New networked technologies and carers of people with dementia: an interview study

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ABSTRACT

Dementia is one of the greatest contemporary health and social care challenges, and novel approaches to the care of its sufferers are needed. New information and communication technologies (ICT) have the potential to assist those caring for people with dementia, through access to networked information and support, tracking and surveillance. This article reports the views about such new technologies of 34 carers of people with dementia. We also held a group discussion with nine carers for respondent validation. The carers' actual use of new ICT was limited, although they thought a gradual increase in the use of networked technology in dementia care was inevitable but would bypass some carers who saw themselves as too old. Carers expressed a general enthusiasm for the benefits of ICT, but usually not for themselves, and they identified several key challenges including: establishing an appropriate balance between, on the one hand, privacy and autonomy and, on the other: maximising safety; establishing responsibility for and ownership of the equipment and who bears the costs; the possibility that technological help would mean a loss of valued personal contact; and the possibility that technology would substitute for existing services rather than be complementary. For carers and dementia sufferers to be supported, the expanding use of these technologies should be accompanied by intensive debate of the associated issues.

KEY WORDS – dementia, carers, information technology, qualitative methods.

Introduction

Dementia care is one of the greatest challenges created by increased life expectancy and is a priority for many health-care systems, not least for the United Kingdom (UK) National Health Service (NHS) (Department of Health 2009). Alongside experiencing failures of memory and speech and a reduced ability to manage the activities of daily living and to control

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emotions and behaviour, the person with dementia is increasingly de-
pendent on others. Caring for a person with dementia can be a significant
strain, whether the carer is a family member, friend, volunteer or pro-
fessional (Livingston, Manela and Katona 1996), and there are consider-
able costs to society (Knapp and Prince 2007). Another recent feature of
many countries' health and social care systems has been substantial in-
vestment in care-related information and communication technology
(ICT) systems and devices. The dominant discourse is that technology is
likely to be a key part of the solution to the rising care needs, enabling not
only shifts in the management of long-term chronic conditions from the
professional to the patient and from hospital to home, but also prolonging
independence and promoting community living (*e.g.* Department of
Health, Older People and Disability Division 2005). It has been shown
that such interventions have particular benefits when caring takes place at
a distance (Watari *et al.* 2006), and in remote and rural areas where both
social contacts and access to health and social services are problematic
(Schopp, Demiris and Glueckauf 2006). The claimed benefits include a
reduction in the need for formal health services and social care for frail
older people (Brownsell, Aldred and Hawley 2007), improvements in carers'
quality of life, and reduced placements in institutional settings (*e.g.* Bowes
and McColgan 2006; Woolham 2005). Such interventions tend to move
responsibilities and risks from the state to the individual, however, and
some interventions such as remote monitoring have been seen as violating
privacy (Essen 2008).

We defined networked technologies as ICTs that allow the transfer of
digital information between geographical locations using physical or
wireless connections. They include networked telecare applications as well
as the internet. Examples include Web 2.0 social networking resources,
email, movement sensors and detectors of gas or temperature levels,
tracking devices with satellite technology, and webcams used in private
dwellings. Such technologies are emerging as aids to care provision, by
reducing a carer's isolation, improving access to health information and
to health services and formal social care, and providing facilities for re-
mote monitoring of the cared-for person. Web 2.0 technologies allow
carers to share experiences and to organise themselves socially and pol-
itically as virtual communities. Networked technologies are also used for
activities which ease the burden of caring but are not directly related
to health-care or social-care delivery, *e.g.* internet shopping. Networked
technologies are certain to become more widely available, particularly
given the convergence of communications platforms such as digital tele-
vision and mobile telephony, so an understanding of users' perspectives is
essential.

The study

This project sought to investigate the perspectives of carers of people with dementia about new networked technologies. We attempted to understand how carers view networked information and communication technologies, whether and how they use them, the possible benefits and disadvantages, and the barriers and facilitators to future implementation. As there has been little previous research in this area, we adopted a qualitative approach that used semi-structured interviews to identify and explore in depth the views of carers. The study was in one region of England for practical reasons. We recruited carers in the City of Coventry and the surrounding County of Warwickshire. The area has urban and rural populations, a large minority ethnic population (16 per cent of the total population, predominantly South Asian), and Coventry has relatively high levels of social deprivation. Following a literature review and interviews with health services staff, social-care practitioners and representatives of local authorities and voluntary organisations, and three pilot interviews with informal carers, an interview schedule was developed.[1]

