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Title: An integrated approach for individualised support: Carer's views

Authors: Professor Pam Moule EdD, MSc, BSc(Hons), RN
University of the West of England, Bristol Faculty of Health and Applied Sciences, Glenside
Campus, Blackberry Hill, Stapleton, Bristol, BS16 1DD pam.moule@uwe.ac.uk, 0117 328
8422(Correspondence author)

| Dr Katherine Pollard, PhD University of the West of England, Bristol
Jackie Clarke (Carer)
Christine Fear, University of the West of England, Bristol
Bob Lawson (Carer)
Dr Rennie Thompson, EdD, University of the West of England, Bristol
Dr Pat Young, University of the West of England, Bristol

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Author biographies

Professor Pam Moule has experience of undertaking a range of evaluations in health and social care and aims to disseminate activity to influence good practice development.

Dr Katherine Pollard is a Senior Research Fellow with expertise in evaluation of health and social care services.

Jackie Clark is a carer with experience of co-ordinating a package of care delivery for a dependent relative.

Tina Fear is a lecturer, lead for the Independent Sector and Associate Postgraduate Dean for Nursing in the School of Primary Care (GP training) with expertise in social gerontology.

Bob Lawson is a carer with experience of supporting elderly relatives.

Dr Rennie Thompson, Research Associate, has a wide-ranging professional background in education.

Dr Pat Young is a lecturer in Educational Research in Health and Social Care with a background in Social Policy and experience of researching initiatives in health and social care.

Abstract

Purpose- The purpose of this study was to capture carers' views of a service in Bristol funded jointly by the Local Authority and the NHS Clinical Commissioning Group, which offers support to carers in the form of a one-off payment which they can use for anything they choose.

Design/methodology/approach- A multi-method evaluation of this integrated service was conducted between August 2012 and October 2013 to explore its impact on carers' health and wellbeing. This paper presents findings from 40 interviews conducted with carers as part of the evaluation.

Findings- Many carers have little respite from very stressful situations; the break enabled them to focus on their own needs. Carers' needs included actual short breaks away with or without those being cared for, as well as items like household equipment or exercise classes.

Research limitations/implications- The study was centred on an innovation and integrated approach to support carers in one city and provides a snap-shot of the short-term effects. Longer lasting effects are not known.

Social implications- Most carers found the support beneficial, and in some cases reported a positive effect on their own health and wellbeing. Effective inter-agency communication and collaboration is essential for the success of the integrated service.

Originality/value- There is limited research available on the outcomes of integrated approaches to support carers.

Key words: Carers, individualised support, carer breaks, integrated approach, qualitative evaluation, health and wellbeing, community

Article classification: Research paper

Introduction

Carers are seen as those providing essential support and help, without payment, to a family member, friend or neighbour (Carers Trust, 2012). There were approximately six million carers in the UK in 2009 (National Audit 2009), with a proportion of one in eight of the UK adult population having a caring role in 2012 (Carers UK, 2012). It is suggested that informal care by a friend or relative is often the only source of help and support for many older people living in the UK and across the whole of Europe (Reidal 2011).

The burden of informal caring has been shown to have a detrimental effect on the health and wellbeing of carers and their ability to provide care (Cecil 2010, Arber & Venn 2011, King & Pickard 2013). Carers can suffer from a range of physical and psychological problems as a result of their caring role (Mannion, 2008). Those caring for dementia sufferers report sleep deprivation issues (McCurry *et al.*, 2007) and distress and depression (Schulz and Sherwood, 2008). Loss of independence and freedom in addition to the physical stress of caring often results in depression and exhaustion and in a very short time can become overwhelming (Cecil *et al.*, 2011, Levin *et al.*, 1994). Those caring for prolonged periods of time and for more than 50 hours a week are particularly vulnerable to health ~~issues- problems~~ (Carers UK, 2004).

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The ramifications of carer health concerns for statutory service provision have been recognised and support for carers has been enhanced. Developments include the provision of a revised strategy for carers implemented by the Department of Health (DH2008, 2010), which is accompanied by funding to provide carers with annual health checks and short breaks, as well as training for General Practitioners (GPs) and other health care professionals to identify and support carers (CIRCLE 2010). Investing in carers' services and support can help to reduce the negative effects of carer stress and burden. Short breaks for carers of children with disabilities have been shown to improve family relationships and reduce the stress of daily life. It helped carers to continue caring between regular breaks with an opportunity to just sit and relax (Robertson 2010).

