Caring for others: A qualitative study of the positive aspects of caring and coping strategies used by the caregiver

Christine Williamson

Supervised by: Laura Brown

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ABSTRACT

There are six million people in the UK providing care and it is suggested that without these unpaid caregivers, the NHS would collapse and the country would face a £119 billion care bill, (Carers Trust, 2012).

Although most people will at some time in their lives provide care, the personal cost can be high and a literature review revealed that previous research had focused mainly on the negative aspects of caregiving. The aim of this study was to explore the positive experiences of seven heterogeneous caregivers who cared for diverse care recipients.

A qualitative research method used semi-structured interviews as a means of obtaining information regarding the subjective experiences of these caregivers. Thematic analysis identified nine themes relating to the objectives of this study; the positive aspects they derived from caregiving, the effects it had had on their lives and the strategies they used to cope.

The implications found from this study were that helpful interventions were needed and readily available information was required, as the number of caregivers is expected to rise to 9 million by 2037.

It is acknowledged that this study is small and further qualitative and quantitative research is needed to illuminate future informal care requirements.

KEY WORDS: CAREGIVER POSITIVE COPING CARING STRATEGIES
Introduction

There are six million people in the UK providing informal care and it is suggested that without these unpaid caregivers, the NHS would collapse and the country would face a £119 billion care bill (Carers Trust, 2012). Of these, 1.25 million provide unpaid care for more than 50 hours per week. A caregiver is best described by the BMA as:

‘Someone who gives unpaid care to a family member, relative or friend who is dependent because of age, physical or other disability, illness and who would, if cared for, require support from the state or by other means.’ (BMA, 1995, p.3, cited in NCSS, 2004, p.4).

A caregiver can be of any age or gender, the peak age for caring being 50-59, but a startling fact is that the number of carers over the age of 65 is increasing more rapidly than the general population (Carers UK, 2012). In a lot of cases the burden of care has switched to family members and this is largely attributed to medical advances, shorter stays in hospital and the development of home care technology (Family Caregivers Alliance, 2006).

This research is concerned with the effects that caregiving has on the caregiver, and explores the experiences of seven heterogeneous caregivers. Caregiving has a multi-faceted impact on people’s lives, especially in the loss of a large portion of their life which is given over to caregiving (Gallop poll, 2011). It can also have impact on the caregiver’s employment, Wakabayashi et al., (2005) say it is critical, that the effect caregiving contributes to poverty rates amongst elderly women is investigated, p.484.

Jones and Peters, (1992) found that more than a quarter of carers in their study reported that caring had detrimentally affected their social life. All of these factors could prove detrimental to carer’s physical and mental well-being.

It would seem that with medical advances, people are surviving serious illness and are living longer and this is not a situation that is going to go away, by 2037 there will be 9 million caregivers in the UK and future policies ‘…should focus on the emotional, financial and time constraints that are faced by informal caregivers’ (Care UK, 2012). Age UK estimate a £5.3 billion cost a year to the economy when carers ‘fall out’ of work; these costs are from lost earnings, tax revenue and additional benefit payments, (Age UK, 2012).

In a Carers Week 2012 survey, carers overwhelmingly reported a negative effect on their physical health (83%) and mental health (87%), including injury through manual handling, stress and depression. Nevertheless, not all experiences of caregiving have negative consequences. This study explores the positive aspects of caregiving and the coping strategies a caregiver may adopt to regulate their own well-being and manage any problems which arise from complex caregiving situations. Hastings and Taut (2002) postulate that research on positive perceptions of caregiving could move to the development of a new theoretical position. This will be important in the future as more adult children will be expected to combine family caregiving with paid employment.

Cohen et al.’s (2002) study of caregiving concurred with Hastings and Taut (2002), concluding that the positive aspects of caring, as well as the negative aspects, may be useful when planning interventions. In Cohen’s study, the results showed that
more than 70% reported positive and happy feelings about caregiving, however, these figures could be misleading, as the vast majority of participants highlighted only one positive aspect. Nonetheless, there was a positive correlation between the caregivers who reported more positive feelings were less likely to report symptoms of depression or illness.