Selection of interview participants

Semi-structured interviews were undertaken with informal carers who were the main care-givers for people with dementia living at home. We defined informal carers as those individuals who provide, predominantly in the home setting, extraordinary, uncompensated care that involves large amounts of time and energy for months or years, and requires the performance of tasks that are physically, emotionally, socially or financially demanding (Biegel, Sales and Schulz 1991). We used purposive sampling, aiming to capture the views of participants of diverse ages, ethnicity, use of technology, and relationships to the person being cared for. We sampled carers who were caring for people at different stages of the progression of dementia, including some with early-onset dementia, and carers for whom English was not their first language.

Most participants were recruited with the help of community psychiatric nurses employed by NHS community mental health teams and of the group leaders of user and carer voluntary organisations. Others came forward having seen flyers, after hearing an introductory talk, or having seen adverts circulated by email or on the internet (on either the university website or on users' organisation websites). Once potential participants had been identified, we purposively selected respondents who covered the diversity of the area's population. Recruitment and interviews continued

until theoretical saturation was reached, that is until further interviews failed to yield new themes (Glaser and Strauss 1967).

The interview schedule

The interview schedule covered socio-demographic attributes, the role of the carer, views on technology in general, and attitudes towards and use of new technologies including specific tools such as the internet and mobile telephones. The participants were also asked to comment on five vignettes that illustrated applications of networked technologies: remote monitoring such as movement sensors that send alerts to distant carers or cameras and can be watched using internet or mobile telephone platforms; 'smart home' technologies, namely devices that automatically switch off water or gas taps or can incorporate intelligent systems that recognise changes in usual behaviour; internet health information websites; online medical consultations; and peer support accessed by means of Web 2.0 online social networking sites (*see* Table 1). The majority of the interviews took place in the participant's homes, with one at the university and one at a library. The interviews were audio-recorded and transcribed with written informed consent. We acknowledged the time and expertise of participating carers by giving shopping vouchers (£10 per interview).

Group discussion

A group discussion was conducted with nine informal carers after preliminary analysis of the interview data. The aim was to seek the respondents' validation and confirmation of the emergent themes. The discussion group was held during one session of a weekly support group for people with dementia and their families. We introduced the study including methods and preliminary findings and encouraged discussion of all the emerging themes.

Analysis

The transcripts were analysed using the framework approach (Ritchie and Spencer 1993). This is a grounded method for analysing qualitative data that has several steps: familiarisation with the data, identification of a thematic framework that takes into account deviant cases and alternative views, indexing, charting, mapping, and interpretation. Two members of the research team read all the data and the remaining members read samples. The thematic framework was developed by the research team through discussion of the emerging themes. The framework was validated by two team members by returning to the transcripts and applying the agreed codes. There were no significant areas of disagreement during the

T A B L E 1. *The interview vignettes*

Introduction

In the next part of this interview I would like you to think about three situations we have prepared, and make any comments on them that you want. I will read the situations to you and then ask you what you think of them. Some topics may be relevant to your own situation but others may not, and if that is the case, do say so; however, it would be helpful if you also use your experience to think about the broader implications for people with dementia and their carers.

Situation 1: The smart home

The idea of a 'Smart Home' is of a normal house that has been adapted for a person living alone who has dementia, to help him or her to manage everyday living while remaining as independent as possible. For example, in the bathroom there are monitors in the bath and basins so, if the water level is about to overflow, the taps are automatically switched off. In the kitchen there are monitors that can sense if food is burning or if the gas is turned on but not lit, and they can turn off the gas or the power. In the bedroom, a sensor can tell if the person gets up in the night, and lights in the bedroom and the bathroom are then automatically turned on. There is also a speaking clock that tells the time and date, and it can give diary reminders such as saying 'your daughter is visiting in half an hour'.

Situation 2: Remote monitoring

It can be difficult for carers to spend all their time with the person they are caring for. Maybe they do not live in the same house; or maybe they have to go to work or go shopping, and the person with dementia has to be left alone for a while. New technology might allow the carer to continue looking out for the person, but from a distance. For example, if a sensor detects that the person with dementia has gone out of the front door, an automatic message can be sent to the carer's mobile phone. If sensors detect that the person has not moved for some time during the day, the carer can be alerted in case the person has fallen. At night, sensors can detect if the person has got out of bed and not returned within a set time, and then a call can be made to wake the carer. Another possibility is using video cameras. A camera could be installed in the living room or hallway and the carer could check from time to time that everything is alright, perhaps using the internet or a video feature on a mobile phone. Another possibility is for the person with dementia to carry a gadget which would allow the carer to know exactly where he or she is, using satellite navigation technology.

