraisal* support was provided; Peggy said that they gave them a chance to be with others who 'have been through it 'which indicated that there were mutual understandings and sharing of experiences of *having been* a carer as opposed to currently being a carer. Although it can be argued that carers groups attended by several former carers could be beneficial in similar ways, three quarters of those who said that there should be more emotional support postcaring felt that this could be provided by groups specifically for former carers.

Another limitation applies to both carers groups and those for former carers; a few of those who attended the carers groups highlighted some of the disadvantages of groups per se. One was that groups do not suit everyone; four said that some people are simply not 'group people', and it was felt that there should be 'individual helpers' with whom carers and former carers could 'talk things over'. 27% of the male participants thought that these groups could be less useful to men. This was because, as in Christopher's experience 'they tend to be elderly ladies, I'm the only man. They sort of talk a lot about their caring experiences and it's developed into more like a social group than anything else'. As a result he said 'I don't get as much out of it.' Paddy talked about the way that his carers group had overcome this problem; they had 'a male section' which he felt was useful because 'we sit down and talk, you know'. In his view, this was better than having to listen to the women talking about things in which he had no interest!

Discussion

The findings reported in this article build upon the existing literature about the role of carers groups *during caring* in several ways. More importantly, the data about their role *post- caring* represent the first set of findings about the role of carers groups post-caring.

With reference to the role of these groups during caring, the study showed that in addition to the benefits and types of support previously identified in the literature, they contribute to their members' social lives, are a useful source of friendship and provide appraisal support. The fresh and unprecedented data about their role post-caring demonstrated how they continue to provide users with emotional and appraisal support, act as valued sources of friendship and social activities, and meet other post-caring needs, such as compensating for the loss of the role of carer.

This study also included the identification of factors that can limit the value of carers groups, such as individual members' professional backgrounds, previous caring experiences, feelings about participation in groups and gender. In addition, it identified ways in which the role of carers groups for carers and former carers could be developed, including opportunities to attend gender specific groups. With reference to former carers, it highlighted the need for an increase in emotional support, and that former carers groups could be an effective way of providing this.

Although the analysis provided some explanations as to why those interviewed found carers groups beneficial and continued to attend them, the concepts of social integration and social support provided further insights. The concept of social integration was originally developed by Durkheim (1968) and is about the relationships between individuals and institutions in society. It focuses on societal relationships, which means those between individuals and societal institutions in society, such as the family, employment, and religious, political and voluntary groups. Durkheim argued that integration into these societal institutions helps people to cope when facing stressful life events because they provide mutual moral support and access to resources which enable them to cope.

There is a constant interchange of ideas and feelings from all to each and each to all, something like a mutual moral support, which instead of throwing the individual on his own resources, leads him to share in the collective energy and supports his own when exhausted. (Durkheim, 1968, p.210)

Thus individuals do not have to depend solely on themselves. He hypothesised that the more people were socially integrated, the more they were able to cope with stress and were 'protected' during life's crises (Durkheim, 1968; Freund and McGuire, 1995).

The concept of social support is similar but there are important differences. Berkman et al. (2000) locates the concept of social support in Bowlby's work on attachment theory developed in the 1960s and 1970s because it articulates individuals' 'needs for secure attachment for its own sake' (Berkman et al., 2000, p.845). It has also been used and refined in the many studies carried out in the past four decades on social networks, kinship and community. Whereas the focus within social integration is on relationships at a societal level, the concept of social support focuses on interpersonal relationships between individuals in particular contexts at micro level, such as in relationships between friends. However, its effects are similar to those of social integration in that such social support can also act as a mediator for stress and offer resources in tackling life's troubles. There are different explanations of the effects of social support. These include the way these interrelationships enhance our 'sense of security and self esteem' and 'empower individuals' (Berkman et al., 2000, p.845), and are 'a source of self-validation' (Freund and McGuire, 1995, p.114; Oakley, 1992; Whelan, 1993; Berkman, 1995; Freund and McGuire, 1995; Penninx, 1997; Berkman et al 2000; Gabe et al, 2004).

