

Caregivers' interactions with health care services – mediator of stress or added strain?

Running Head: Caregivers' interactions with health care services – mediator of stress or added strain?

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Experiences and perceptions of informal caregivers of people with dementia - A qualitative study

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Caregivers' interactions with health care services – mediator of stress or added strain?

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Abstract

Background: There are an estimated 46.8 million people worldwide living with dementia in 2015, being cared for usually by family members or friends (informal caregivers). The challenges faced by informal caregivers often lead to increased levels of stress, burden and risk of care-recipient institutionalisation.

Aim: The overarching aim of this study was to explore the experiences and perceptions of informal caregivers of people with dementia when interacting with the health care system, and whether the support received acted as a mediator of caregiver stress. The secondary aim was to investigate healthcare professionals' views and current practice regarding people with dementia and their interactions with informal caregivers.

Method: We employed a qualitative research design, using focus groups and one face-to-face interview with a purposive sample of informal caregivers and healthcare professionals (HCPs) in Lincolnshire, UK. Data were collected between March and July 2015. We used the stress-process model of stress in caregivers as a theoretical framework.

Results: We interviewed 18 caregivers and 17 HCPs. Five themes, mapped to the stress-process in caregivers' model, captured the main challenges faced by caregivers and the type of support they wanted from health care services. Primary stressors included the challenge of diagnosing dementia; caregivers' needs and expectations of an in-depth knowledge and understanding of dementia from HCPs; and need for carer education. Secondary role strain included lack of support and mismatch of communication and expectations. Caregiver involvement in monitoring care and disease was a potential mediator tool.

Conclusions: Fragmentation of dementia care services, lack of training for HCPs and the dearth of information for caregivers means health care services are only partially fulfilling a support role. In turn, lack of support may be intensifying caregiver stress leading to

Caregivers' interactions with health care services – mediator of stress or added strain?

worsening in their health and well-being; thus, potentially increasing the risk of institutionalisation of their care-recipient.

Keywords

Dementia, challenges, support, informal caregivers, healthcare professionals, health care providers, stress-process model of stress.

Background

There are an estimated 46.8 million people worldwide living with dementia in 2015, projected to reach 115 million by 2050 (Alzheimer's Disease International, 2015). In the UK, there are approximately 850,000 people living with dementia, cared for on a day-to-day basis by about 670,000 informal caregivers (usually family members or friends), saving the UK Government around £11.6 billion a year (Alzheimer's Society, 2014). However, only 344,000 patients had a recorded diagnosis of dementia in GP practices in England in 2013-14 (Health and Social Care Information Centre, 2014), suggesting that there were many people with cognitive impairment, being looked after by informal caregivers, who had not **yet** received a formal diagnosis.

In addition to the lack of diagnosis, informal caregivers of people with dementia often have to struggle with: increased levels of depression (Cassie et al., 2008), stress and burden (Cassie & Sanders, 2008; Sörensen et al., 2006); reduced self-efficacy (Sörensen et al., 2006); and feelings of entrapment and guilt (Martin, Gilbert, McEwan, & Irons, 2006).

Caregivers are also likely to have poor self-rated health and high levels of chronic conditions, such as cardiovascular disease (Brodaty & Donkin, 2009). Caregivers also face many other challenges in their role, including financial constraints due to caregiving duties conflicting with work responsibilities (Sörensen, Duberstein, Gill, & Pinguart, 2006), difficulty maintaining gainful employment (Sörensen et al., 2006), and a surrendering of social and

Caregivers' interactions with health care services – mediator of stress or added strain?

leisure pursuits leading to social isolation (Brodaty & Hadzi-Pavlovic, 1990; LoGiudice et al., 1999). Caregivers' poor physical and psychological health, combined with their increased burden of care, have been linked with an increased risk of institutionalisation as well (Brodaty, McGilchrist, Harris, & Peters, 1993).

In England, the National Dementia Strategy (Department of Health, 2009) has identified providing good-quality information and enabling easy access to care, support and advice for those diagnosed with dementia and their carers as key strategic objectives; but studies still show an unmet need for information and support among carers of people with dementia (Department of Health, 2013; Lawrence, Murray, Samsi, & Banerjee, 2008; Newbronner, Chamberlain, Borthwick, Baxter, & Glendinning, 2013). Many carers receive inadequate or no support and information on dementia (e.g. information on legal and financial matters and/or advice on dealing with agitated behaviours of the person with dementia) (Alzheimer's Society, 2014; Bowes & Wilkinson, 2003; Ducharme, Lévesque, Lachance, Kergoat, and Coulombe, 2011; Tetley, 2013), have trouble accessing services/support (Bowes & Wilkinson, 2003; Ducharme et al., 2011; Peel & Harding, 2014; Tetley, 2013), and often report a lack of preparedness to provide effective care (Ducharme et al., 2011).

