

**Up Close and Personal: A Qualitative Study Exploring the Lived
Experience of Older Carers**

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Abstract

This study explored the experiences of informal carers who were aged 65 years and over. It has been estimated that 15 per cent of those aged 65 or over provide some form of informal care in England. Despite a growing literature on the involvement of older people in research, there is a paucity of literature on the involvement of older carers. In this study, older carers were identified via a General Practice (GP) register in one urban medical practice. Data was collected through a series of focus groups, which were transcribed and analysed using thematic analysis. Every carer aged 55 or over and registered with the medical practice was invited to take part in the study. Four female carers and one male carer took part in the study (age range 65-83). Themes that emerged during data analysis included, 1) managing things in an emergency, 2) feeling valued because they took part in the research and 3) the day-to-day reality of living with social exclusion. GP registers provide a valuable tool for identifying older carers who may otherwise be difficult to engage in research. However, persuading GPs to engage with qualitative research may be a challenge.

Key words: Older Carers, Informal Care, Qualitative Research, Participatory Methodologies, Carer Involvement.

Background

The key role older people play in the generation of social and human capital was identified by the former Prime Minister (Tony Blair) in 'Winning the Generation Game' (Performance and Innovation Unit 2000) and in 'A Sure Start to Later Life' (Office of the Deputy Prime Minister 2006). Research by Reed et al (2006) however found that older people continue to be more often consulted, and less often involved, in the decision-making process. This finding echoes earlier research by the Joseph Rowntree Foundation who highlighted that:

despite the rhetoric of involvement, in most cases the level of involvement of older people (personally in their own lives and collectively in local and in national initiatives) remains low, probably even lower than for disabled people' (Older People's Steering Group 2004: 5).

However, research, including Biggs (2001) identified that, given the right support, older people may have the capacity to contribute to the decision-making processes more effectively than previously thought.

Patient and Public Involvement

Patient and public involvement (PPI) in health and social care in the UK is a central plank in the development of user-focused services (Local Government and Public Involvement in Health Act 2007). Many different levels and types of user involvement have been identified, including involvement in the commissioning process, quality checking, evaluation and development (Boote et al 2010). Running parallel to the involvement of users in services is the need for PPI in the research process. The UK government, past and present, is committed to the notion that 'Research is essential to the successful promotion and protection of health and wellbeing, and also to modern, effective health and social care services' (Research Governance Framework for Health and Social Care 2005: 2). Over the past ten years, while

some progress has been made towards the involvement of older people in research (Tetley 2010), the involvement of particular groups, including older carers, remains problematic.

An initial search of the literature identified a number of papers outlining the difficulties faced by older carers of people with dementia (Lewis 1998), mental illness (Murry and Livingstone 1998) and learning disabilities (Maggs and Laugharne 1996). However, only one study, by McGarry and Arthur (2001) focused on the needs of older carers *per se*. A literature review by Fudge et al (2007) identified thirty studies involving older people in research using participatory methodologies. Participatory methodologies is usually taken to mean that people are involved in advising on a research project, assisting in the design of a project, or in carrying out the research, rather than being viewed as data repositories. None of the studies identified by Fudge (2007) involved older carers as a discrete group. Despite a growing number of government initiatives and publications designed to end discrimination against older people (Department of Health (DH) 2001; Phillipson & Scharf 2004; Scharf et al 2005; DH 2006; DH 2007) it appeared that the invisibility (and therefore vulnerability) of older carers remained problematic. This current paper addresses this gap in the literature by reporting on a study that involved older carers in the development of a research topic, in the confirmation of the study's findings, editing of the draft report and in the dissemination of the results nationally and locally (Parker 2010).

Research by the Social Care Institute for Excellence found that:

'society often disables older people simply because they are old and by assuming they cannot perform certain tasks' (Carr 2004: 5).

This paper argues that older people in general and older carers in particular have the knowledge, skills and expertise to be involved in all types and in all levels of research. In order for this to happen, however, researchers need to build the necessary time into research proposals from the beginning of the research process.