An explanation of the findings based around the concept of social integration would argue that societal relationships between individuals and institutions in society provide moral support and resources (Durkheim, 1968; Freund and McGuire, 1995). The brief outline of this concept above shows that these 'institutions' would include groups for carers and former carers. Consequently, a Durkheimian explanation using the concept of social integration would focus on how these societal 'institutions' work as a form of social integration, which help to 'protect' those interviewed from, and cope with, the stresses of both caring and post-caring.

There were several examples in the study of the socially integrating

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effects of carers groups. One was the way the mutual moral support of Penny's carers group helped her to cope with reaching the decision to use respite care for her father, despite his antagonism. This also gave her the break she needed to 'protect' herself from the stress of caring. Another came from Paddy's illustration of the resources that stem from the social integrating effects of carers groups, when he talked about how his group leader used his professional contacts to help him obtain residential care for his wife whilst he went into hospital himself.

That the carers groups in the study also operated at an interpersonal level and were a source of informal one-to-one relationships with 'friends' means that the concept of social support can be used to interpret other aspects of the findings. An explanation using this concept would highlight the various types of social support they provided and how the social relationships that took place within them enhanced respondents' self esteem. For instance, Brenda clearly demonstrates how the fact that she could now 'help somebody' in her carers group because she had experienced caring improved her feelings of self-worth and her self-confidence.

Therefore, the use of the concepts of social integration and social support explains how these sources of group support provided those interviewed with the psychological protection and resources that met particular needs, both during and after caring, in ways that other sources did not. Moreover, the literature on groupwork would endorse the arguments presented about the socially integrating role of carers groups and the way they can be used to provide social support. It is widely recognised within this literature that, when effectively planned and facilitated, groups have the potential to engage people at both societal and interpersonal levels and offer them the type of resources identified (Douglas, 2000; Phillips, 2001; Doel, 2006; Preston-Shoot, 2007).

However, before any conclusions can be drawn from the findings presented, factors that could have influenced them need to be taken into consideration. First of all, they cannot be considered in isolation from the rest of the study. As mentioned above, those interviewed had positive experiences of support from several sources, including family and other voluntary organisations. An example of the latter was a local hospice from which three had received support post-caring. This hospice was particularly good at maintaining contact with former carers

and offering longer-term emotional support if required, as described by Joan in the following excerpt from her transcript:

I had that opportunity if I'd felt as if I'd wanted to speak to someone, at the hospice last Christmas, I even had a Christmas card come from the carer that used to come out from the hospice and that, you know, they are always contacting me, different things, so although he was only there 4 days, they still kept you, you know, in touch and that with you. You're welcome to go you know, whenever you want to go up there if you want to, or I'd got the option that I could go in and have a talk.

The discussion of the concepts of social integration showed that there are various types of societal institutions and these other sources can also be viewed as societal institutions. Therefore, the extent to which the interviewees were also integrated into these and the amount of 'protection' they afforded needs to be considered when evaluating the role of carers groups during and post-caring. For instance, if any of these other sources met their needs well, they may have required less 'protection' from their carers group. As a result, their assessment of their carers groups may have been more positive. This is because it could easily accommodate their reduced dependency levels, whereas increased dependency on such groups due to lack of other forms of support could have produced more negative experiences of the extent to which carers groups met their needs.

Secondly, there were specific characteristics of the sample which could have affected the data that emerged about the respondents' use of, and dependence on, carers groups during caring and after caring. As explained at the beginning of the article, there were high proportions of females and older former carers who had cared for an average of nine years and relatively recently ceased caring. In addition, very few had onerous paid working commitments, all of them had been bereaved and for 65% of the sample, this had meant the loss of a partner.

These characteristics could have had several implications. For instance, it can be argued that *during caring*, sample characteristics such as the length of caring, age, gender and their employment commitments increased the likelihood of a closer involvement with their carers group. This in turn could have increased the role of such groups in their lives and the nature of the support they received from them. With reference

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to *post-caring*, there are many reasons for the numbers of those using carers groups to have been inflated, and the role of these groups in their lives to have assumed more significance than other former carers. These include, their existing strong relationships with their group and its members, and the high numbers of those in the sample who were now without a partner or time-consuming employment commitments. In addition, the relatively short time since caring had ceased could have meant that they had not yet developed new social networks. Consequently, the circumstances of the participants in this study may have shaped their experiences of carers groups in both their caring and post-caring lives.