Longitudinal analysis could have more bearing on these findings; Wong et al. (2009) suggested that, as time goes by, the caregiving experience can change caregiver’s perspectives on the way they live their lives. This can emerge as a re-evaluation of their goals and expectancies which could materialize in a more positive or a negative outcome.

Other studies have shown that positive effects of caregiving can include increases in self-esteem and a feeling of satisfaction, (Lawton et al.,1991, Cohen et al., 2002, Pinquart and Sorenson, 2004, Malhotra et al., 2012). However, these feelings can be greatly influenced by undesirable interference from outside agencies, (Malhorta et al.,2012). Involvement of an outside agency, such as Social Services could reduce the caregiver’s feeling of control and self-esteem and have a negative effect on the caregiver’s mental health. Nevertheless, the study does have considerable strengths as their findings were derived from a large population based survey, but due to the low-response rate, it could not be said to be nationally representative of all caregivers (in Singapore).

Al-Krenawi et al. (2011) looked at the impact of intellectual disability on family functioning and his findings revealed that the families with disabled children reported more problematic family functioning and less marital satisfaction. Hanson et al. (2012) also found that caregiving to a parent may also cause marital discord. However, as Beach et al., (2000) point outs, the intensity and complexity of the caregiver’s stressors may not be taken into consideration when comparison is made with ‘normal’ groups.

When researching coping strategies with caregivers of Alzheimer sufferers, Garcia-Alberca et al. (2012) found that caregivers who were prone to what they claimed were ‘disengagement strategies’ were more anxious or depressed than caregivers who used ‘engagement strategies’. ‘Disengagement strategies’ were problem avoidance, wishful thinking, self-criticism and social withdrawal, whereas ‘engagement strategies’ were classified as problem solving, cognitive restructuring, expressing emotion and social support. An explanation as to why engagement strategies have a more beneficial effect on the psychological and mental health of the caregiver is that these coping strategies help the caregiver to adapt to the stressful situations and have a feeling of control. Disengagement strategies may lead the caregiver to believe that they have no control over the situation and can therefore see no end.

In a study of bereaved cancer caregivers’ accounts of negative and beneficial aspects of caregiving, Wong et al. (2009) concluded ‘...participants were able to construct accounts that illustrated positive and rewarding aspects associated with their caring experiences’ p193. Their thematic analysis showed that there were three main aspects associated with caregiving which provided direct benefit for the caregiver.
• Participants reported possessing strength they did not know they possessed.
• Many reported an enrichment of the relationship between themselves and the person they cared for.
• Caregivers reported that the experience of caring for someone else changed their perspective on living and the way they dealt with challenges and difficulties.

Davies et al. (1998) asserts that this ‘self-discovery’ was for the caregivers, an insight into their own abilities and personal growth as they adapted to sometimes traumatic circumstances.

One criticism of Wong et al.’s (2009) study is that the participants were interviewed retrospectively, after the person they had cared for had died, this could have the effect of looking back at their experience ‘with rose tinted glasses’. Nevertheless, this kind of qualitative research can be a way of attaining rich insight into the processes caregivers go through, and this information could be included in policies aimed at improving informal care.

Although there has been considerable research on caregiver issues, most previous research has had a restricted theoretical approach, being selective in its recruitment of participants from usually one perspective, for example spouses, elderly dependents or Alzheimer’s sufferers. The present study is unique in as much as it looks to give an overview of some of the issues that apply to a selection of caregivers (n=7), of varying ages, who care for different patient groups to establish any re-occurring themes across a variety of circumstances.

The aims and objectives of this study are theoretically grounded, with reference to the findings in Wong et al.’s (2009) research.