The evaluation of 25 National Demonstrator Sites for Carers (DH 2009) providing support services, which included Bristol, confirmed the benefits for carers, cost-benefits and highlighted the important of multi-agency partnership working (CIRCLE 2010). Involvement in this pilot work informed the subsequent development of the Carers' Breaks in Bristol.

Bristol has a joint carers strategy across adults, children's and health services, supported by Bristol City Council (BCC) and Bristol Clinical Commissioning Group (BCCG). As an extension of this work, both organisations agreed to pool carers breaks monies with carer's budgets.

This "Pooled budget" was set up under a section 75 agreement. The Carers' Breaks are non means tested and administered through an Integrated Carers Team, line managed within Bristol CC adult services. The team includes; a Team Manager, one social worker, two unqualified practitioners and a Customer Services Officer. They can work directly with any carer to provide a seamless carer service. Those teams support carers of people eligible for, and receiving, provision from adult social care teams. The new initiative was widely advertised with details available via Care Direct and Bristol Parent Carers, and leaflets distributed to libraries and GPs, promotion throughout the voluntary sector and links on the Bristol CCG website.

The Integrated Care Team has a particular role in relation to carers who are experiencing an impact on their health and wellbeing but would not otherwise be eligible for carers support.

These carers are assessed to identify eligibility for one off direct payments to address the outcomes identified. The team also assesses and supports carers of people funded through Continuing Health Care, who would not otherwise have access to social work support. The needs of this group are much more complex, and the pooled budget enables the team to meet those needs. Parents of children with disabilities have not previously been entitled to a separate assessment of their needs outside of the holistic assessment for their child. The service has enabled small direct payments to offset impacts on their health and wellbeing, as well as providing payment for specific items for young people with caring responsibilities. As well as carrying out assessments directly, the team sign off, and provide direct payments on the basis of assessments carried out by specific accepted assessors. This includes social workers in adult or children's teams, staff within The Carers Support Centre health team, and bridging workers employed within the Disabled Children's services.

This paper presents an evaluation of the experiences of carers receiving a 'Carer's break' following a carer assessment process. It presents qualitative interview data from a spectrum of local carers, collected as part of a wider study (Moule *et al.*, 2013). The term 'Carers Breaks', is one that Family Carers are familiar with, even though it doesn't always mean a traditional 'break'. Most Carers see any help that alleviates the constant hard work of caring as a 'break' and a change from the usual.

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Study design and methods

The project secured ethical approval from the University of the West of England, Bristol, Faculty Research Ethics Committee. This included processes for data storage and support of the carers should they become distressed during the interviews. The wider evaluation employed mixed methods (survey and interviews) to address a variety of research problems (Bryman 2012). Semi-structured interviews with carers, reported here, were employed to capture carers' experiences and views of the 'break' (King & Horrocks 2010).

A sample of forty carers was identified from an initial survey of 155 questionnaires, in which respondents were asked to volunteer to take part in follow-up interviews. The Integrated Care Team assessors offered the survey to all carers coming forward for assessment. It was anticipated that this sample size would allow theoretical saturation to be achieved. The sample were selected to represent a wide range of characteristics, for example, age of interviewee, age of person being cared for, relationship, number of people being cared for, ethnicity, gender, length of time caring and nature of condition leading to requirement for care. A priority was to include carers caring for individuals with complex needs, requiring continuing health care. Ninety-one respondents indicated that they would be willing to be interviewed, and of these, researchers attempted to contact 68. It proved impossible to establish contact in 26 cases, and two respondents decided not to participate in an interview.

The study ran for 15 months and interviews were conducted over a seven-month period between February and August 2013. Interview dates were arranged with carers by telephone, accommodating their caring and personal responsibilities. A brief explanation from the interviewer during the initial set up call and an information sheet sent to them by post gave them time to consider what they might say during an interview planned to take a maximum of an hour. All interviewees were sent a participant interview information sheet outlining the nature of the project and their involvement in it. It also gave assurance of confidentiality through anonymisation of data and provided information about

dissemination of findings and contact details for further information or support. Informed consent was sought and secured from all participants prior to data collection (King & Horrocks 2010). This process involved the researcher reading out a consent form and recording agreement to take part.

