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ARTICLE

Carer-centered care: general practice support to family caregivers

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Abstract

Rationale, aims and objectives: In February 2009, the UK's Department of Health invited bids for funding to host demonstrator sites in order to test new approaches to working with and for carers within the National Carers' Strategy [1,2]. This paper discusses some of the findings of the local level evaluation of one of the host sites, situated in Northamptonshire, England, UK.

Methods: A mixed-method approach was used to gather data from a range of participant groups. This paper presents the findings of 2 of those methods; a postal survey of carers and an audit of support offered by general practices.

Results: The findings of the evaluation show a considerable improvement in the extent to which carers' roles were identified by their surgeries. However, there is a need to ensure that this information is recorded and used in ways which benefit carers. Carers noted challenges in dealing with practice staff, particularly administrative staff who were not aware of their needs. Practices noted a range of services which were offered to carers; however, carers were not always aware that these were available, suggesting that further publication of these opportunities is needed.

Conclusions: The paper argues the importance of the role undertaken by carers and signals the range of ways in which primary care can support or inhibit these activities.

Keywords

Carer support, expert partners, familial carers, general practice, informal carers, person-centered healthcare

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Introduction

The role(s) that carers¹ play make a significant contribution to local communities and to Society as a whole in the UK. The number of full time unpaid carers in the UK exceeds the size of the workforce in the NHS and continues to grow [3], showing the need for targeted efforts to support their endeavours. In order to implement effective, personalised approaches for both the cared for and those who undertake caring, there is a need to recognise not only the needs of carers as carers, but also as individuals and patients in their own right. This paper draws on the findings of an evaluation of the Carer Strategy Demonstrator Site (CSDS) in Northamptonshire, England, UK (a national evaluation report of this programme is available [2]). The overarching aim of the

study was to evaluate the implementation and effectiveness of the pilot Carer Strategy Demonstrator Site in Northamptonshire, England, UK, with a view to informing its future development.

A number of factors can affect the likelihood of an individual becoming a carer including age, gender, ethnicity and employment situation [4,5]. A majority of carers are related in some way to the person that they care for, whether this be a member of their immediate family or not [6]. The role(s) that carers undertake further differentiates their experiences and, in turn, their needs. Carers may provide a high level of practical, medical and emotional support for the person that they care for, support the person that they care for in accessing services, or may even take the lead in commissioning a personal package for them, becoming 'expert partners' [7,8]. The profile of carers as experts in health has been raised within a number of policy documents. The accompanying handbook to the NHS Constitution [9] discusses the importance of treating carers as experts and partners. Similarly, the National Carers' Strategy promotes the significance of carers as

¹ The term 'carer' represents a varied and complex set of needs and roles; there is no single carer 'profile' [1]. Here, the term 'carer' relates to those individuals who care on an informal basis, rather than those who are formally employed to do so.

expert care partners [1], signalling the developing profile of carers and the importance of their involvement in decision-making relating to the needs of the individual that they care for.

While there are undoubtedly positive aspects of undertaking a caring role, including a sense of satisfaction and enjoyment [10], a wealth of literature also reports negative relationships between the health of a carer, the type of care that they provide and the number of hours that they spend caring [11]. The support that carers receive from services is an important element in supporting health and wellbeing [3]. A lack of professional understanding of carer needs, limited recording of carer responsibilities and minimal information for carers accessing support are all barriers to carers accessing services in their own right [12]. The health of carers is important not just for carers themselves, but because poor health can have an impact on the ability of the carer to care.