• To investigate the positive aspects of caregiving as reported by the caregiver. The research will examine any benefits caring for family or friends can bring to the caregiver, this could be personal gain or a sense of fulfillment
• What coping strategies does the caregiver use to alleviate the stresses involved in caregiving
• What impact has caregiving had on the caregiver in relation to their own physical and mental health

Method

Design

As the research question looks at human inter-action and behaviour, this study used qualitative methods to provide ‘a sense that lies within…an illuminative representation of the meaning of a delimited issue or problem’ (Banister et al., 2002, p3).

Complex behaviour is not best encapsulated by quantitative techniques, thus in order to explore the perspectives of the caregiver, a qualitative semi-structured interview schedule was used. This provided a more focused and relevant picture than that of
an ordinary conversation as qualitative methods show the variations of complex human behaviour in context.

Thematic analysis was used as a method of data analysis as this allows for a flexible approach. Thematic analysis can abide to essentialist methods, and takes the subjective experiences of the participants into account and attempts to understand the reality of the participants in relation to the research question.

Participants

The researcher used opportunity sampling, within a specific group who satisfied the criteria that they provided care for a person who required assistance with their daily living to recruit participants. The participants were known to the researcher were approached and recruited personally.

Qualitative thematic methods of research tend to use fewer participants than quantitative research as the analysis of the data is time consuming, this because it requires total emersion in the data by reading and re-reading of the data-set (Braun and Clarke, 2006) but provides significant subjective data. Seven participants (4 females and 3 males) were recruited and as they provided enough rich and descriptive information, so no further recruitment was thought necessary. There was however, a contingency plan to recruit further participants via the Carer’s Resource Centre using a poster campaign should it be necessary (appendix 8). Details of the participants are detailed below:

- Participant 1, Charles is aged 60-69 and cared for his father in law, George who was 70-79 year of age and suffered from Prostate and bone cancer.

- Participant 2, Michelle is aged 30-39 and cares for her son, Joe who is 10 years of age and suffers from Cerebellar Hypoplasia.

- Participant 3, Beryl is aged 70-79 and cared for her sister, Lucy who is 60-65 years of age and suffers from Down’s syndrome and Alzheimer’s.

- Participant 4, Steve is aged 70-79 and cared for his sister-in-law Lucy (as above).

- Participant 5, Charlotte is aged 50-59 and cared for her Mother Anne who suffered from COPD.

- Participant 6, Mike is aged 40-49 and cares for his wife, Sue, who suffers from bi-polar, his 14 year old son, Nick who has Asperger’s Syndrome and his daughter, Lily who has Down’s syndrome.

- Participant 7, Ann is aged 40-49 and cares for her mother Jane, who is aged 60-69 and suffers from Alzheimer’s.

When all the participants had been recruited, suitable times were arranged for the interviews. In order to protect the identities of the caregiver and their care recipient, pseudonyms were used to replace their real names (see appendix 9).
**Procedure**

After the participants were recruited they were interviewed in their own homes in order to provide a comfortable and relaxed atmosphere. This allowed them to speak about very personal and emotive issues in a private and familiar setting. The interview with Charles which was run as a pilot interview was used in the study as it did provide valuable subjective material.

Prior to the interview commencing, the participants were given an instruction/briefing document (appendix 1) to read. This explained the purpose of the research, the reason why they had been chosen to participate, how the interview would take place and explained the duty of responsibility that the researcher had to disclose any illegal information that they may divulge. Very importantly, it advised of their right to withdraw from the study at any time up to the end of January 2013.

Participants were then asked to complete an information sheet (appendix 2) which gave personal information regarding themselves and the person they cared for. They were then asked to read and sign a consent form (appendix 3) to confirm that they understood the purpose of the research and their right to withdraw.

According to Marshall and Rossman, (1999), ‘…qualitative methodologists have described three major purposes for research; to explore, explain, or describe the phenomenon of interest.’ (p.33). With this in mind an interview schedule (appendix 4) was developed to focus and investigate the research objectives. During the interviews the schedule was not followed word for word, but it did act as a general guidance for the interviewer to follow.