Thirty-nine interviews were conducted by telephone and one was scheduled to take place in the carer's residence at their request. The interview schedule was developed from the literature and with input from two carer members of the research team and the members of the project advisory board, which included carers and staff from both organisations. The questions addressed three main areas:

1. carer's experience of the assessment process for the break
2. nature of the break chosen
3. possible impact of the break on the carer and the cared for person

All interviews were recorded and transcribed verbatim. Both recorded and transcribed data were available to the researcher conducting the analysis to minimize loss of social encounter factors resulting from transcription.

The interview data was subjected to thematic analysis using a recognised framework to support content analysis (Miles & Huberman 1994). This involved three stages: i) Data reduction: familiarisation, segmentation into coded categories, ii) Data display: comparing categories to look for common and divergent themes and iii) Conclusion drawing: identifying relationships in the themes emerging from the data.

Findings

Four themes were identified: administration; circumstances of the carers; the break; and the effects of the break. Where verbatim quotes are used, carers are identified by a number code.

The Respondents

Thirty-one women and nine men were interviewed. Their ages and the length of time they had been carers are shown in table 1.

Age	Female	Male	Total	Caring <5 yrs	Caring 5-10 yrs	Caring >10 yrs
Unknown	1		1		1	
21-30 yrs	2		2	1	1	
31-40 yrs	4		4	2	1	1
41-50 yrs	10	2	12	4	3	5
51-60 yrs	6	1	7	3	2	1
61-70 yrs	3		3	1	1	2
71-80 yrs	4	4	8	5	2	1
81-90 yrs	1	2	3		1	2
Total	31	9	40	16	12	12

Table 1. Interviewees by Age and Gender, and by Age and Length of Time as a Carer

Thirty-four carers identified themselves on their questionnaires as being 'White British'. Two carers identified themselves as 'Black British', two as 'Any Other White', and another

identified herself as 'Mixed Race'. One interviewee did not indicate ethnicity. Disappointingly the respondents are mainly White British and adult, with minimal representation of ethnic minority and child carers.

Almost half of the interviewees were caring for spouses or partners, while others were caring for parents or children, and in a few cases for friends or neighbours. In four cases, women carers were caring for two individuals. Table 2 shows the ages of those cared for.

Age	Spouse/Partner	Child	Parent	Friend/Neighbour	Total
Unknown		1			1
1-10 yrs		4			4
11-20 yrs		7			7
21-30 yrs					0
31-40 yrs	2				2
41-50 yrs	1	1	1		3
51-60 yrs	2		1		3
61-70 yrs	5		2	1	8
71-80 yrs	4		1		5
81-90 yrs	4		2	1	7
91-100 yrs			2	2	4
Total	18	13	9	4	44

Table 2. Individuals being cared for by Age and Relationship to Carer

Those being cared for suffered from a variety of complex conditions, including Alzheimer's disease, Lewy Body disease, Down's syndrome, epilepsy, multiple sclerosis, autism and attention deficit hyperactivity disorder (ADHD), impairment results from a stroke, and cancer.

The themes

1. Administration of the scheme

Interviewees became aware of the Carers' Breaks scheme through a variety of sources, including GP practices, social services, community nurses, the voluntary sector and word of mouth. Some interviewees were not aware of the new scheme:

I didn't know this existed... I have spoken to some other carers and they have no idea that this is available...it seems quite secretive at the moment. (5)

Whilst the scheme had been well advertised, many carers were unaware of its existence, highlighting the difficulties of accessing carers because of their isolation. Once aware of the scheme, the carer assessment process appeared to be straightforward for most, though assessment formats varied. While many carers were visited in their homes and helped to complete the paperwork, others received a phone call and were sent paperwork to complete by themselves. There was no evidence that any carer struggled with the assessment process.

In one case, a carer reported that completing the paperwork for the assessment had been '*a little bit upsetting*', bringing home the extent to which her caring role affected

'everything in [her] life'. Many carers found the assessment to be a positive experience, especially when conducted face-to-face:

sometimes you need to unload or unburden yourself, and maybe it was good that I was able to talk to somebody who actually understood what I was going through. (12)

These quotes demonstrate the impact of the caring role of family members and the potential benefit that merely the assessment process can bring.

When interviewed, 17 carers had not yet had a break through the scheme. Nine of these individuals had received funding, and had breaks planned. For the other eight, there appeared to be delay in the allocation of funding and some resulting confusion. The 32 carers who had been allocated funding had received sums ranging between £200 and £500, paid directly into their bank accounts. For most, the transfer of funds was efficient, although a minority reported frustrating delays. While most interviewees were asked to keep receipts in case they were needed at a later date, some reported this had not been mentioned.