Situation 3: The internet

The internet has web pages with information for carers. In addition, people can leave messages for one other to discuss issues that concern them. A previous research study of carers and the internet showed that an internet discussion group provided social support and informal advice, and made carers feel less isolated. Using this kind of system, carers can type messages on a keyboard, and read messages left by others. If two or more carers are online at the same time, they can chat by viewing messages displayed as they are typed; or they can use microphones and cameras to see and hear each other as they talk. In the future it may be possible to consult with doctors and other professionals over the internet – by email, or using cameras and microphones. This might reduce the number of trips people need to make outside the home.

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coding process, and all minor discrepancies were resolved through discussion. The group discussion was summarised by two researchers working from their field notes and the recording, and they took particular note of expressions that confirmed or challenged the preliminary analysis of the interviews.[2]

Characteristics of the participants

Interviews were held with 34 informal carers. Sixteen were recruited through the NHS, and others through voluntary sector organisations (13)

T A B L E 2. *Characteristics of the interviewees*

Attribute	N
Gender:	
Male	12
Female	22
Age group (years):	
20–29	1
30–39	3
40–49	7
50–59	9
60–69	7
70–79	5
80–89	1
90–99	1
Ethnicity:	
White-British	27
Other ethnic origin	7
Relationship to person with dementia:	
Spouse or partner	15
Son or daughter (-in-law)	15
Grandson or granddaughter	3
Friend	1
Sample size	34

and the internet (four), and there was one personal contact. The characteristics of the participants are shown in Table 2. Their ages ranged from 23 to 91 years, with a mean of 57 (standard deviation 15.2). Two-thirds (23) had personal internet access. As to living arrangements, 18 were co-resident with the person with dementia, five others were staying semi-permanently with the person with dementia to provide care, and of the 11 remaining dyads, in four cases the cared-for person had recently died or moved into residential care, and seven lived separately from the carer that we interviewed.

The findings

The carers discussed the current and future use of networked technologies against the background of the challenges they faced in the caring role. They touched on the beneficial and harmful aspects of new technologies, the tensions between the personal nature of human contact and the impersonal character of technology, whether networked technology would complement or substitute for existing care, and dilemmas around privacy and autonomy versus safety. They also expressed concerns about

responsibility, ownership, costs, the opportunities and threats of online information; and the need for requirements for simple and practical solutions. We report all the emerged themes in this paper (no other themes were identified). The interviewees' comments relating to each of these themes are discussed more fully below.

Current and future use of networked technologies

Throughout the interviews, the carers repeatedly referred to the difficulties and stresses of caring for people with dementia, in particular the isolation, emotional impacts, time demands and financial struggles. Both the interviewees and the group discussion participants had a general expectation that new technologies would increasingly be used to support carers. As Katherine, a daughter-carer aged 49 years, put it, 'because technology is relied on increasingly for just about everything we do, I can't imagine it not happening'. The trend was seen as inevitable and was broadly welcomed, provided that the technology was useful and driven by needs rather than by technological possibility. Eric, a son-carer aged 59 years, believed that technology should not be adopted for its own sake. He elaborated, 'in its place, I think technology should be a tool and not … it shouldn't be the leader and your life shouldn't be governed by technology, you should use technology to help [you in] your life'.

'Usefulness' was understood as a trade-off between benefit to the carer and the costs (in time, effort and expense) to the carers. Despite the acceptance that technological innovation was inevitable, only a few examples of innovation were described. Some interviewees were frequent internet users, and some had experience of assistive devices (technological aids designed to promote greater independence), but the majority saw networked technologies as having a role for others rather than themselves. In the interviews and the group discussion, technology, including the internet, was seen as something that would be more useful for the 'next generation' of carers. This did not reflect a negative attitude to adoption, but rather an attitude of not having the requisite skills or time. Information on the internet was considered as potentially helpful, but not everyone knew how to find it, and not everyone had access to a computer. The carers pointed to the need for training and for ongoing support to enable them to use technology.