Carer demonstrator sites

In February 2009, the UK Department of Health invited bids for funding to host demonstrator sites aimed at testing new approaches to working with and for carers within the National Carers' Strategy [1]. Twenty-five sites were commissioned and a national evaluation undertaken [2]. Each site was also required to conduct a local evaluation of process and impact. The Northamptonshire demonstrator site was one of 25 across England and one of 7 *Better NHS Support for Carers* sites (others focused their efforts on the delivery of health checks or breaks for carers) [1]. The Northamptonshire project employed dedicated Carer Assessment and Support Workers (CASWs), trained to support carers and primary care professionals working with them. Their role was 2-fold: to identify and support carers within the County and to liaise with General Practice surgeries to improve services for carers. This paper reports on changes during the timeframe that the CSDS site was in operation (evaluation period: August - November 2011) via a discussion of 2 key themes; carers as expert partners in care and carers as patients.

Methods

The project team invited the views of carers through a short questionnaire survey about their experiences of primary care services. All carers known to the NHS and social care organisations in the County were invited. The questionnaire asked carers to reflect on any changes in the support that they and the person that they cared for received from GP services during the time that the CSDS site had been in operation (approximately 18 months). The views shared via this medium offered rich insights into the areas of support offered to carers through general practice and where improvements could be made.

Data were also collected from GP practices in the County. These GP practices were surveyed in order to gather baseline information of the support that was offered

to carers (the dissemination of this survey coincided with the timeframe that carers were asked to reflect on). A total of 57 practices were identified for the survey. The questions focussed on the services available to carers from their GP practice. Twenty-one practices provided information (37% response rate). The carer survey was sent to 1,797 carers who were recorded on carer databases held by a local third sector carer support organisation. The GP survey was distributed to 57 practices across the County and responses were drawn from practices of varying sizes, with between 2 and 12 GPs per practice (the mean number of GPs per practice was 6.1, sd = 3.2). Table 1 summarises the response rate of the surveys.

Analysis

Responses to both surveys were entered onto an electronic spread sheet and 10% independent error checking was completed. Descriptive statistics were used to summarise the data. In addition to the closed questions posed to carers in the postal surveys, respondents were offered the opportunity to share any additional views in an open comments section (*'Is there anything else that you would like to tell us about your experience, as a carer, of primary care services [GP practices]?'*). These comments were subjected to thematic analysis. The initial coding was undertaken by a single member of the research team and sections of coded data were independently reviewed.

Ethical review

In the UK, studies defined as evaluations do not normally require formal NHS ethical approval. This project was defined as an evaluation by the local NHS Research and Development Lead and therefore the protocol was vetted by a University Research Ethics Committee. Full approval was obtained.

Results

Sample

Carers responding to the questionnaire survey associated themselves with a range of caring responsibilities, illustrating the diversity of their experiences. Some cared on a full-time live-in basis, while others supported the health needs of a relative living in assisted living or residential care. Further, carers recording their experiences noted a range of relationships with the people that they cared for. Carers held caring roles for parents, a spouse, a son or daughter (both children and adults). In addition, a small number of carers noted that they were in a dual-caring relationship (e.g., where a husband and wife carried out caring responsibilities for each other).

What follows is an account of the findings drawn from the carer and GP surveys which relate to General Practice

Table 1 The response rate of the surveys

	Date of distribution	Sample	No. of respondents	Response rate (%)	
Carer survey	Change over time (18 months)	August 2011	1,797 carers	552	31
GP survey	Audit of current services	October 2011	57 practices	21	37

Table 2 Carers as patients: summary of responses

Question	Yes, always has % (n)	Yes, provided in last 18 months % (n)	No, never has % (n)	Don't know % (n)
Does your Practice offer home visits for carers?	7 (34)	1 (6)	22 (113)	70 (353)
Does your Practice offer flexible appointment times for carers?	10 (51)	3 (17)	24 (120)	63 (320)
Does the practice offer priority appointments for carers?	3 (13)	3 (13)	27 (140)	67 (343)
Can you bring the person you care for to the surgery and still have a private consultation?	33 (162)	1 (6)	14 (67)	52 (251)

Table 3 Services offered by GP practices to carers

Service	Frequency	% of practices
Home visits for carers	14	67
Flexible appointment times for carers	16	76
Priority appointments for carers	10	48
Bringing cared for person to surgery and still having a private consultation	18	86

support offered to carers, both in relation to their caring role and their own needs as individuals / patients. The carer survey asked carers to comment on whether the services that they received had worsened, stayed the same or improved during the preceding 18 months (the timeframe that the initiative had been in operation).