The interviews were recorded using an Olympus Dictaphone to ‘capture the deep meaning of experience in the participant’s own words’, (Marshall and Rossman, 2010, p.93). The researcher manually transcribed the raw data; the transcriptions can be found in appendix 10a-10g, (R) corresponds to the researcher and (I) the interviewee.

To put the interviewees at ease, the first question asked them to ‘describe a typical day when caring for (their care recipient)’, this was an ‘ice-breaking’ question, which firstly helped the participants to relax and allowed the researcher to get an insight into the carer’s lives. The other three questions were related to the research objectives, asking about the positive side of caregiving, strategies for coping and how caregiving had effected their lives and relationship with the care recipient.

After the interview had been completed, the participants were handed a Debrief document (appendix 5) to take with them; this reiterated their right to withdrawal and gave the participant a chance to ask any questions. The document assured the participants that the information they had given would be treated with respect and confidentiality. It also contained an email address to contact should they require a copy of the completed report and a list of useful care organisations (e.g.Carers UK) which they could contact to obtain information and assistance.

If the participants decided they wanted to withdraw from the study, they would be able to contact the researcher personally.
Data Analysis

In order to explore the participants’ accounts from a phenomenological perspective, a thematic analysis was used. Thematic analysis in research is uniquely suited to uncovering unexpected themes and allows the researcher the flexibility to explore new avenues or themes (Marshall and Rossman, 1999). Thematic analysis is described by Braun & Clarke, (2006) as a qualitative analytic method for:

‘...identifying, analysing and reporting patterns (themes) within your data. It minimally organizes and describes your data set in (rich) detail. However, frequently it goes further than this, and interprets various aspects of the research topic’ (p79).

As the researcher had first-hand knowledge of the interview process she transcribed the interview data personally, (11,120 words) and was able to interpret both verbal and non-verbal exchanges. This is proven to be an excellent way of familiarising oneself with the data (Halcomb & Davidson, 2006).

Although there is no one way of conducting a thematic analysis, the six phase analysis described by Braun & Clarke (2006) was utilized to analyse the participants’ accounts. Braun and Clarke contend that thematic analysis is a ‘...poorly demarcated, rarely acknowledged methodology within psychological research’ (p.77) but they argue that ‘it offers an accessible and theoretically-flexible approach to analysing qualitative data’ (p.77).

The six stages involve:-

1. Immersion in the data, by repeated reading
2. Producing initial codes which are features of the data which are of particular interest to the analyst with regard to the research question
3. Broader levels of themes are considered, and can be sorted into themes (such as emotions, relationships, social life)
4. Review and refinement of the themes
5. Further refinement and naming of the themes
6. The final phase is the production of the report, this is the final opportunity for analysis, ‘...final analysis of selected extracts, relating back to the analysis to the research question and literature, producing a scholarly report of the analysis’ (Braun and Clarke, 2006, p. 87).

This research is driven by the research question which requires an empathetic and sensitive interviewer; the researcher is not a neutral or distant observer within the process, but he/she is actively involved, looking for honesty and openness from his/her interviewees. This requires sometimes showing empathy for opposing views, Rubin and Rubin, (1995) say that a great strength of this type of methodology is the personal involvement of the researcher, but that he/she must be aware of his/her own biases and prejudices which may be brought to the interview.

Ethical Considerations

Ethical guidelines set out by the British Psychological Society were used in this research. An Application for Ethics Approval Form (AEAF) (appendix 6) and an
Ethics Check Form (ECF) (appendix 7) were completed and approved by a supervisor at the Manchester Metropolitan University.