Personal versus impersonal

Networked technologies were mostly seen as impersonal and machine-driven, which was contrasted with the human contact provided by non-technological solutions. Carers valued human contact and were concerned

about what might be lost when using technology. Imogen, a daughter-in-law carer aged 56 years, elaborated this view particularly well:

It's just cutting out people all of the time, isn't it? I'm sure that will happen, but it's just so lovely to be … for me personally, I would rather be face-to-face and be able to talk to people. … I think people need people – not just gadgets, you know? That's the worrying thing really, with the elderly in particular. The gadgets replace people, and there isn't any comparison.

One group discussion participant condensed this idea into a slogan: 'We don't want technology – we want people'. This attitude was prompted both by remote monitoring equipment and, for some, internet social contact, which was described by Roger, a spouse-carer aged 64 years and an occasional internet user as like 'talking to a machine'. He added, 'to me, the internet is a faceless thing. You know, I'd rather be talking to a person rather than talking to a machine. I mean I know there's a person on the other end of the machine that you're talking to, but to me, it's still a machine you're talking to'.

Complementarity or substitution

Carers were concerned that networked technologies might be used to replace rather than complement existing care provision and, as with Imogen's remarks quoted earlier, they were worried about whether it would be appropriate or adequate. It was recognised that 'remote monitoring' is becoming established in many commercial premises and public spaces, but carers felt technology should assist them not substitute for them. This was linked partly to a fear of technology failure, and partly to a concern that technology would replace existing service provision. Hannah, a spouse-carer age 72 years, was particularly worried about the reliability of new technologies:

You can trust another person but I think technology would be a bit … well, what if the technology went wrong? You can't be 100 per cent sure that the person would be cared for when you walk out of the door, can you? If somebody else is there, then you know.

Privacy and autonomy versus safety

The carers could see advantages in remote monitoring systems, but had concerns about privacy and autonomy. They were aware that there needed to be a trade-off between ensuring the safety and preserving the privacy of the cared-for person, and that the optimum balance would likely change as the dementia progressed, with more intrusion as their caring role intensified. Scenarios of remote monitoring and intelligent systems were

seen as being able to facilitate caring at a distance, allowing greater flexibility for carers who are often very constrained in their movements. At the same time, however, such benevolent surveillance was also seen as a threat to the privacy and autonomy of the person being cared for. The autonomy of the carer could also be threatened by an expert computer system that automated elements of their role. The debate around privacy and safety was most clearly evident in their reactions to the remote monitoring vignette, particularly the account of networked video-camera surveillance, which prompted many comments about 'intrusion' and 'Big Brother'. While there was a more-or-less uncritical welcome for remote sensor devices, many saw cameras as a step too far. This was explicitly the view of Angela, a spouse-carer aged 68 years: 'Well, I think it [video camera surveillance] is a bit intrusive really. It's … I don't know, it smacks of Big Brother or something. I mean it might sound silly that, but it does'. Others were willing to accept, however, the different balance between privacy and safety. Will, a spouse-carer aged 59 years, expressed this view very well:

I think in the situation of dementia your dignity has almost gone out of the window anyway. You have to sort of – if it is in the best – if you feel it is in the best interests of the person you are caring for, then you do it. You don't sort of think of the ethics of whether it is spying or anything. Just get on and get it done, because you can think, accidents can happen in a second.

This issue was a dominant theme in the group discussion, during which nonetheless opinions were divided. Most thought that remote monitoring would be used by responsible carers for the benefit of the person cared for, rather than to intrude on the person's privacy. Many also felt that some people with dementia can be a danger to themselves and to others, and that in these circumstances, issues of civil liberty were less important than safety and peace of mind. In addition, it was recognised that not all people with dementia have the support of family carers, and remote monitoring was seen as preferable to neglect. Many agreed, however, that effective safeguards were required to prevent the misuse of monitoring technology, and that there should be no question of compulsory surveillance. The broader concern was expressed well by Joseph, a partner-carer aged 77 years: 'The basic idea is very good … but again you've got to decide where the information goes to, who's going to take note of it and what can or can't be done about that'.