Methodology

How the Literature was Searched

Several literature searches were undertaken during the course of the study between 2006/07 and again prior to publication of this article. Databases searched include, ISI Web of Knowledge, Bio-Med Central, Blackwell Synergy, WileyInterscience, British Nursing Index, Proquest Nursing Journals Database and Google Scholar. Search terms included (but were not restricted to) research involving older people, older carers, inclusion, exclusion, poverty and elderly people, qualitative case study, ethical issues and participatory methods.

The Conceptual Framework

The world of older carers is so under-represented in research that exploring any aspect of their lives would doubtless reveal a valuable seam of rich, deep and original insights. I was very aware, however, of the necessity to focus on just one aspect of their lives. So, for the purposes of this study, I did not focus on the social processes involved in sustaining older carers, for that aspect of the case would be better served by utilising a grounded theory approach to data collection and analysis (Glaser and Strauss 1967). Neither did I present a statistical analysis of event occurrence, for that would be better served by a study with a positivist slant (Yin 2003).

Instead, I focused on how each older carer perceived and interpreted their unique experience in a range of situations, which I hoped would present the reader with multiple views or

interpretations of the described experience. As advocated by Stake (1995) an interpretivist approach to data collection and analysis was adopted. This encouraged data triangulation through the use of multiple methods of data collation (Morse & Field 1996; Yin 2003).

Sampling Framework

Since so little was known about the work and world of hidden carers, and my goal was to enable older carers to reveal their hidden world, revelatory case sampling was used (Teddlie and Yu 2007). Moreover, I believed the best way to gain an in-depth understanding was to engage with the carers directly. In the first instance, I wrote an introductory letter to all GP medical practices in the town. Only one GP medical practice agreed to take part. In order to recruit enough participants, I invited all carers aged 55 and older to participate in the study. I then set up an introductory meeting at the GP medical practice. This meeting was successful in recruiting five older carers to the study. At the time of the study, older carers were aged 65-83 and had informal caring responsibilities for their spouse (1), adult child with mental health problems (1) and adult child with learning disabilities (3). Demographic data for the older carers can be found in table 1.

Table 1

Biographical data for the older carers in the study					
	Carer 1	Carer 2	Carer 3	Carer 4	Carer 5
Gender					
Male	X				
Female		X	X	X	X
Age range					
60-70		X			
70-80			X	X	X
80-90	X				
Relationship to dependant					
Adult child with moderate learning disabilities					X
Adult child with Profound and Multiple Learning Disabilities			X		
Adult child with mental health problems		X			
Adult child with Down's Syndrome				X	
Wife with Alzheimer's Disease	X				

The Research Setting

In qualitative research, the selection of the research setting is of particular significance. Morse and Field (1996) for example, pointed out the importance of visiting the research setting before the development of the proposal to gain the permission and cooperation of staff. With this in mind, I visited several settings before making my final choice. Older carers could not be involved in making this decision, as this had to be decided before I submitted the proposal to NHS research governance and research ethics committees. After much deliberation, I decided to hold the focus group meetings in a local Church community hall. I did this for a number of reasons:

1. The Church was near to the town centre and conveniently situated on the main bus route.
2. All of the facilities were on the ground floor with good access for people with disabilities.
3. A lunch club was held every Thursday, providing a tasty lunch at a very reasonable cost.
4. There was a separate meeting room where focus group members could meet in private after lunch.
5. The meeting room was available at no cost (the study was unfunded so this was important to me).
6. Staff at the Church were extremely friendly and sympathetic to the aims of the study.

Of particular significance to me was the provision of a hot midday meal in a relaxed setting. I believed that creating space for focus group members to get to know each other socially would be pivotal to the success of the study. Stewart and Shamdasani (1990) suggested a number of ice-breaking activities to help put people at ease before the start of a focus group meeting. However, I wanted to do more than just put people at ease. I wanted to demonstrate my appreciation of the commitment older carers had made to the study (by providing a tasty lunch and an opportunity for some social chit-chat), and I wanted to get them in the mood for story telling (Jackson and Esse 2006).