Five basic ethical considerations were identified which are applicable to research; informed consent, no deception, the right to withdraw, debriefing and confidentiality, (Willig, 2008). Participants were asked to read the information sheet which gave full details about the purpose and structure of the interviews. It also advised that if they disclosed any information which was deemed illegal, then it was the duty of the researcher to disclose this information to their supervisor. Participants were then asked to sign a Consent form to confirm that they understood the nature of the research and their right to withdraw. There was no deception involved, and following the interview the participants were given a Debrief document which reiterated their right to withdraw. The debrief document also contained a names and addresses of useful Carer’s organisations which the caregiver may wish to contact for information and assistance. Personal details (names) were changed so that they could not be identified from the research. Consent forms and any recordings will be destroyed upon completion of the study. The data collected was not confidential as it was discussed with a supervisor, but participants were advised of this prior to the interview in the information sheet.

Results

Using Braun and Clarke’s (2006) thematic analysis framework, nine major themes were identified; Table 1 illustrates the themes which were detected in accordance with the three objectives of the study.

Table 1: Table showing objectives and main themes.

<table>
<thead>
<tr>
<th>Objective</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Effects on Life and Relationships</td>
<td>i.)  Adverse feelings</td>
</tr>
<tr>
<td></td>
<td>ii.) Work Life</td>
</tr>
<tr>
<td>2) Positive Aspects of Caring</td>
<td>i.)  Altruistic tendencies</td>
</tr>
<tr>
<td></td>
<td>ii.) Personal Development</td>
</tr>
<tr>
<td></td>
<td>iii.) Acceptance</td>
</tr>
<tr>
<td>3) Coping Strategies</td>
<td>i.)  A Sense of Order</td>
</tr>
<tr>
<td></td>
<td>ii.) Relaxation</td>
</tr>
<tr>
<td></td>
<td>iii.) Outside Assistance</td>
</tr>
<tr>
<td></td>
<td>iv.) Stoicism</td>
</tr>
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1) Effects on life and relationships

All the participants reported that the difficulties and challenges associated with caring had had adverse consequences on their lives, both emotionally and in their working lives.
Theme i: Adverse Feelings

Beryl describes how despondent she had become after caring for her ageing sister for 25 years, “I broke down whilst she was here, the care manager… ‘I can’t do any more’, I’d got to rock bottom you know…”, (35-37).

Mike further exemplified this when his relationship with his 14 year old son Nick became difficult after Nick was diagnosed with Asperger’s Syndrome. Mike felt he was becoming “…the object of his (Nick’s) frustrations”, (195) and this caused friction and a stressful situation for them both.

Michelle showed that when her son was first diagnosed she found it difficult at first to come to terms with the situation, ‘Things like that happen to other people … oh no, stuff like that doesn’t happen to us’, (75-77).

Theme ii: Work Life

The second theme in this category which emerged was the effect on work life. Charlotte and Mike had to give up their jobs, Mike states “I would probably have lost my job, far before I made the decision to stop working”, (177-179). Michelle took the decision to finish work as it was causing problems between her and her husband, “We were arguing who was going to have to have time off work and it wasn’t good at all”, (152-153). Ann also had to make changes, “… I have had to reduce my hours at work from full time to part time” (42-43) to help her manage.

2) Positive aspects of caregiving

Many of the participants identified positive benefits from being a carer; they reported discovering a strength which they did not know they possessed. Most undertook their caring duties altruistically, undertaking a responsibility of care without any tangible reward.

Theme i: Altruistic tendencies

Altruistic propensities were portrayed by Charles who says, “The feeling that he gave, that he was really pleased to see you and you know, it wasn’t a chore to carry out these things for him”, (39-41) and Steve when speaking about caring for his sister-in-law states “The only other thing was the satisfaction of doing it”, (134-135).

Six of the carers seemed to accept their role with good grace and Mike showed how he had gained by becoming a carer to his daughter:

“It has been fantastic being her primary carer… and the opportunity to do that is something that is a fantastic experience I think, something that I would never of considered but in a way circumstances were thrown upon me…”, (188-192).