Responsibility, ownership and costs

Networked technologies were generally perceived as having financial costs for carers (*cf.* Deguili 2010). Many of the interviewees had already reported financial difficulties with the caring role; they were concerned about who

would pay for such innovations and generally assumed that they them-selves would have to fund them. They felt formal services were unlikely to provide new devices because of financial constraints, and several cited the resource limits they had experienced when trying to obtain medication for Alzheimer's disease. Vivien, a granddaughter-carer aged 40 years, ex-pressed a common concern: 'It might be very costly – costly on the old electric[ity] as well, I should think, if it comes on automatically'. Questions were asked about who would be responsible for monitoring remote de-vices, such as who would respond to alarm calls, and would the technology decrease or increase the costs and workload for carers? It was striking that no participant talked about any time or money savings through using networked technologies.

Access to online information

Having access to information was seen as important by the interviewees, who had had varied experiences of using the internet that to some extent were related to age, with older carers in general describing less experience and lower self-confidence in the internet. There were also varied responses to the value of the internet as an information resource. Some people welcomed the opportunity to be able to access 'everything', but others were apprehensive and worried that they could be alarmed and unnecessarily upset. For example, Roger, a spouse-carer aged 64 years, expressed a fear about what information he might find (especially regarding prognoses of his health condition):

I haven't used the internet to get information or anything like that … because sometimes the more information you get, the more … anxieties and worries you get, whereas the less you know … I think you sort of cushion yourself. I dread to find out what … you know … I'm frightened to find out anything new, anything that will show me how hard things will get or can get. I don't think I want to know just yet.

The symptoms and situation of someone living with dementia change over time, and the carers understood that their information requirements also change. The group discussion participants reported the need for support in finding timely, appropriate and reliable information, and the value of carers' groups in providing this.

Simplicity and practicality

Carers need assistance with simple, practical tasks and could see a role in this for new technologies, but they were not seeking cutting-edge devices for new or complex problems. Participants felt that 'low tech' solutions

might be as important as advanced or new technologies – equipment such as fire alarms, burglar alarms and microwave ovens were considered useful for people with dementia and their carers, although it was acknowledged that not all had or needed such devices. In the participants' reactions to the vignettes, simple movement sensors or alarm systems that are networked to allow remote alerts were the most enthusiastically received. There was great concern about the person with dementia 'wandering', and tracking devices were welcomed, albeit with reservations about privacy. Carers who perceived a higher likelihood of the cared-for person wandering had fewest reservations. A further and perhaps unexpected concern was the potential for technology to confuse the person with dementia, and for them to interfere with or disrupt its functioning. Hannah envisaged a worrying scenario:

That could actually be distressing as well, because they know that when they switch something on, normally they would switch it off, so they'd be wondering why it's switched off or how has that happened? It could create that confusion, couldn't it?'

Carers wanted more information about what technologies were available, and again the main need was for information about simple, practical devices (without networked features). It was clear that a wide range of different solutions might be required to meet the need for simplicity and practicality, in the context of the diverse challenges faced by people with dementia and their families. A technology lending library was suggested by a participant in the group discussion, and the idea was supported by others.

Discussion

This exploratory project sought to understand the experiences and attitudes of a diverse sample of carers towards new networked assistive technologies and whether they were likely to use them more in the future. Overall a positive attitude was displayed, although there was not unbridled enthusiasm. The participants saw technological innovations as an intrinsic feature of societal change and inevitable. The expectation was that the use of technology would increase, particularly for the next generation of carers who would have the aptitude and skills to adopt them. Some participants were using technology to support their caring role, particularly the internet, but they were the exception rather than the rule and, as found in previous studies, tended to be among the younger carers (Blackburn, Read and Hughes 2005). Carers with no experience of

technology tended to accept uncritically that it would benefit professional carers and younger people or the next generations but not themselves, a stance that may have elements of reluctance to change and anxiety about the unknown. Some carers simply did not want new tools and did not see any benefit in acquiring new skills, particularly as this would use time that most could ill-afford. Although ICT solutions are being vigorously promoted across the UK, there was a widespread lack of awareness of which new technologies could support carers in their role, and carers clearly have unmet information needs about the availability, roles and efficacy of potentially helpful technology (McCreadie, Wright and Tinker 2006).