Carer identification

A number of questions in both the GP and carers surveys focussed on aspects of support from general practice that carers received in their role as carers. Examples from the carer survey included whether their surgery was aware of their caring status, if carers felt that their caring role was taken into account in their dealings with general practice and the extent to which they were involved in the care of the person that they cared for.

Carers were asked whether their GP surgery was aware of their caring status. Although 43% of carers reported that their practice had always known that they were a carer, a further 25% reported that their practice had only become aware of their status in the last 18 months. These figures suggest a considerable improvement during the previous 18 month period. Eighty-six per cent of GP practices surveyed during the study reported that they had a protocol in place for identifying carers; over 50% reported that patients' carers were identified on the patient's record and 43% reported that patients' caring responsibilities were always recorded on their records.

Carers were also asked whether they felt that their caring role was taken into account by the doctor or nurse at their GP practice. Fifty-two per cent did not know whether their caring role was taken into account and 22% felt that there had been no change during the preceding 18 month period. The importance of a carer's role being recognized by professionals was also represented in reflections of their interactions with healthcare professionals. Parents who provided care for a child with a disability, for example, highlighted tensions where the additional issues related to providing care for someone with increased needs were not considered by healthcare staff during their interactions with them. Similar thoughts were also forthcoming from those who provided care for a spouse:

“The fact that I care for 2 autistic children is irrelevant to everything, no help, no support, no understanding, oblivious to the fact that I am a carer, very poor. They do not see parents as carers, just parents.”

“I mentioned being the carer for a disabled child earlier in the year - was told ‘all parents are carers’. Haven't broached the subject since as felt completely misunderstood.”

“There is no real evidence that my role as a carer is distinctly recognised at my GP practice (perhaps my role is taken for granted as I am the husband of the person cared for).”

In addition, a key theme arising from the open-text question on the carer survey signalled the importance of practice staff understanding the needs of carers when they made contact. In particular, carers highlighted the challenges experienced in making their needs known to reception staff:

“Receptionists need urgent training in how to help and deal with carers.”

“Receptionists do not take any notice of situations which can make the visit to the practice stressful for both carer and Alzheimer’s patient.”

“I am not treated any differently to any other patient. When I had cause to complain it was not taken seriously. No extra consideration is given and a receptionist laughed at my lack of availability for appointments.”

There are, therefore, potential impacts of this issue for both carers and those who are cared for.

Carers as expert partners in care

Carers were asked whether practice staff involved them in the care of the person that they cared for. Ninety per cent (446) of respondents answered this question. Fifty eight per cent reported that the practice always had done this, compared to 33% of practices who never had. Ten per cent (43) said that the practice had started to do this in the last 18 months.

An important aspect of involving carers related to correspondence between the patient and GP surgery. Carers were asked whether they were sent a copy of the letters written about the person that they were caring for when these were sent to refer them to other services. Eighty-two per cent of respondents (411) responded to this question. Sixty-six per cent of those responding to this question reported that this had never happened, 30% that it had always happened and a further 4% (16) that it had started to happen in the last 18 months, illustrating limited change during the evaluation timeframe.

In turn, general practices were asked if they involved carers in discussions or decisions about the person that they cared for. Nearly half (48%) reported that they mostly did. Seven practices (33%) reported having an information sharing protocol in place for carer-related issues and 43% of practices said that they sometimes copied carers into referral letters relating to the person that they cared for (whilst one-third of practices (7) said that they never did this).