Only one carer, Charlotte, reported any ill-feelings around caring for her mother, “I really resented having to care for her”, (24-25) but she later admitted that the situation had brought some benefit to their relationship, “…in hind-sight, I am glad I am here for her, it must be very frightening and lonely for her”, (66-67)
**Theme ii: Personal Development**

All of the carers reported gained strength through the adversity of their situations, Charlotte shows this when she speaks about the physical aspects of caring, “I have done stuff I never thought I could do… I am amazed that I have done it”, (64-65)

Other carers have also developed a confidence which they would not have had if they had not been put into the caring situation. Michelle had a very difficult time with her first child when he became ill and she felt that if the medics had taken her more seriously in the first place, then he would not have been so badly incapacitated. She now feels that she is much more confident, particularly in medical situations:-

“I would never be in that situation again with (child 2), ‘cos I wouldn’t take him home, I would stand my ground (laughs) and say ‘I am not going anywhere’, so I suppose it has changed me in that way”, (130-133).

Mike very clearly sums up the matter of personal development when he says “I think one of the satisfying aspects, of caring is being able to look back and see the changes in me as a person and how I have developed into something I was most definitely wasn’t when I first had to give up work.”, (116-119).

**Theme iii: Acceptance**

Apart from Charles, who was not a primary carer, participants spoke of how their acceptance of the situation had strengthened their ability to deal with the challenges of caregiving.

Beryl became very emotional when she talked about her decision to place her sister into a small care facility, “… but I know she’s in the right place now, we could have never have done any more for her”, (68-69). Beryl had accepted that although it was a difficult decision, it was one that had to be made, but it has now allowed her and her husband to enjoy their latter years without their ‘burden’ of care, “It’s given us a new lease of life you know”, (48).

The act of caring allowed acceptance of a difficult relationship between Charlotte and her mother, “I’m glad that at last we have some sort of relationship, I do love her, and we have talked over many things,…I do realise that she could not always help the way she was”, (35-37).

Mike accepted that whilst his wife was ill and his children were still young, that he would be unable to return to full time employment “… the long term goal of returning to work…would not work, I am well aware that strain on the household… detrimental to my wife … so therefore it is quite unrealistic”, (169-175).

**3) Coping strategies**

When asked how they managed and coped with caregiving, four main themes evolved, these were orderliness, outside assistance, social-life and a stoic acquiescence.
Theme i: A Sense of Orderliness

All of the carers talked about how they had to be organised to help them to cope, Michelle explains, “It’s just being organised and we get everything out for the morning the night before, we have to sort of plan”, (48-49) and she also goes on to say that organisation gives her the feeling of control, “I do like to be organised and control things...”, (91).

Mike also explains how uses his organisation skills to keep the household on an even keel:

“... I keep the house running, I do pretty much everything in the house, and if I am not in the house, I have done most of everything that needed doing...”, (18:20).

Organisation was seen not just to be a benefit for the carer, the care recipient also gained benefit from having a set routine and Ann typifies this when she says,

“... it is better for Mum and myself... as we both have a routine and she does not have that interruption.”, (27-28)

Three carers, Beryl and Steve (husband and wife) and Charlotte (only child) spoke about being aware that they would eventually have to take on a carer role to their family member. With this pre-knowledge they had planned and organised their lives accordingly, as Charlotte explains:

“.. I always knew that I would end up caring for her, and although it may have seemed a bit selfish,...did a lot of stuff, like...ermm...long holidays, before she got worse”, (40-43).

Beryl explained that, “... we always said from when we got married eventually we would have to have Anne, we talked about it...”, (55-56), showing that they were aware of the situation for a long time prior to accepting Anne into their home when their parents died.

Theme ii: Relaxation

All of the primary carers spoke about the importance of their social life and having time away from caregiving, Ann epitomises this when she explains, “I do try to go out occasionally on my own and take regular exercise.” (21-22).

It also emerged that it was not always easy to get this time and Michelle explains how she got around this, “I used to go out with my friends and (husband) used to go out with his friends, but we never sort of went out together (laughs)”, (162-164).

Beryl and her husband adapted by arranging people to come to their house, “...but then after that we didn’t go out... so our friends used to come to us because we could not leave Lucy to go to them”, (101-104).