It appears that new devices and systems would be adopted if carers could see their practical benefit and believed that they would not be financially disadvantaged. Simple, practical solutions, with obvious and quick benefits, are most likely to be implemented. The involvement of carers in the design of new tools may assist this (Orpwood *et al.* 2004). Help with costs, or other incentives to adopt technology would be welcomed. Help with learning to use new tools was also requested, as was ongoing support. Carers wanted to be reassured that safeguards will be in place to prevent the misuse of new technologies. They were keenly concerned about threats to the privacy and dignity of the person with dementia, about the disruption of their habitual routines (many asserted that people with dementia have difficulties dealing with change), and about them disrupting the functioning and integrity of devices and systems. Rialle *et al.* (2008) found the technologies which are most appreciated are those that increase the safety of the person with dementia and allay carer anxiety, those that increase the social connectedness of carers, and those that allow carers to go out and leave the person with dementia on their own for a period. Selwyn *et al.* (2003) studied the use of ICT by older people in everyday life and also found that perceived usefulness was a key factor in adoption, and that 'usefulness' often related to prolonging independent living. They also identified three practical barriers: cost, poor health and lack of skills (associated with little previous exposure to ICTs).

A key finding from the interviews was that new networked technologies are perceived to bring both benefits and disadvantages. Carers appeared to apply their own evaluative frameworks in weighing the balance between these, for example the trade-off between safety and threats to autonomy and dignity. This echoes findings of other authors such as Percival and Hanson (2006) and Essen (2008), who among other things described carers' dual, opposed reactions to both remote monitoring and technology-mediated social support – the realisation that they could reduce carers' social isolation at low cost, but lack the important qualities of human

contact. Sävenstedt, Sandman and Zingmark (2006) reached similar findings in their interview study of professional carers.

The participants felt that while new tools might save formal health-care and social-care resources, they were concerned that the burden on family carers would increase. They wanted new networked technologies to complement existing services, but feared that they would replace them. This is in line with the finding of a recent review of telecare solutions, that in general people want solutions that combine with conventional approaches rather than replace them (Botsis and Hartvigsen 2008). Of course, not all barriers and facilitators to the implementation of new solutions are carer-related, for some concern the person with dementia, and others relate to organisational and cultural factors (Barlow, Bayer and Curry 2005). This project did not set out to identify these, but they are nonetheless very important. The qualitative approach has not enabled numerical estimates of the uptake of and need for new technologies, but understanding carers' attitudes is a crucial component of any future plans for technology expansion or development. We purposively recruited a diverse sample of carers with disparate needs for assistance and information to identify commonalities among their concerns. The aim was to generate evidence that will usefully inform national policies, in some cases by challenging taken-for-granted assumptions, and partly to guide the future research that is required to build the evidence base. Of particular interest was to hear the views of people with dementia.

Conclusions

Many networked technologies that might improve the lives of people with dementia and their carers are becoming available. The interviewed family carers acknowledged this potential but had concerns about the costs and the impact on their time, and lacked confidence in the technologies. There was also a concern that technology to increase support through online social networks and by remote monitoring might replace valued human contact and be intrusive. Carers acknowledged that trade-offs had to be made between issues such as safety, on the one hand, and autonomy, on the other. Carers applied their own evaluative framework to this trade-off, which was clearly influenced by the cared-for person's condition, behaviour and needs, which in turn were related to the stage of the dementia illness. For example, the fear of interference with autonomy was less of a concern among those who had experience of caring for someone with advanced dementia. Carers wanted new tools to complement rather

than substitute for existing provision. Making networked technologies a part of the lives of people with dementia requires active facilitation of their uptake, flexible provision of a menu of technologies to assist with simple tasks, deeper debate about issues such as human contact, resource provision and privacy, and the development of generation-sensitive technologies. More research is required on how networked technology tools can meet diverse carers' needs, attitudes and beliefs. Only if the current barriers to adoption are understood and addressed will more successful implementation be achieved. Pilot studies of networked technology tools that support remote caring or reduce carer isolation need to be followed by randomised controlled trials to evaluate their effectiveness and cost-effectiveness.

Acknowledgements

NOTES

1   Ethics approval for the research was granted by the local NHS Research Ethics Committee (LREC). The full project included a systematic literature review published elsewhere (Powell, Chiu and Eysenbach 2008) and a group interview with paid carers, the findings from which are described in an unpublished report to the commissioners (Powell *et al.* 2008).

2   NVivo software was used to assist the management of data (NVivo qualitative data analysis software, QSR International Pty Ltd, Version 7, 2006). In reporting the findings, all the names used are pseudonyms.

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