Data Collection

In this study data was collected via four focus group meetings, four research diaries completed by the older carers and reflective notes, field notes, minutes from meetings and memos. Two of the four focus group meetings were audio recorded. One was fully transcribed and one was partially transcribed. Copious field notes were made during and after the two meetings not audio recorded. All data produced in this way was typed up and sent to the older carers for editing and amending as necessary.

Data Analysis

Thematic analysis was used as a conceptual framework to analyse the data (Miles & Huberman 1994). Analysis (or data reduction) took place on eight levels:

1. Older carers completed a research diary. These were completed at home and then read through at the next focus group meeting. At the focus group meeting, older carers added anecdotal reflections that added context and significance to diary entries.

2. Older carers identified themes from the research diaries and these were used as topics for discussion at the next focus group meeting.
3. At the next focus group meeting older carers expounded upon the previously identified themes, offering many examples to illustrate their points. This meeting was audio-recorded.
4. At the third focus group meeting, older carers went through the typed up manuscript of the previous meeting sentence by sentence, marking with a highlighter pen anything they found to be significant. This meeting was also audio-recorded.
5. As we worked through the manuscript, older carers expanded upon why something was being highlighted and in this way, further revelatory insights were added to the manuscript.
6. I then went through the field notes, memos and typed up manuscripts and coded the main themes into overarching categories. After a discussion with older carers the final themes were agreed.
7. Literature (grey and mainstream) from the fields of health, social care, education, psychology and business was searched and used to provide context for the study's identified themes.
8. Older carers read through a draft of the completed report and made a number of important points, which are discussed later in the paper.

Discussion of Themes Identified by the Older Carers

Social Exclusion

Scharf et al (2005) identified that the death of a partner, the onset of chronic ill health and the assumption of caring responsibilities are all risk factors in older people becoming socially excluded. Although social exclusion is not always synonymous with social invisibility, in the case of older carers, it would appear that as their vulnerability increases (in terms of decreasing family networks, increasingly poor health and the continuation - or assumption - of caring responsibilities) the cloak of social invisibility is wrapped ever more tightly around them.

The purpose of this study was not to directly ask older carers about their experiences of feeling socially excluded. However, even a cursory reading of the research diaries and transcripts from the focus group meetings demonstrated that older carers were at risk from social exclusion on multiple fronts. For example, older carers in this study had serious health problems ranging from insulin-controlled diabetes, advanced heart failure and osteoporosis. This meant that for some, mobility was a constant challenge and when combined with exhaustion posed serious threats to their health. This often meant that they were too tired to make the effort to socialise. And when they did get a break they liked to spend it quietly, contemplatively.

Older carers identified that balancing the need for companionship against the need for solitude was a daily challenge. On the one hand, because conversation at home was often limited to giving directions or answering the same questions day after day, older carers looked forward to chatting with friends, having what Mick called 'a proper conversation'. But, paradoxically, although the need for companionship was strong, the busyness of their everyday lives made them long for a quiet space to re-charge their batteries.

Vignette 1

Margaret reads out her diary from the previous week. On day five she wrote about one activity:

Went to Café for lunch. Thoughtfully, Margaret added, that she really needed this time of just sitting, alone (but in a crowd). Somehow being alone in the Café, watching everyone pass by was different to being alone at home. Not so lonely. Margaret remarked how she even got a little irritated if someone she knew came and sat with her, as this was much needed private space. Everyone nodded in recognition of this and shared how they too needed this 'private time'.
Research diary Margaret, Day 5.

A number of researchers have written about the danger of consultation/research fatigue with easily accessible groups of older people (Butt & O'Neil 2004; Holland 2005). Sin (2004, cited in Holland 2005: 6) for example, noted how community organisations are often targeted by researchers that 'have swooped in, gathered their data, and left nothing of clear benefit to the researched'. The 'researched' (even in these easily accessible groups) however are only rarely involved in actually doing the research.