By identifying and understanding better the areas that caregivers find challenging, we can give carers accessible information, appropriate advice, and support, thus improving their wellbeing and capability to support the person in their care more effectively. It should be noted, however, that not all caregivers are distressed and burdened; some have intrapersonal resources (Sörensen et al., 2006), adapt effectively to situations (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Kramer, 2000), feel more positively towards caregiving, and experience less burden (Cohen, Colantonio, & Vernich, 2002; Kramer, 1997; Rapp & Chao, 2000). These intrapersonal resources act as mediating factors to prevent stress in the caregiving role (Pearlin, Mullan, Semple, & Skaff, 1990). Social support, for example, can act as a mediating factor, helping to ameliorate the negative effect on health, and offering a buffer against burden and stress, by increasing caregivers' available

Caregivers' interactions with health care services – mediator of stress or added strain?

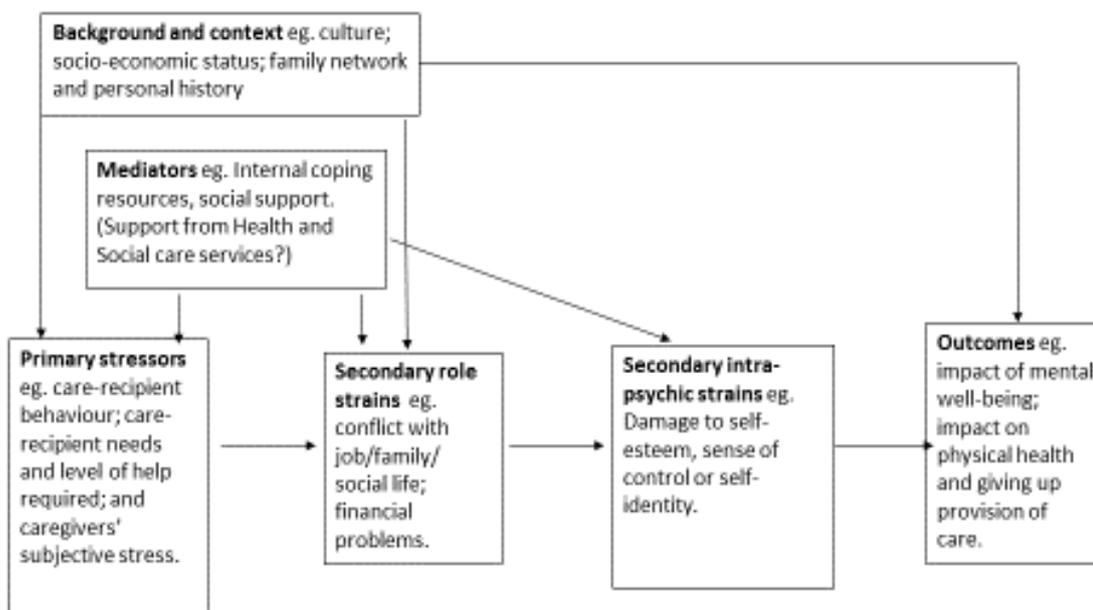
resources (both perceived and objective) to handle stress (Cohen, 2004). Other types of support that would help decrease caregiver burden and stress, could be of a practical, emotional, or informational nature. Healthcare professionals (HCPs), for example, are ideally placed to give information support (Elmore, 2014), together with direct health promotion interventions, regarding the health risk of caregiving (Castro, Wilcox, O'Sullivan, Baumann, & King, 2002).

Theoretical perspective

We used caregiving and the stress-process model for individuals with dementia (Pearlin et al., 1990) adapted by Shah, Wadoo, and Latoo (2010) as our theoretical perspective. The stress process model has four domains: background and context of stress; primary stressors and secondary strains; mediators of stress; and the outcomes or manifestations of stress. The background and context considers socio-economic characteristics of the caregiver as these have an impact on the entire stress process in terms of the personal and social, including family network, resources available to deal with the stressors (see Figure 1).

Caregivers' interactions with health care services – mediator of stress or added strain?