This research clearly indicates that future developments in meeting the needs of carers should acknowledge and maximise the potential of carers groups. More significantly, in view of the unique nature of the findings about the hitherto unrecognised role of carers groups postcaring, it not only shows that former carers continue to need support post-caring, but also that support groups such as those identified in this study are an invaluable resource which are worthy of further consideration. Two possible foci for the research required in order to do this emerged from the study. These are:

- the application of knowledge from groupwork literature and theory (such as that on group processes, structure and size and groupwork planning and leadership) to enhance carers groups sessions in terms of meeting the needs of both carers and former carers.
- further exploration of users' experiences of carers groups in order to develop more effective ways of organising and delivering these groups for both carers and former carers. For instance, the reduced satisfaction with carers groups experienced by some of the male participants when attending mixed sex carers groups suggests that options for same sex provision could usefully be explored. The establishment of groups for former carers only should also be a subject for future research.

Conclusion

This article has not only extended existing knowledge of how carers groups meet the needs of those who are caring, but also made an original contribution to knowledge in terms of the findings it has presented about the previously unexplored role of carers groups post-caring. Areas for further research have been suggested; these include research into ways in which the use of carers groups during caring and post-caring can be developed.

The author also hopes that in addition to the above, the study has two further outcomes; one is that it will act as a catalyst for the exploration of the value of group support post-caring. The second is that research into the areas identified can be used to help and support the increasing number of those who take on the role of carer, as a result of the expansion of community care policies across the European Union.

References

- Anfilogoff, S. (2007) Carers of substance misusers suffer as needs are neglected. *Community Care*, 24th May, p. 35
- Arksey, H. and Knight, P.T. (1999) Interviewing for Social Scientists. London: Sage
- Barnes, M. (1997) Care, Communities and Citizens. Harlow: Longman
- Berkman, L.F. (1995) The role of social relations in health promotion. *Psychosomatic Medicine*, 57: 245-54
- Berkman, L. F., Glass ,T., Brissette, .I, and Seeman, T.E. (2000) From social integration to health: Durkheim in the new millennium. *Social Science and Medicine*, 51: 843-57
- Blackburn, C., Read, J., and Hughes, N. (2005) Carers and digital divide. factors affecting internet use among carers in the UK. *Health and Social Care in the Community*, 13, 3, 201-210
- Chien, W.T., Norman, I., and Thompson, D.R. (2006) Perceived benefits and difficulties experienced in a mutual support group for family carers of people with schizophrenia. *Qualitative Health Research*, 16, 7, 962-981
- Coulson, N., Aubeeluck, A., Buchanen, H., Semper, H., and Rooney, E. (2004) Exploring the provision of social support within a computer-mediated Huntington's disease support network. *Psychology and Health*, 19, 1, 35-49

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Cimarolli, V.R., Sussman-Skalka, C. J., and Goodman, C.R. (2004) 'Programs for partners': Support groups for partners of adults with visual impairments. *Journal of Visual Impairment and Blindness*, 98, 2, 90-98

Doel, M. (2006) Using Groupwork. London: Routledge

- Droes, R.M., Meiland, F.J.M., Schmitz, M.J., and Van Tilburg, W. (2006) Effect of the meeting centres support program on informal carers of people with dementia: Results from a multicentre study. *Ageing and Mental Health*, 10. 2. 112-124
- Durkheim, E. (1968) Suicide: A Study in sociology. London: Routledge
- Easton, K, McComish, J.F., and Greenberg, R. (2000) Avoiding common pitfalls in qualitative data collection and transcription. *Qualitative Health Research*, 10, 5, 703-707
- Fielding, N (1990) A group with a difference. *Community Care*, 11th January, pp.14-15
- Freund, P. and McGuire, M. (1995) *Health, Illness and the Social Body. A critical sociology.* Upper Saddle River, NJ: Prentice-Hall
- Gabe, J. et al. (1994) Challenging Medicine. London: Routledge
- Glaser, B. and Strauss, A. (1967) The Discovery of Grounded Theory. Chicago: Aldine
- Glosser, G. and Wexler, D. (1985) Participants evaluation of educational support groups for families of patients with Alzheimer's disease and other dementias. *The Gerontologist*, 25, 3, 232-236
- Han, H. and Belcher, A.E. (2001) Computer-mediated support group among parents of children with cancer: An exploratory study. *Computers in Nursing*, 19, 1, 27-33
- Hepworth, D. (2005) Asian carers perceptions of care assessment and support in the community. *British Journal of Social Work*, 35, 337-353
- Hinrischsen, G., Revenson, T., and Shin, M. (1985) Does self-help help? An empirical investigation of Scoliosis peer support groups. *Journal of Social Issues*, 41, 1, 65-87
- Logsdon, R.G., Mccurry, S.M., and Teri, L. (2006) Time-limited support groups for individuals with early stage dementia and their care partners: Preliminary outcomes from a controlled clinical trial. *Clinical Gerontologist*, 30, 2, 5-19
- Michell, F. (1996) Carer support groups: The effects of organizational factors on the character of groups. *Health and Social Care in the Community*, 4, 2, 113-121