Theme 9: Outside Assistance

All of the carers reported that they have some sort of outside assistance to varying degrees, these were Meals on Wheels, School Support Worker, Day Centre, Community Nurse and Social services.
Although the study was looking at positive aspects of caring, one fact that did emerge was the difficulty in finding information about what assistance was available. As Charlotte says,

“No one tells you anything… you have to fight for everything,… mostly I got information from other people or by the telephone and internet, no-one comes and tells you what to do, you have to find it out for yourself.”, (54-57),

this is also re-iterated by Michelle who thought there should be:

“…something that provides you with all the information , like I say, whether it be benefits , people who can help or activities that are going on so you’re not having to trawl through everything.”, (114-117).

Beryl and Steve were only able to find out a residential facility which was suitable for her sister from a friend who was an Occupational Therapist. When asked if they had found it difficult to find that kind of information, Steve replied “Yes, it wasn’t forthcoming, in fact it was (friend) who directed us that way and had connections.”, (58-59).

**Theme iii: Stoical**

There was a real feel of stoicism from the caregivers; they seemed to accept their role with fortitude showing patience and endurance during adversity. The general feeling of its “Just something you took in your stride…”, Steve, (111) and even Charlotte who had some misgivings said “you just get on with it I suppose.”, (40), a feeling that is reiterated by Michelle when she says:

“….no matter how much time I spend and think about things, it’s not going to make any difference, so you just sort of have to get on with it.”, (88-89).

Perhaps the stoic philosophy that happiness can only be achieved by accepting life’s ups and downs can be summed up by Charles who said “I don’t know really… you just carried on talking and got through and probably made him another cup of tea”, (62-63).

**Discussion**

This qualitative study was designed to be reflective of the experiences of a variety of caregivers who provide care to recipients of different ages and who have varied and challenging needs. The findings of this study indicated that the participants were able to provide accounts which showed positive and rewarding outcomes, whilst elucidating on the approaches they used to cope. They also provided rich subjective material regarding how the transition to caregiver has changed their outlook and the way they live their lives.

Nine themes emanated from the analysis from three research objectives, the positive aspects derived from caregiving, the effects on caregiver’s lives and coping strategies.

Personal development was the main positive benefit to which the caregivers prescribed and they spoke of a gaining of strength that was ‘…an insightful understanding of themselves, (and) their abilities...’ (Wong et al., 2009, p.194).
Davies et al.’s (1998) study supports this theory and asserts that individuals learn something about themselves in traumatic situations. Participants reported that due to the changes in their lives they had had the opportunity to learn new skills such as learning to drive; confidence, they felt stronger when dealing with bureaucracy (e.g. Social Services) and adjustment from their working lives had allowed them to pursue other avenues, such as new academic ventures.

The majority of the caregivers acknowledged altruistic tendencies, caring for no obvious reward other than to give benefit to another. Beach et al., (2000) state that the fact that a person is able to do something to help, acts as a counterbalance to physical and emotional strains. All of the participants seemed to have accepted their caring role and by positively engaging with the situation had gained benefits. García-Alberca et al.’s (2012) study found that ‘…caregivers who used more engagement coping strategies reported lower anxiety and depression levels.’ p.1329.

The transition to becoming a caregiver can have a catastrophic effect on people’s lives. Hanson et al. (2012) points out that ‘…care work in itself can be physically, mentally and financially challenging.’ and the analysis did provide examples of adverse feelings such as resentment (Charlotte), stress (Michelle) and guilt (Beryl). Participants reported they had had to adapt their social lives to care for their loved ones and had also involved outside agencies, such as Day Centers and one-one support to lessen the burden. However, there was criticism that information about outside agencies, benefits etc. was not easy to come by and that this sort of information should be given as a matter of course and be more easily available.