2. Carer Circumstances

Thirteen interviewees spoke spontaneously about the difficulties of their lives, for example:

(caring) takes over your whole life, morning, noon and night, and you're constantly on the go (4)

Six interviewees explained how their caring responsibilities were exacerbated by excessive dependence:

My mum is at that stage ... she will only do everything with me. (16)

These carers depict the personal impact of the caring role on their quality of life, where constant demands and isolation are real issues. The situation can be exacerbated if minimal support is available. Interviewees reported receiving varying levels of support. Fourteen felt they were well supported by family and/or friends. Nine carers said that they received little or no help from friends or family. Five interviewees said that they had been helped by public and/or third sector services. In contrast, two interviewees described very unhelpful encounters with external agencies.

Twenty-five of the interviewees detailed health ~~issues~~ **problems**. Some were longstanding, for example, two interviewees suffered from fibromyalgia. Nine carers mentioned they suffered from stress, anxiety and/or depression, while another spoke of suffering from panic attacks. For five carers, headaches and tiredness caused by lack of sleep and/or continuing demands made on them created on-going problems.

I have been feeling very down. I am not a person given easily to crying, but when the new year came in I felt ... oh dear, another year, I don't know what's going to happen ... I suffer with stress

and I have had this silly little cough and my eyes water and my nose runs... (17)

A 77 year old carer reported:

... ageing problems ... I found it hard with the bathing and that, I have always had a bad back and I can't bend down without my back going. (1)

The carers present a picture of coping with their own health issues-problems, which are potentially exacerbated by the caring roles they manage.

3. The Break

Most interviewees reported having a free choice on the nature of their break. Although some received written information only, many were engaged in telephone or face-to-face conversations with assessors, who helped them make decisions. This high level of freedom was received positively by most carers, though one seemed daunted by lack of clear direction on options. Carers were generally responsible for arranging the break themselves. Only one interviewee would have preferred the break to have been arranged for her.

Table 3 illustrates the break chosen

- Short breaks away, with or without the person being cared for;
- Alternative care for the person needing care;
- Swimming, gym or exercise classes/membership, for example, Tai Chi, Slimming World;
- A range of therapy sessions, including massage and counselling;
- Transport for carers to travel with or without the person being cared for;
- Courses, for example, cartoon animation and painting;
- Craft materials;
- Equipment for the home;
- Home cleaning;
- Technological equipment, for example, a mobile phone or computer.

A range of factors influenced the breaks chosen. Some needed time away from their caring responsibilities. However, nine interviewees stated that they could not, or did not want to, leave the person for whom they were caring. These carers chose either to arrange time away with the cared-for individuals, or opted for something that would only necessitate their absence for a matter of hours. One carer stated that, although she had been assessed as being eligible for a break, it would not be possible for her to use the scheme at all, due to the onerous nature of her caring responsibilities.

Concern for their own mental/psychological health was also a pertinent factor for some carers. A carer who chose to visit a gym explained:

I have had a little bit of depression and anxiety in the past ...but exercise was one of the things [that helped](30)

Despite the fact that the explicit aim of the scheme is to provide carers with support, two older men (79 and 72 years old) chose to use the funding allocated for equipment for their wives. One explained that a new lighter wheelchair would however be easier for him to manoeuvre. Another man (54 years) thought that putting the funding towards adaptations to his wife's bathroom would make life easier for him in the long run.

4. *Effects of the Break*

Interestingly, there were mixed views among interviewees about whether or not carers should receive funding to spend on themselves, with some feeling that somehow they were 'cheating'. This reflects the selfless nature of a number of the carers. However, others were clear that they deserved support:

I felt I was cheating somebody; and I suppose thinking about it now, the first time the money went into my bank it stayed there for two weeks. (3)

Whatever their feelings about the appropriateness of the scheme, all the interviewees who had received and spent at least some of their funding commented positively about the effects of the break. Some carers recounted how the break had impacted positively on their own health and wellbeing:

It has made me feel a lot better about myself ... it's given me something of myself back. (29)

Carers associated an improvement in their own wellbeing and/or their ability to care with a positive impact on those being cared for. In a few instances, carers reported a direct impact of their receiving the break on those for whom they were caring. This was mostly positive, although some difficulties were also apparent:

I will say he is not entirely happy about me leaving him for an entire length of time with a complete stranger. (10)

Just the fact of being awarded a break also appeared to have a positive effect, as anticipation resulted in pleasurable feelings. Where interviewees interpreted their being awarded a break as evidence of their caring work being recognised and valued externally, this appeared to be very significant for them:

someone out there values the work that you actually do. (30)

For some carers, although the break had had positive effects for them, these were perceived as limited:

It's not long-term, is it? It was a lovely gesture, a nice bonus, but you know like anyone in normal life, you come back from holiday and it's all back to normal. (6)

Discussion and implications for carers and integrated care delivery

This study captured carers' views of a jointly supported service funded by the Council and the CCG, which offers individualised support to carers in the form of a one-off payment, to be used at their discretion. The involvement of carers as full partners in the process provided useful insights and informed the development of data collection tools, recruitment, analysis and final development of the report.

Overall the carers were very pleased to have received the break and a number gave very positive feedback on the opportunity offered, which was only available as a result of the integrated approach taken and demonstrates the benefits of multi-agency working (CIRCLE, 2010). There were however some limitations to the study that should be acknowledged.

The research interviews with carers were unable to identify and reach those carers with high burden and complex needs in receipt of continuing health care support. This study reports the findings of a local population of carers, which may not be typical of the national caring population. Finally, the evaluation concentrated on capturing data on the short-term benefits and any longer-term impacts are not known. Despite this, it is clear that in offering an integrated service a number of benefits were secured for carers, which would not have been available otherwise.

All but one of the 32 carers who had received funding prior to the interview had been able to exercise control over the nature and timing of the break. The variety of breaks taken was considerable and most were appreciative of the ability to use the break to meet their individual need, often undertaking an activity away from the home to help counter the issues of social isolation (Arksey *et al.*, 2002, [Levin *et al.*, 1994](#)). This indicates that the prime objective of the integrated service had been achieved. It is worth acknowledging that 23% of the carers were unwilling to leave their cared-for person for a prolonged period of time. [A finding seen in previous research \(Levin *et al.*, 1994\)](#). They often chose to use the funding in other ways, sometimes involving the purchase of household items or having a break alongside the cared-for person. The innovative approach taken by the Council and CCG enabled the carers' to meet their individual needs in this way.

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Receiving a Carers' Break had a positive effect for many carers, with some recounting benefits for their own health and wellbeing. Whatever form the break took, carers' ability to cope with the stress of caring seemed to have been improved, supporting previous research findings (Robertson 2010). Others recounted that they felt the break had had a beneficial effect on the cared-for person, either associated with improvements in their own well-being or as a result of direct benefits from the break, such as through financing the purchase of equipment for the cared-for person. For some carers, the positive effects of the break were limited, though they appreciated the support offered, which had enabled them to either meet their own needs or those of the cared-for person, and cope with some of the challenges of the caring role (Mannion, 2008).

The administration of the service through the Council seemed to work well for those interviewed. The assessment process for eligibility to receive a break was clear and able to accommodate specific individual preferences and need. For most it was a very positive experience, however, there is a need for assessors to be alert to those carers who may find the process intimidating or upsetting.

A number of areas for further development of the scheme were also identified. Despite a co-ordinated information campaign around the Carers' break scheme, the challenges of

reaching an isolated group were apparent, with carers learning of the scheme through a variety of avenues. In taking the service forward it would be beneficial to further develop and implement a systematic approach to providing carers with relevant information, which should continue to exploit existing services such as GP practices and voluntary services.

There appeared to be inconsistency in the quality of information provided to carers during the assessment, with some being asked to keep receipts and others not. This suggests the service should develop detailed information on what is required and ensure those completing the assessment are familiar with this.

The carer experiences reinforce what is already known about the negative impact of caring on carers' health and well-being (Parker *et al.*, 2010, Arber & Venn 2011, King & Pickard 2013). This is particularly evident when the cared-for person is very dependent on the carer. Whilst appropriate support can mitigate the impact on caring (Levin *et al.*, 1994, Roy & Gillespie 2011), this is often absent. Despite changes in government policy (DH 2008, 2010) it is interesting to note that two respondents felt the formal support received was unhelpful. It was evident that when caring by a relative or friend is absent, reliance on more formal support mechanisms increases.

The main recommendation arising from the carer interviews is that an integrated approach to carer breaks which provides the ability to tailor the break to individual need should be maintained.

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