Munns-Giddings, C. and McVicar, A. (2006) Self-help groups as mutual

support: What do carers value? *Health and Social Care in the Community*, 15, 1, 26-34

- O'Grady, C.P. (2004) Stigma as Experienced by Family Members of People with Severe Mental Illness: The impact of participation in self-help/mutual aid support groups. Canada: University of Toronto
- Oakley, A. (1992) Social Support and Motherhood. Oxford: Blackwell
- Penninx, B.W.J.H., Tilburg, T. van, Deeg, D.J.H., Kriegsman, D.M.W., Boeke, A.J.P., and Eijk, J.T.M. van (1997) Direct and buffer effects of social support and personal coping resources in individuals with arthritis. *Social Science* and Medicine, 44, 3, 393-402
- Preston-Shoot, M (2007) *Effective Groupwork*. (2nd ed.) Basingstoke:Palgrave Macmillan
- Reed, M. and Davis, E. (2006). Improving wellbeing and promoting optimism with carers of first episode of psychosis through psychoeducation groups. *Schizophrenia Research*, 86, 1, 152-153
- Schure, L.M., van den Heuvel, E.T.P., Stewart, R.E., Sanderman, R., de Witte, L.P., and Meyboom-de Jong, B. (2006) Beyond stroke: description and evaluation of an effective intervention to support family caregivers of stroke patients. *Patient Education and Counselling*, 62, 1, 46-55
- Smith, G. and Cantley, C (1985) Assessing Health Care. Milton Keynes: Open University Press
- Smith, K. and Biley, F. (1997) Understanding grounded theory:principles and evaluation. *Nurse Researcher*, 4, 3, 16-29
- Strauss, A. and Corbin, J. (1990). Basics of Qualitative Research: Techniques and procedures for developing grounded theory. London: Sage
- Strauss, A. and Corbin, J. (1994) Grounded theory methodology:Anoverview. in N.K. Denzin and Y.S. Lincoln (Eds.) *Handbook of Qualitative Research*. London: Sage
- Strauss, A. and Corbin, J. (1998) Basics of Qualitative Research: Techniques and Procedures for developing grounded theory. (2nd ed.) London: Sage
- Thorgrimsen, L., Schweitzer, P., and Orrell, M. (2003) Evaluating reminiscence in dementia care. *Journal of Dementia Care*, 11, 5, 35-36
- Tinker, A., McCreadie, C., and Salvage, A. (1994) The information needs of elderly people. *Assignation*, 11, 3, 44-46
- Twigg, J., Atkin, K., and Perring, C. (1990) Carers and Services: A review of research. London: HMSO
- Twigg, J. and Atkin, K. (1994) *Carers Perceived.* Buckingham: Open University Press

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- Whelan, C. (1993) The role of social support in mediating the psychological consequences of economic stress. *Sociology of Health and Illness*, 15, 1, 86-100
- Wilson, J. (1988) Caring Together. Guidelines for carer's self-help and support groups. London: Kings Fund
- Wilson, J. (1995) *Two Worlds. Self-help groups and professionals.* Birmingham: British Association of Social Work
- Winter, L. and Gitin, L.N. (2006) Evaluation of telephone-based support group intervention for female caregivers of community-dwelling individuals with dementia. *American Journal of Alzheimer's' Disease and Other Dementia*, 21, 6, 391-397