Figure 1 Pearlin's stress-process model of stress in caregivers (adapted from Shah 2010)



Stressors are divided into primary and secondary. Primary stressors are based on the needs of the person with dementia (in terms of severity and behaviour) and the difficulty of caregiving activities, including dealing with problematic behaviour increasing the carer's subjective stress levels. Secondary stressors include role strains and intra-psychoic strains. Role strains refer to potential conflicts with other family members (regarding the care-recipients' well-being and care provision) and job-caregiving conflicts (on occasions where one's caregiving situation affects their work). Economic strains and a constriction of social/recreational life (due to growing caregiving responsibilities) are two further potential types of role strain. There are also secondary intra-psychoic strains (mental trauma), for example in terms of role captivity leading to lower self-esteem, reduced self-identity and loss of control. The outcomes or manifestations of stress are anxiety and depression; reduction in ability to cope; and, a decline in carer health. Such deterioration in both the mental and physical health of the caregiver can lead to reduced or reluctant caregiving.

Caregivers' interactions with health care services – mediator of stress or added strain?

Mediating conditions seek to explain how different people exposed to the same stressors are affected by them differently. Internal coping resources and social support are generally regarded as the two principal mediators. Although not explicitly detailed in the Pearlin (1990) stress-process model, health care services could be seen to be having an influence as a potential mediator, building up internal coping resources within the social support context, particularly in terms of reducing primary stressors and thereby improving secondary intra-psychic strains and outcomes.

Aim of the study

The overarching aim of this study was to provide an in-depth qualitative exploration of the experiences and perceptions of informal caregivers of people with dementia, specifically around the challenges and stressors they face when interacting with the health care system. We also wish to explore whether these experiences act as mediators or strains in terms of caregiver stress impacting on carer outcomes. The secondary aim was to investigate HCPs' views and current practice regarding people with dementia and their interactions, if any, with informal caregivers.

Methods

Study design and recruitment

Most patients with dementia (or those with cognitive difficulties, but as yet undiagnosed) and their caregivers access the primary care system for their clinical care, so we have focused our attention on this aspect of care. We used a qualitative design conducting focus groups, and one individual interview, with informal caregivers of people with dementia and focus groups with HCPs working with patients diagnosed with dementia and their caregivers.

Caregivers' interactions with health care services – mediator of stress or added strain?

Purposive sampling was used to identify and recruit both carers and HCPs, as we were interested in people that are especially knowledgeable about and experienced with dementia and its effects on both carers and their care-recipients, who were also willing to participate (Bernard, 2002; Cresswell & Plano Clark, 2011; Spradley, 1979; as cited in Palinkas et al., 2015). Therefore, our inclusion criteria were broad, as our main focus was the experience of dementia rather than the individual characteristics of the participants. More specifically, inclusion criteria for caregivers were being an unpaid family member or friend caring for someone diagnosed with dementia; whereas for HCPs the only inclusion criterion was working with patients diagnosed with dementia and their caregivers.

Informal caregivers of people with dementia were recruited by various methods, including through carer support groups (from different geographical areas of the rural county of Lincolnshire), the University of Lincoln, and a Patient and Public Involvement (PPI) Group. Healthcare professionals were recruited from two Lincolnshire general practices (in different geographical areas) and the main mental health provider of care for patients and caregivers of people with dementia within Lincolnshire. Although our focus was on HCPs working in primary care, we included staff from the local Dementia and Specialist Older Adult Mental Health Service, as they received referrals from community health professionals regarding patients with dementia. In addition, these staff had everyday contact with people with dementia and their informal caregivers as they provide both specialist short-term in-patient assessment and treatment, as well as individualised care and management plans for patients with dementia and their caregivers.

Approval from the University of Lincoln Research Ethics Committee was obtained prior to starting the study. Full NHS ethics approval was not necessary as caregivers were not recruited or interviewed on NHS premises. Instead, NHS Research Governance approval was sought and obtained prior to the start of the study. Written informed consent was secured by study staff either before or on the same day that the focus groups/interview took place. To ensure the confidentiality and anonymity of information gathered, all participants

Caregivers' interactions with health care services – mediator of stress or added strain?

were allocated a pseudonym. Verbatim transcriptions (of all verbal and non-verbal utterances) of the audio recorded focus groups and interview were undertaken by the research team and experienced independent transcribers, bound by confidentiality agreements.