Older carers could in no way be described as an easily accessible group, so there was no danger of them experiencing consultation or research fatigue. In fact, Mick shared a story of how (just a few days before the research study began) a market researcher knocked on the door of his home and before administering the survey, asked Mick if he was working or retired. Upon finding out that Mick was retired, the market researcher said he was only interested in the views of the employed and was therefore unable to ask Mick any further questions. The survey was about the possible development of a large superstore in the town in which Mick lived – a development to which there was much local opposition. Surely this was one issue that affected every community member? It would seem that nothing much had changed since Carr's (2004) finding several years earlier that older people were excluded from just about everything, simply because they are old.

The Value of Involvement

Older people want to be involved in research, but they are clear that they want to be involved in research that makes a difference (Reed et al 2006). This was a view shared by older carers taking part in this study who noted that the work they were undertaking was novel and could have far-reaching consequences in their small community.

This is pioneering, isn't it?...hopefully a lot of good will come, more and more'
Transcript of focus group meeting, Alice.

Although there was little doubt in my mind that older carers – because of their extensive life experience – had the knowledge, skills and expertise to act as co-researchers, I needed to convince them of that. Using naturally occurring activities, such as research diaries and focus group meetings to collect the data proved to be instrumental in enabling older carers to see how they could contribute towards achieving the aims of the study. During the study it came to light that this was the first time anyone had asked the carers to document their day-to-day life. The following quotation illustrates how it was the 'everydayness' of the research tools that rendered them easy to use and how being involved in the research activities made carers feel valued.

The atmosphere, the down-to-earthness of it, how we described our daily life, our daily working...I've never been asked to do that before...we weren't numbers

any more, we have a rightful place in this life.
Focus group meeting transcript, June.

This and other comments made by the older carers were hauntingly reminiscent of the comments made by Frantz Fanon in his exposé of the damaging effects of colonialism and of how he felt when at last his personhood and humanity was (albeit) temporarily valued, 'At last, I had been recognised, I was no longer a zero' (Fanon 2003: 69).

Older carers recognised the transformative effect that being involved in this research study had had on their lives saying,

June
...you've given us a name, you've given us a place we never had before [to other carers] do you feel that?

Alice – in response
Yes, especially as an older parent
Focus group meeting transcript, p.3.

That the older carers managed to attend almost all of the research meetings was testament to the commitment they showed to the research study. Several of the older carers experienced traumatic life events during the period of time the focus group meetings were running, but despite this, their commitment to the research was unwavering. That unwavering commitment is poignantly illustrated in the vignette below.

Vignette 2

It was lunchtime and focus group members were chatting together over lunch. The room was noisy and full of hustle and bustle. Threading his way through the crowd towards our table, I spotted Mick and gave him a cheery wave. He was running late, but it didn't matter, lunch was a relatively leisurely affair. The work of the focus group started after lunch. Following closely behind Mick was a woman I hadn't met before; intuitively I knew it was Mick's wife. This was unusual as Mick's wife usually attended a day care facility on Thursdays for people with Alzheimer's disease.

Mick came up to me and said apologetically:

I'm really sorry, but Marie was too poorly to go the day centre today. I couldn't leave her at home on her own and I didn't want to miss our research meeting, so I've brought Marie along. I hope that's alright.
Researcher memo, p.1.

Managing Things in an Emergency

Research by Carers UK (2005: 2) found that 'The very thought of having an emergency causes anxiety for many carers'. The issue of what to do when things go wrong was a constant challenge for older carers in this study. The reality of how hard it is to respond to an emergency was brought into sharp focus by the comments of the older carers who gave numerous examples of when they had to put their own lives (and health problems) to one side, in order to focus on the person they cared for. Trying to avoid situations arising in the first place was a priority for everyone.

Lisa for example, a carer in her mid-sixties, supports her daughter (Mary) who has enduring mental health problems. Lisa's daughter monopolises her time during the day and late into the

evening, to the point that Lisa will restrict her own activities in order to reduce the likelihood of her daughter becoming angry or upset.