The open-text responses across each survey recounted the challenges posed where carer involvement was minimal. Some suggested that GP surgeries cited issues of confidentiality to justify their lack of involvement. Other carers recounted challenges and associated frustrations of attempting to define their involvement:

“I do not always get information appointment times *etc.* They are sent to my mum mostly who tends to throw things away if she feels they are nothing to do with her.”

“The person I care for has Alzheimer’s dementia. If the surgery send letters regarding her mental health they send me the letter - but if it is anything to do with her physical health, for example, healthy heart clinic or flu jabs they send the letters to her and she cannot deal with them properly and it is lucky if I find them.”

A number of carers across each survey suggested that where they were not involved by healthcare staff they would try to ensure that they could access the information sent by surgeries by reviewing written correspondence sent to the person that they cared for.

Some carers noted the ways in which information sharing between themselves and GP practices could be improved, for example, by being able to see the same GP each visit. Continuity of care was considered important because it minimised the need for carers to restate the needs of those that they cared for at every consultation or to stress the importance of their involvement. Both of these issues were a source of stress for carers. Delays in obtaining appointments often resulted from attempting to see a particular GP regularly.

Carers as patients

Carers were asked a range of questions which focussed on the services that were provided to support their own needs, for example, whether information about caring was made available to them and the flexibility of practices to meet the needs of carers who needed to seek medical help in their own right (including offering home visits or flexible appointment times for carers and opportunities for carers to have a private consultation where they needed to bring the person that they cared for with them to the GP surgery).

The responses to the carer survey showed a trend towards carers having limited awareness of which aspects of support GP surgeries offered. For example, 70% did not know if their practice offered home visits for carers, 63% did not know if flexible appointment times were provided and 67% did not know if their practice offered priority appointments for carers. Table 2 summarises these responses.

Carer reflections on the ways in which their needs were (or were not) met were also apparent in the open text question across each of the surveys:

“No one cares about carers. As long as you are able to do it, they leave you to get on with it. When you take ill, no one cares, you have to manage.”

“The person I care for goes to a day centre three days per week from 10am-3pm. It is very difficult to get an appointment to see a doctor within those times...I cannot bring the person I care for with me, as he is too violent.”

Additionally, some noted improvements that had been observed during the evaluation period:

“It is easier to get appointments, flu jabs are offered earlier.”

“Carers’ leaflets and information on a board have been prepared within the last 18 months.”

Although carers cited many instances of very supportive care by individual GPs, there were others who did not feel that their own healthcare needs, or the impact on their wellbeing of being a carer, were understood or taken into account by healthcare professionals.

In turn, the GP survey asked practices about the range of services that were offered to carers. A high percentage of practices reported that carers had the opportunity to bring the person that they cared for to the surgery and have a private appointment and that flexible appointments and home visits were offered for carers. Less than half of practices offered priority appointments for carers. These responses are summarised in Table 3.

In addition, GP practices were asked to share information about any other carer support initiatives that were in place at their practices. None were operated and one practice manager expressed surprise at the question, feeling that it wasn’t the responsibility of the practice to offer this. Others cited financial pressures as a reason for not offering additional support.

Discussion

The findings of this study have highlighted a number of areas for discussion in relation to the support that is offered to carers by GP practices. The findings of the study show a considerable improvement in the extent to which carers’ roles were identified by their surgeries over the 18 month period that the demonstrator site was in operation. Eighty six percent of GP practices surveyed reported that they had a protocol in place for identifying carers. This is encouraging given that the identification of carers by GPs has been cited in previous literature as a key barrier to the level of support that is offered, with up to 45% of GPs in previous studies feeling confident in being able to identify carers in their practice [13].

In this study, under half of the surveyed GP practices reported that the caring responsibilities of carers were noted on their patient records. While responses to the carer survey suggest improvement in the identification of carers, there is a need to ensure that this information is recorded and used in ways which benefit carers. Where clinical staff are not aware of the caring responsibilities of patients, their access to effective services which meet their needs can be inhibited [14]. Over half of those replying to the carer survey did not know whether their caring role was taken into account by clinical staff when they visited for an appointment.