Participants

Eighteen caregivers were initially recruited and interviewed. One carer decided to withdraw their data and, therefore, was not included in the analysis. The final sample consisted of 17 informal caregivers of patients with dementia and 17 healthcare professionals, including eight general practitioners (GPs), four practice nurses, a phlebotomist, an occupational therapist, a ward sister, a ward manager, and a charge nurse. Most caregivers were female (14/17) and aged between 47 and 84 years. Twelve caregivers were spouses, four were adult children and one was the daughter-in-law of the person with dementia. Focus groups with caregivers lasted from 64 minutes to two and a half hours; the one face-to-face interview lasted 45 minutes. Focus groups with healthcare professionals lasted from 25 to 48 minutes.

Data collection

Data were collected between March and July 2015. Data collection continued until saturation was reached. We considered data to be saturated when researchers stopped generating new codes and themes from different interviews transcripts (Guest, Bunce & Johnson, 2006). Interviews were recorded and transcribed verbatim. The carer focus groups were conducted by three researchers (DL, JM, TK). Two focus groups took place at the University of Lincoln and a third focus group was conducted in the premises where the group usually held their meetings. One face-to-face interview took place in the carer's home, due to the carer's inability to attend any of the scheduled focus group meetings.

Caregivers' interactions with health care services – mediator of stress or added strain?

Semi-structured interview schedules for caregivers consisted of open-ended questions focusing on the type of information and support they felt they had received, their satisfaction with this and what they would like to receive from health care providers. Participants were also asked about the challenges faced by caregivers and their care-recipients particularly in terms of difficult behaviours, communication and practical difficulties, as well as their preferences on potential interventions aimed at improving their quality of life. In parallel to this qualitative study, the research team had been developing an educational intervention for informal carers of people with dementia, aiming to improve their overall health and well-being. As part of this second endeavour, research team members were investigating the potential usefulness of having carers involved more “actively” in their care-recipients' care, for example by using diaries. Therefore, caregivers were also asked their views on having a more formal monitoring role in terms of recording in a diary how their care-recipient's disease was evolving, including mental state, physical and psychological health.

Healthcare professional focus groups took place in general practice premises (two focus groups) and a mental health centre (one focus group with mental health staff only).

Our aim was to focus on the issues informal caregivers typically faced and view them from the perspective of both caregivers' and health care professionals'.

Data analysis

We used thematic analysis, following the Braun & Clarke (2006) framework method. Transcribed (verbatim) interviews were imported into NVIVO 10 software to facilitate analysis. All researchers read the transcripts to immerse themselves in the data. Two team members (DL, JM) coded the data independently, met weekly to discuss their analyses and decided final codes and themes jointly with a third researcher (NS). Initial codes were generated by drawing out consistencies and commonalities within the text, and emerging themes were identified and labelled with descriptive codes. Finally, themes were re-

Caregivers' interactions with health care services – mediator of stress or added strain?

examined to produce higher level themes. Codes and themes were developed iteratively to ensure consistent and correctly attributed meaning. The final themes were created to reflect the different perspectives of both participant groups (i.e. caregivers and healthcare professionals) of the same topic. We then applied the findings from these themes to explore what impact contact with health care had in terms of primary stressors, secondary strains and outcomes in caregivers in line with the stress-process model.

Rigour and trustworthiness of the study were ensured through the application of the criteria of credibility, transferability, dependability and confirmability. We used multiple analysts; frequent debriefing sessions between researchers were conducted to ensure lack of bias, accuracy of ideas and data interpretations; a multisite design, in different settings and different geographical areas of the rural county of Lincolnshire; detailed description of the research process and context in which this work was undertaken, such as the number and main characteristics of participants, the data collection methods, the number and length of the focus groups/interview, etc. (Shenton, 2004).

Results

Five themes were identified capturing the main challenges faced by caregivers of people with dementia and the type of support they want from health care services. These themes reflected the views and opinions of both caregivers and HCPs, offering different perspectives of the same issues. These were mapped to the stress-process in caregivers model: the challenge of diagnosing dementia (primary stressor); caregivers' needs and expectations of an in-depth knowledge and understanding of dementia from healthcare professionals (primary stressor); need for carer education (primary stressor); lack of support and mismatch of communication and expectations (secondary role strain); and carer involvement in monitoring care and disease (potential mediator tool).

Caregivers' interactions with health care services – mediator of stress or added strain?