I can't do anything, really. I mean, if Mary had decided that...it wasn't good for her, or good for me, something would have been arranged so that I wouldn't have been able to come [to the research meeting]...It's easier for me to, sort of, play along with her than to say, I am doing this, that and the other, because, I wouldn't know what I'd find when I got back home...

Focus group meeting transcript, Lisa.

For other older carers the pressure of knowing there is no one else around to look after the person you care for, means that their own health can become seriously affected before they will seek help (Carers UK 2005), not surprisingly, fighting exhaustion became an everyday battle.

Jack's new wheelchair is not as easy as I thought...We are going for a walk after lunch as I need to get used to Jack's chair. I feel very tired, would rather go for a lie down, but not possible.

Research diary, Margaret, Day 4.

As illustrated in the following story, becoming ill unexpectedly can have disastrous consequences. Mick's wife Marie was diagnosed with Alzheimer's disease while he was undergoing inpatient treatment in hospital. Unable to cope without him at home, Marie had to be detained under the Mental Capacity Act (1983) for the duration of Mick's treatment (12 weeks). Both Mick and his wife found the experience very distressing.

She went bonkers, she really did go mad. She tried all the hospitals in the north to find out where I was, of course they wouldn't tell her anything. Eventually, she was sectioned and put into hospital.

Focus group meeting transcript – Mick.

Carers UK (2005) have identified a number of strategies that need to be in place to support carers when they face emergency situations like this:

- Details of who to contact in an emergency in the form of a key fob or similar
- Training on how to care effectively
- Good advice on what is already available locally
- Information on emerging technologies, helplines, alarms, detectors, automatic switches, etc.
- Ensure carers are better informed about their rights/benefits
- Emergency plan in place.

Provision of these vital services however remains patchy across the country. Carers in this study reported that even in situations where support could be pre-planned, what was offered was often not the right kind of support and sometimes it came too late, or not at all.

Often they say there's help available, but often it's just not the type that you want...it all looks good on paper, because there's respite care and all that, but sometimes it has to be arranged months and months ahead...if there was an emergency and you had to go somewhere, or even if you were rushed into hospital, you wonder where they're going to go.

Focus group meeting transcript – Alice.

Ordinary Spaces as Research Settings

Miles and Huberman (1994) attached so much importance to the management of the research setting that they suggested including a room-plan in the appendices of the research report. Richards (2005: 24) on the other hand talked about the setting in terms of ‘...entering the field’ and the requirement upon the researcher to map the physical, social and cultural terrain. I spent a lot of time thinking about these issues, as I was very aware of the necessity to provide a safe space for older carers to share their stories and for me to conduct my first ‘real’ research study. I thought my efforts to map out the ‘physical, social and cultural terrain’ had gone mostly unnoticed by the older carers, however, as the next vignette illustrates, they understood my game plan, perfectly.

Vignette 3

The issue of keeping everyone ‘on task’ is a prickly one. For instance, reading the diary entries aloud prompted the reader to set the entry in its wider context – so that it made more sense to the listeners. Often these diary entries prompted other carers to retell other closely related stories, adding depth and richness to the original story. However, stopping these digressions when they become more than once removed from the original, proved tricky. This was noted by the carers themselves who assumed a self-moderating role by saying

We can only talk about things like that when we are over there (pointing to the previously food-laden table), once we come over here (indicating the circle of chairs) we have to concentrate on what’s important to the research.
Focus group meeting – researcher field notes.

Reflections on the Research Tools

If older carers had been involved from the very beginning, it is likely that the focus of the study may have been very different. I write this because carers struggled with the idea that their everyday lives were interesting and it was not until the diaries were read aloud at the first focus group meeting that they began to see value in what they had written. A reflective and appreciative silence followed the end of each diary reading and the reader often used this time to regain their composure or add any further insights/comments.