Caregiver’s also displayed stoic predispositions towards their situation, their attitude being that you just have to get on with it, which seemed to help them to cope with matters. In order to feel that they had an element of control, participants talked about the need to be organised. This was not just about everyday things but also how they organised their lives over time, for example, Charlotte, Beryl and Steve were aware for many years that eventually they would have to take on caregiver’s duties and they organised their lives accordingly. Michelle also planned for the future so that her husband would take over more of the caregiver duties when their son became older and more difficult for her to physically manage.

The caregivers in this study had been giving care for between two and twenty five years and although they acknowledged adverse effects, the majority accepted their role with graciousness. However, one of the limitations to this study is that the participants may have been reluctant to be disparaging of their position because of their reluctance to admit this to the researcher, only Charlotte admitted feeling resentment towards her mother.

Caregiving also has a devastating effect on employment and although three million people combine work with caring responsibilities, one in every six carers has had to give up work or reduce their hours. According to Carers UK (2012), one of the main reasons for this is the lack of suitable practical assistance. The findings in this study showed that all of the caregivers of work age (4 of 7) had been affected by their caring duties; three had totally given up their full time employment whereas the other caregiver had been forced to take reduced hours.
This study was designed to discover the positive aspects of caregiving identified by a variety of caregivers, (age and gender) in order to understand how informal caregivers can be supported. The caregivers in this study seem to have constructed satisfying meanings to their caregiving in an attempt to find a sense of coherence and positive reasons for being a carer but it is accepted that the subjective experiences of these individuals cannot be generalised to all caregivers.

However, any interventions that are developed to assist the informal caregiver need to take into account these positive benefits of caregiving; the individuals in this study reported a satisfaction from caring for their loved ones and seemed to gain personal strength and growth from the experience. These results supported Wong et al.’s (2009) findings, where positive reflections were reported by the carers of deceased cancer patients retrospectively.

One very important intervention could be in the workplace, as one in six caregivers either give up work or take reduced hours, there is a need for a more flexible approach from employers and support services. As it is estimated that there will be over nine million informal caregivers by 2037 (Carers UK, 2012), it is important that suitable interventions are planned and implemented. Social services support is important and this is perhaps where major change could be radical, as according to Carers UK (2012), there are approximately 673,000 new caregivers each year who give care for twenty hours or more.

Policy makers should identify that although informal caregivers may give help and time altruistically, there is a great need for information and support to be readily available to assist. Suitable assessment and reviews of a caregiver’s needs are paramount in finding appropriate support for both the caregiver and the care recipient.

Qualitative methods used in this research allowed for a subjective exploration of the positive and beneficial aspects of informal caring. It would be beneficial for future research using qualitative and quantitative methods to further examine the perceived benefits and the psychological consequences. The study adds to existing literature in this field; informal caregivers must be supported in their caregiving responsibilities to give them a good quality of life.

**Reflexivity**

As a carer myself I was aware of the effect that caregiving has had on my own life and that my personal experiences may be reflected in the research. I am a mature undergraduate student studying Psychology at Manchester Metropolitan University and I have over ten years of caregiving experience. I have found this to be at times distressing but also a rewarding and enlightening experience. As there is a plethora of research which reported the adverse effects of caregiving, I chose to investigate any perceived positive aspects of caregiving and how caregivers manage their own lives in these sometimes difficult circumstances.

Although I am an inexperienced interviewer, I attempted to keep the interviews on track by keeping to the interview schedule, but I was aware at times that the participants were revealing very personal information, so I did allow some slight deviations from the schedule. As the interview took the form of a guided conversation and because the participants were known to me, I found it difficult at
times not to talk about my own situation and experiences, and not to lead the interviewee’s replies. However, it was important to show empathy and understanding and gain a good rapport with the participants.

Due to the unique nature of this design into the positive effects of caregiving there were other issues that could have been explored in more depth, but due to a limited word count, this was not possible. Nonetheless, the findings and the limitations of this study provide a basis for further investigation of the patient-carer relationship and exploration of beneficial support mechanisms.

References


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