The challenge of diagnosing dementia and obtaining appropriate health care

A key challenge faced by caregivers was the initial diagnosis of dementia in their care-recipients. Both caregivers and healthcare professionals believed that there were barriers to timely diagnosis and treatment, including for other health issues. The main reasons given for this were patients' memory difficulties and failure to admit they had a problem. This could be very challenging for both healthcare professionals and caregivers themselves:

'Dementia has a lot of issues, but the main issue as a GP is when the person is not willing to accept that he's got dementia, not accepting help, doesn't want to be referred.' Dr J., GP

Caregivers felt they could not get through to or be heard by GPs and that their opinions and observations of problems with the person they were caring for were not taken seriously. As a result, caregivers felt that these issues delayed diagnosis and receiving the proper help and support needed for the person they were caring for. This was a source of frustration and stress for caregivers:

'And you cannot get past that because that person's told the GP there's no problem and the GP believes that, despite there being a diagnosis of dementia. It is so difficult...And that's been my worst barrier really, getting through to the GP.' Kathy, daughter-in-law, 54 years old

Caregivers' need and expectation of an in-depth knowledge and understanding of dementia from healthcare professionals

Caregivers' interactions with health care services – mediator of stress or added strain?

Caregivers strongly believed that there was a need to educate healthcare professionals about dementia, since they felt that HCPs, especially family physicians, lacked understanding of how it was to live with dementia. According to caregivers, HCPs might feel they have a theoretical knowledge of dementia, but caregivers felt that HCPs did not really understand how dementia affected patients and their caregivers or how best to help them. This was both in the community and within a hospital setting:

“... a lot of them do need educating, don't they? No they haven't got a clue, the professionals, GPs in particular, need educating on dementia! They really do not know!” Victoria, wife, 74 years old

“We had a situation where my mum was in hospital and they didn't seem to have a clue about dementia at all, even though they said they were dementia trained...” Jackie, daughter, 47 years old

HCPs themselves felt that it was difficult to understand what it was like to have dementia unless they had personal experience of this:

'I think dementia isuntil you've probably had personal experience of it, it can be something sort of difficult to understand what's going on within a family.... It's a bit like... before you had children you probably weren't able to relate to patients with young children really.' Nina, Phlebotomist

Need for carer education

Caregivers' interactions with health care services – mediator of stress or added strain?

Caregivers expressed a need for information and education. Both caregivers and HCPs reported that there was little or almost no information or education about dementia offered to caregivers. Caregivers reported not having received as much information as they would like. Information was usually provided to them in the form of leaflets or as digital material rather than structured information or education:

'The only information I got...I got leaflets from Age Concern and all the other organisations, which you put in a folder and you read them and then you forget them! But there wasn't anything that really told you how it would progress and what to expect.' Mary, wife, 84 years old

"...If there was one site online where all of this information was available that you need, that would be good. And I think what they will say at social services is that the site is there already. It is until you start delving into it.... It isn't comprehensive enough..." Thomas, husband

Consequently, caregivers often lacked understanding of dementia, why patients behaved the way they did, and how to deal with patients' challenging behaviours:

'And there isn't a lot of education for caregivers. Sometimes they get it but sometimes they will, like you say, come up to you and question why is my husband doing this or why is my mum doing that, and it's about educating caregivers on the nature of the disease.... And it's giving them the education and the details– and it can be put in layman's terms so it's not talking medical.' Peter, Mental Health Nurse

Caregivers' interactions with health care services – mediator of stress or added strain?

Caregivers expressed a need for information around various issues, such as disease progression and prognosis (i.e. what to expect); how to access available services; financial and legal advice (e.g. getting power of attorney, attendance allowance); tips and guidelines on how to deal with patients' challenging behaviours (e.g. communication difficulties, repeated asking, wandering off, etc.) and practical difficulties (e.g. showering, dressing, fall prevention, etc.); stress reduction and relaxation techniques; how to modify the home environment to compensate for the patients' everyday difficulties (e.g. reducing the thermostat on the hot water heater to prevent accidental scalding, installing a toilet seat of contrasting colour so they can see it better, removing mirrors to reduce any confusion seeing themselves in the mirror); and sleep management:

'I would like to know. I mean I am worried about the future...Because I don't know anything!' Pam, wife

Lack of support and mismatch of communication and expectations

Caregivers expressed that they often did not receive the support that they wanted and needed from health and social care services. They also had to pay for many types of support such as respite care, help around the house, and use of wheelchairs for the patient, etc.:

'I don't know really... I just don't understand why they are so unhelpful...I think something needs to be done, because we don't seem to get any help really from anywhere. You're just a bit left on your own.' Rose, wife, 74 years old

'We don't have a support worker or anybody, that's it. We've had nothing.' Emma, daughter, 52 years old

Caregivers' interactions with health care services – mediator of stress or added strain?