For me, hearing the diary entries read aloud was a very powerful and humbling experience. I was very aware of the privileged nature of the information I was hearing and of the effect that reading the diaries had on carers. While the diaries were being read, everything in the room seemed to recede into the background, except for the soft voice of the reader. It had the same impact on listeners as ‘fly on the wall’ documentaries do on television viewers, except more so. This was a real person (someone we knew), telling their real story, detaching from the experience was not an option. In a way, we became part of the re-telling of the story (Frank 2000). It was without doubt an intensely emotional experience for both the reader and the listener. Would the same impact have been achieved if I had read the diaries as I had originally planned? I don’t think so. Also, I think the study was immeasurably enriched by the inclusion of the anecdotal comments added in along the way as memories from earlier times rose to the surface, strengthening the weave of the story.

Asking carers to complete the research diaries at home had a number of benefits. For example, there was no pressure to complete the daily entries at a certain time of day, or even in a particular format. Carers wrote what they could, when they could. However, I presumed that if carers were uncertain of what they had written that they might ask for help from family or friends. Without exception, however, carers had limited access to outside friendships and family members often lived some distance away. Also, I had not bargained on the fact that

even though carers knew the diary entries would be shared with other carers, they wrote candidly on deeply personal issues. That the diaries were able to capture both the public and private lives of the carers was picked up by Alice who revealed that she had never talked about her day-to-day life with her daughter who had learning disabilities – not even to her closest friends.

And we can say to you [the researcher], and put it down, when you couldn't to your friends because they know you, and you wouldn't dream of talking that way really... Focus group meeting transcript, Alice.

Ethical Issues

Doing research with older carers involves thinking through a range of ethical issues, such as the use of inclusive language and materials, appropriate research tools and training for their use, involvement in the research process and many other ethical challenges. The importance of tackling these issues was obvious, even to me - a novice researcher. However, the more subtle issue of the power of the researcher over the researched was not so obvious, nor easy to navigate. Price (2002: 273) concerned about the issue of researcher power pointed out 'Appropriately briefed respondents have power over the level of responses they decide to offer'. In an attempt to 'appropriately brief' the older carers, I followed the recommendations of Hanley et al (2003) to included them in as many elements of the study as possible, but the fact remained that it was I who set the research agenda, not the older carers.

Permission to conduct the research in the NHS was granted by the Local Research Ethics Committee, the NHS research governance committee and the local Primary Care Trust.

Limitations of the Study

When I initially planned the involvement of older carers in the study, I had hoped to facilitate at least five or six focus group meetings. However, due to the length of time it took to negotiate NHS ethics, some scaling back occurred on the level and types of involvement that older carers could choose to take part in. Moreover, due to time constraints, it was not possible to facilitate the in-depth training sessions on research methods that older carers would have needed in order to take part in the study at a deeper level. Although time was taken at each focus group meeting to explain the research process and what steps we needed to take in order to move on to the next stage in the study, it was by necessity only a brief introduction to what is a very complex process.

Also, because older carers could not be involved in the development of the research proposal (for this had to be agreed by the research ethics and governance committees before I could approach the older carers), I did not always ask the right questions. For example, when they reviewed and edited the draft report, older carers felt it was somewhat lacking in demographical and biographical data. Older carers felt that the study would have been enhanced by the inclusion of a brief 'pen picture' of each older carer and their dependent, as this would have provided a richer context for their subsequent stories. Older carers also identified that the inclusion in the appendices of a complete list of all the issues raised by them, together with their suggestions for overcoming them, would have been very useful.

Conclusion

In the UK today, there are numerous ways in which older people can influence decision-making within the statutory, independent and voluntary sectors. Despite this however, older carers remain one of the least consulted and least included groups in research, policy and service development. In this paper we argue that using participatory research with vulnerable

groups such as older carers has the power to be emancipator and, although not without its difficulties, emancipatory research is, according to Lynch, (1999: 41) ‘...analytically, politically, and ethically essential if research with marginalised and socially excluded groups is to have a transformative impact’. Older carers in this study experienced something of that transformative impact and were eager to be involved as much as their busy schedules allowed them to be.

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