At the outset of this paper we signalled the significance of the contributions that carers make at an individual and community level. Their expertise and knowledge of those that they care for is key to ensuring personalised care. Fully supporting carers in their role is therefore fundamental to the needs of the person that they care for, who is ultimately vulnerable to the type of care

that their friend or relative offers [15,16]. A study in The Netherlands [17] found that carers of individuals with mental health issues reported a lack of information, consultation and support. These issues were perceived to hinder their active participation in the treatment of the person that they cared for.

Encouragingly, 10% of carers had noticed an improvement in the extent to which they were involved in the care of the person that they cared for during the 18 months that the demonstrator site had been in operation. Many published papers discuss the challenges associated with professional / carer relationships and which impact upon the extent to which carers are involved in practice. The theme of ‘conflicting agendas’ has been used, for example, in relation to the communication observed between informal caregivers and mental health staff in Australia [18,19]. Carers in their study discussed limited opportunities for them to participate in planning support for the person that they supported. A key issue here was the barriers that they experienced in relation to unwillingness from some health staff - in this case nurses - to support participation, an issue which was also replicated in the current study.

Services which support carers to maintain their own health are clearly prioritised in both national and local level strategies in the UK. As we have discussed above, carers may experience a range of medical problems which relate specifically to their caring role [1]. Where supportive services which enable them to maintain their health are not forthcoming this may lead to undesirable outcomes not only for themselves, but also for the person that they care for. The importance of recognising the needs of carers as individuals - and patients - in their own right, is therefore of the utmost importance. Previous research has, however, signalled the issues associated with General Practices supporting carers effectively, suggesting that whilst GPs often have an awareness of the emotional and physical impacts that caring may have, they are constrained by time and limited resources with which to identify carers [13,20].

Encouragingly, a high percentage of practices responding to our survey reported that home visits, priority appointments and the opportunity to bring the person that they cared for to the GP surgery and still have a private consultation were offered. Conversely, large numbers of carer respondents did not know whether these services were offered by their surgery. In 2005, a detailed review of studies which considered potential barriers to carers accessing health services in their own right was completed by the National Coordinating Centre for the Service Delivery and Organisation Programme [12]. They identified 5 issues of particular importance in this area including *professional response* (professionals showing a lack of understanding towards carers needs as carers), *service organisation and delivery* (services did not record patients’ caring responsibilities or provide for them), *language or culturally held beliefs and practices* (e.g., non-English speaking carers could not communicate their emotional needs), *characteristics of carers* (carer’s approach, behaviour and values in accessing services) and *lack of information and knowledge* (lack of information in

relation to support). It is not possible to compare the responses of carers directly to the services that were offered by their own practice, however, a broad comparison of the services offered by GP practices and the practices cited as available by carers suggests that there is room for improvement in the methods that practices use to share information about the services that they provide.

Carers' use of GP services will likely change at any given time according to the amount of care that they provide, who they are providing it for and the length of time that they have been undertaking these duties [14]. There is a growing awareness that information provided to carers by health and social care organisations often varies in quality and accessibility [21] and accessible information which is regularly updated is therefore of paramount importance in supporting carers to support themselves and those that they care for [22].

Conclusion

While this study was completed as part of a wider evaluation of the national roll out of the Carer Demonstrator Sites in the UK, it has signalled a range of areas for improvement in supporting carers with their needs. The detailed information gleaned from a large number of carers and a range of GP practices, has highlighted the importance of practices identifying where their patients have caring responsibilities and where their patients have an informal / familial carer. The evaluation of the demonstrator site pilot began to show important improvements in this area; however, work is still needed to ensure that, following collation of this information, a targeted response to carer support is implemented. In addition, effective methods of publicising available services to carers are essential to ensure that they are supported both as caring experts and as individuals with diverse and changing needs.

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