Caregivers also felt that HCPs and care providers did not work together or communicate enough, leading to a fragmented service that left them struggling to receive the support they wanted and needed:

'The other thing that people need to be aware of is that, with dementia, you will need all the Trusts working together, and they don't. And you get moved from one organisation to another and you've got to keep going back to the GP [family physician] to get re-referred and then you get moved around from [one named] unit to the next unit to the next... It's not joined up, you know...and this is the battle that you've got.' Thomas, husband

Healthcare professionals also recognised that caregivers needed support and care, but that this support was not always readily available to them. GPs, in particular, felt that the only thing they could do was refer caregivers to other services that could help support them:

'...the caregivers of the families think there's not a lot being done for them, there's like some cure and that isn't there. So our role is just supporting them and sometimes it can be really challenging. Because you see them only for ten, fifteen minutes, but those people are with them all day long, all night long...and there is the trust that you could have a problem with dementia, go to NHS and they will do everything for you, and unfortunately it doesn't happen... the majority of these patients usually deteriorate with time, and really I think they need more support and care and unfortunately it's not available to them...so all we can do is signpost them somewhere else so that they can access the support...' Dr H, GP

Caregivers' interactions with health care services – mediator of stress or added strain?

Carer involvement in monitoring care and disease

Most caregivers felt that monitoring the progression of their care-recipients condition would be very helpful (for themselves and when dealing with the health and social care services), especially if it was in the format of a diary:

'I've kept a diary and thank God I have! Because you know now it's coming into its own...and so I think keeping a diary is really very important ...' Victoria, wife, 74 years old

Caregivers felt that keeping such a diary would only be useful if HCPs were willing to accept observations as reliable and take them seriously. HCPs seemed happy to accept the caregivers' observations, felt that they would be reliable (probably even more so than their own assessments) and might help caregivers feel more empowered:

'I'd trust the carer's assessment better... so in terms of reliability, I think it would be at least as reliable as done with health professionals if not better....' Dr SB, GP

Most also felt that it would be equally important to record positive things and what was going well with the patient, helping caregivers and HCPs identify potential triggers for patients' behaviours:

'I think with behaviours and diary, that's very useful... so what's triggered things, what's caused the anxiety– because people behave differently in different places.

Caregivers' interactions with health care services – mediator of stress or added strain?

Plus it would also, I feel, give the caregivers the feeling that they're actually doing something to help, and it gives them a purpose and a focus, which can only help.'

Daisy, Ward Manager

However, some HCPs were also apprehensive that keeping such diaries might be an extra burden for caregivers and that it might make caregivers worry more about the condition or progression of the patient:

'If you're writing it in the diary this is a constant reminder that actually things are really bad. So the question I think we need to ask is, yes we can empower people, but are we going to then add extra burden on them and extra worry and anxiety and is that worthwhile eventually in terms of what we achieve, in supporting caregivers and optimizing care for the patient? And, and I don't know the answer to that, but I suppose it's a question to ask.' Dr SB, GP

Discussion

This qualitative study explored the experiences of informal caregivers of people with dementia around challenges they face relating to their care-recipients' dementia and when interacting with the health care system. These challenges were also studied from the HCP's perspective, focusing on their views and current practice regarding people with dementia and their interactions with informal caregivers.

We found that one of the main challenges faced by caregivers was getting an initial dementia diagnosis for the person in their care in a timely manner, mainly due to the care-recipients' reluctance to admit they had a problem. Healthcare professionals also viewed diagnosis as problematic, due to a conflict between patient's denial and what the caregiver

Caregivers' interactions with health care services – mediator of stress or added strain?

was saying. Previous studies showed that a diagnosis of dementia was often missed or delayed (Bradford, Kunik, Schulz, Williams, & Singh, 2009; Iliffe et al., 2009), leading to delays in accessing appropriate care (Sutcliffe, Roe, Jasper, Jolley, & Challis, 2015). The main reasons behind this were reluctance to acknowledge symptoms (Iliffe et al., 2009), concern about receiving a dementia diagnosis (Bradford et al., 2009), and lack of knowledge about which changes were attributed to the ageing process (Iliffe et al., 2009). In terms of the stress-process model, the challenge of getting an initial diagnosis when care-recipients experienced cognitive difficulties was a primary stressor due to care-recipient care needs not being met, resulting in an increase in their subjective stress levels.

In addition, according to the caregivers we interviewed, HCPs required further training and education, to enable them to fully understand dementia and assist them to support caregivers and patients more effectively. Greenwood, Mackenzie, Habibi, Atkins, and Jones (2010) found that nine out of ten HCPs felt they had insufficient training, with half lacking confidence that they met caregivers' needs. In terms of the stress-process model, the HCPs' perceived lack of in-depth knowledge and understanding of dementia meant that caregivers did not feel their needs were being met, further increasing their subjective stress.

Apart from additional training and education for HCPs, caregivers also felt that they wanted and needed more information and education on dementia, since they were not currently receiving enough from health and social care services. This perceived lack of carer information impacted not only on the lack of understanding of care-recipient behaviour (for example understanding that patients' behaviours were often not purposeful or meant to aggravate, but also on what caregivers needed to do to alleviate stressful effects on both carer and care-recipient. Previous research has also evidenced the importance of information and education about dementia for informal caregivers, especially in helping them cope better (Low, White, Jeon, Gresham, & Brodaty, 2013), and has shown that there is still unmet need for information and education (Alzheimer's Society; 2014; Bowes & Wilkinson, 2003; Department of Health, 2013; Ducharme et al., 2011; Lawrence et al., 2008;

Caregivers' interactions with health care services – mediator of stress or added strain?

Newbronner, et al., 2013; Tetley, 2013). As a result, caregivers often report difficulties accessing services or support (Bowes & Wilkinson, 2003; Ducharme et al., 2011; Peel & Harding, 2014; Tetley, 2013; Xiao, Habel, & De Bellis, 2015), and a lack of preparedness to provide effective care (Ducharme et al., 2011).

In England, the National Dementia Strategy (Department of Health, 2009) has identified providing good-quality information and enabling easy access to care, support and advice for those diagnosed with dementia and their caregivers as key strategic objectives, with the potential to improve self-efficacy, reduce stress and feelings of guilt, and improve family relationships. According to Wald, Fahy, Walker, and Livingston (2003), HCPs should try to explain as much as possible about the disease and its effects, at a pace that allows caregivers to feel comfortable asking questions. Wald et al. (2003) suggest that up to three main pieces of information should be provided: information about dementia symptoms and treatment, available services, and management of challenging behaviour and other caregivers' concerns should be addressed. Information when provided, should be in a form that is culturally appropriate, accessible to caregivers who do not speak or read English or who have other disabilities which make accessibility difficult (NICE, 2006).

Caregivers' reported difficulties receiving the support they wanted and needed, often having to pay for relevant services themselves has also been found in other studies (Alzheimer's Society, 2014; Bowes & Wilkinson, 2003; Ducharme et al., 2011; Peel & Harding, 2014; Tetley, 2013). Similarly, in a study by Raivio et al. (2007), just over a third of caregivers were satisfied by the services being offered to them, with the remainder feeling that what they were offered did not match what they felt they needed. This perception was also mirrored in our focus groups with HCPs. Despite the HCPs' belief that caregivers needed and wanted more support in primary care, few services are currently being offered specifically for caregivers in England (Greenwood et al., 2010). These findings highlight the importance, and current lack, of having dedicated support services for caregivers of people with

Caregivers' interactions with health care services – mediator of stress or added strain?

dementia (such as an assessment of their own self-care needs), which could have a large impact on their well-being and ability to care.

In addition, caregivers felt that existing services were fragmented, mainly due to poor inter-professional communication and a lack of joint working; a finding supported by previous research (Peel & Harding, 2014; Wang, Xiao, He, & De Bellis, 2014). The perceived lack of timely and appropriate support added to the secondary role strain, negating the effect of support that caregivers received.

A novel finding from our study was that both caregivers and healthcare professionals felt that having caregivers keep a diary of their care-recipients' progression would be helpful, especially for recording triggers to a patient's behaviour or identifying positive events and behaviours. These findings highlighted the important role that caregivers could play by actively 'monitoring' their care-recipients and offering insights on patients' behaviour, despite HCPs' concerns that this might increase caregivers' burden and anxiety, or caregivers fears that HCPs would not take the information seriously. Generally the recording of a daily diary to help empower caregivers was perceived as a potential mediating tool to increase internal coping resources, improve communication with HCPs, and reduce second intra-psychic strain by increasing sense of control.

Overall, in terms of the stress-process model of stress in caregivers, our findings suggested that appropriate support from HCPs had real potential as mediator for reducing stress. Our data show that fragmented services, lack of training for HCPs and a dearth of information for caregivers, result in health and social care services only partially fulfilling this role. This may inadvertently add to primary and secondary role stressors, increasing mental strain and leading to worse outcomes in terms of both caregiver health and well-being, increasing the risk of caregivers relinquishing care provision resulting in the institutionalisation of their care-recipient.

Caregivers' interactions with health care services – mediator of stress or added strain?

Strengths and limitations of the study

The findings of this study reflect the views of a relatively small sample of caregivers and healthcare professionals. Also, the homogeneity of the sample may limit the transferability of our results, since the majority of the caregivers were female, Caucasian, spouses of the person diagnosed with dementia and living in Lincolnshire, UK. We were unable to explore the views of caregivers providing end-of-life care, those from different ethnic backgrounds or geographical settings, or professionals working in the social care setting. These might be areas for future study. It should be noted that volunteer bias may have affected the results of this study, with caregivers who are least satisfied with the support they have received being more willing to participate. In addition, it could be argued that including staff from the local mental health Trust may have influenced our data, as they may have had more training and experience in dementia than the remaining HCPs. It is our view that their extensive experience (with both people diagnosed with dementia and their caregivers) has enriched our data and was one of the strong points of our study, rather than a limitation.

One of the strengths of the study was that caregivers were looking after people diagnosed with different levels (from mild to severe) and causes (including vascular, frontotemporal, Alzheimer's disease, and mixed vascular with Alzheimer's) of dementia, sharing views and experiences from a broad spectrum. In addition, we were able to recruit a diverse group of HCPs, belonging to different professions and backgrounds, from mental health nurses to GPs and ward managers.

Implications for policy, practice and research

Our results highlight a need for better support for informal caregivers of people with dementia. This includes more structured educational programmes for caregivers and better patient (and carer) pathways for dementia to help caregivers navigate the health and social care system and get the support they need for themselves and the people in their care.

Caregivers' interactions with health care services – mediator of stress or added strain?

In the United Kingdom, the Dementia NICE clinical guidelines 42 (2006) state that health and social care staff should take account of the views of caregivers and relatives who describe behaviour that could be in keeping with dementia, as this will help with diagnosis and in estimating of the person's capacity to make decisions (NICE, 2006). More training of healthcare professionals on dementia (particularly around early recognition and diagnosis) is needed. Future interventions should be developed to address this gap and increase rates of accurate and timely diagnosis of dementia.

Investigating the possibility of caregivers undertaking a more active 'monitoring' role of their care-recipients' progression and behaviour could also be a fruitful area for future research. Caregivers can often identify subtle behavioural changes in people with dementia, and so are invaluable sources of diagnostic information. They would also be ideally placed to assess and monitor the patient with dementia, from initial suspicions of changes in behaviour, to ongoing monitoring progress and medication.

Important ethical issues should be taken into consideration when designing research involving the use of diaries by informal caregivers. Most importantly, the issue of patient consent; as keeping a diary would require the carer to record, and share with the researchers, personal and often confidential information/records about someone else (i.e. the person diagnosed with dementia). Every precaution should be taken to safeguard the person with dementia and, whenever feasible, informed consent should be sought from both caregivers and their care-recipients, although this might be problematic with people with dementia facing cognitive difficulties. In addition, caregivers recording situations and feelings that their care-recipient might find upsetting, and/or keeping a diary private (with the patient having no access to it), might cause issues within the, often already strained, caring relationship.

Caregivers' interactions with health care services – mediator of stress or added strain?

Conclusion

Caregivers of people with dementia report a greater need for information with more structured and cohesive support from health care services, which are not widely provided. Healthcare professionals, by not fully recognising caregivers' and patients' needs may not be providing effective care and support, inadvertently adding to caregiver stress. Obtaining meaningful and in-depth information on caregivers' and patients' experiences, main concerns and needs should be a priority for healthcare professionals. Offering caregivers the support they want and need could help alleviate their caring burden, improve their and their care-recipients' well-being, and reduce the risk of institutionalisation. This should be the focus of future intervention development and testing.

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