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ORIGINAL ARTICLE

Experiences of family carers of older people with mental health problems in the acute general hospital: a qualitative study

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Abstract

Aims. To explore the experiences of family carers of people with cognitive impairment during admission to hospital.

Background. Providing appropriate care in acute hospitals for people with co-morbid cognitive impairment, especially dementia or delirium or both, is challenging to healthcare professionals. One key element is close working with family members.

Design. Qualitative interview study.

Methods. Semi-structured interviews with family carers of 34 older people who had been admitted to a UK general hospital and had co-morbid cognitive impairment. Interviews conducted in 2009 and 2010. Analysis was undertaken using Strauss and Corbin's framework.

Findings. The findings elaborate a core problem, 'disruption from normal routine' and a core process, 'gaining or giving a sense of control to cope with disruption'. Family carers responded to disruption proactively by trying to make sense of the situation and attempting to gain control for themselves or the patient. They tried to stay informed, communicate with staff about the patient and plan for the future. The interaction of the core problem and the core process resulted in outcomes where family members either valued the support of hospital staff and services or were highly critical of the care provided.

Conclusion. Family carers are not passive in the face of the disruption of hospitalization and respond both by trying to involve themselves in the care and support of their relative and by trying to work in partnership with members of staff. Nurses need to foster this relationship conscientiously.

Keywords: acute care, dementia, family care, gerontology, nursing, qualitative approaches

Introduction

Cognitive impairment is common amongst older people admitted through the emergency department to acute general hospitals. At least half of patients over 70 have cognitive impairment (delirium, dementia or both) and up to a third have depression (Holmes & House 2000, Royal College of Psychiatrists 2005, Sampson *et al.* 2009), often in combination with other mental health problems. Half of hip fracture patients have prior dementia. Only a third has no detectable mental health problem (Goldberg *et al.* 2012). One report estimated that 25% of British National Health Service (NHS) hospital beds accommodate someone with dementia (Alzheimer's Society's 2009).

Background

Dementia, in particular, has been the focus of numerous review and policy documents (Alzheimer's Disease International's 2010, Audit Commission 2000, 2002, Department of Health 2001, 2009, Care Service Improvement Partnership 2005, National Institute for Health & Clinical Excellence 2006 and the World Health Organisation 2012). Acute care is an area of clinical practice that poses major challenges (Department of Health 2009) and family carers of people with dementia are often critical of services (Alzheimer's Society's 2009, Care Quality Commission 2011).

These family and other 'informal' carers are especially important to people with dementia. They provide direct assistance, emotional support and act as advocates. They may be elderly themselves and their physical and mental health may be affected by their caring role (Shanley *et al.* 2011). Yet their role and needs are often overlooked by health services (Alzheimer's Society's 2009). They too are affected by the hospital admission of the person they care for. Working with family members has been identified as key to providing appropriate care (Goff 2000, Edvardsson *et al.* 2010, Moyle *et al.* 2011). However, there is little research focused on relatives of older people with dementia in acute care, although research has been conducted which considers how relatives experience acute care more generally (Eggenberger & Nelms 2007, Qiu & Li 2008, Spichiger 2008, Söderström *et al.* 2009, Van der Smagt-Duijnsteet *et al.* 2009, Van Horn & Tesh 2009, Cohen *et al.* 2010, Donnelly & Battley 2010, Thune-Boyle *et al.* 2010, Verhaeghe *et al.* 2010). This paper reports a qualitative study that aimed to explore their experiences and critically integrated the findings into the existing literature.

The study

Aim

The aim of this study was to explore the experiences of family carers while their relative with cognitive impairment receives care in an acute hospital.

Design

Informed by the philosophical approach of person-centred care (Kitwood 1997, Brooker 2007) where professionals seek to understand the world from the perspective of the person with dementia, this study was developed around an interpretive ethnographic approach (Nygard 2006). Using a combination of non-participant observation and interviews, researchers sought to watch, interpret and evaluate the experiences of older people and their carers when in acute hospitals.

Setting and sample

The study was conducted on two sites of a single NHS Trust in the Midlands, UK which provided sole medical and trauma services for a population of approximately 660,000. Linked with a larger study (Goldberg *et al.* 2012), participants were recruited from a cohort of patients aged over 70 years with mental health problems admitted to one of 12 general medical, health care for older people or trauma orthopaedic wards.

For the larger study, 1,000 consecutive admissions to the identified wards were screened using the used the Abbreviated Mental Test Score (Hodkinson 1972), the four-item Geriatric Depression Score, (Almeida and Almeida 1999), the two-item PRIME-MD anxiety screen (Spitzer *et al.* 1994), the four 'CAGE' questions for alcohol misuse (Ewing 1984) and a question asking ward staff if there was any other reason to believe a mental health diagnosis might be present. Two hundred and fifty patient-carer pairs were recruited from among those identified as having a mental health problem. Where patients had capacity, they were asked to give written informed consent. Where they lacked capacity, a carer was invited to act as a personal consultee under section 32 of the Mental Capacity Act (2005). In addition, family carers were invited to give written consent for their own participation. As part of the process of recording consent, participants were invited to indicate if they were willing to be contacted for an in-depth interview as part of this study. Following discharge from hospital, potential participants who agreed to this were contacted by telephone and invited to participate.

Recruitment occurred over 12 months, until data saturation occurred. The sample consisted of family carers associated with 34 patients. The mean age of the patients for whom they were carers was 87 (range 70–99) years; 19/34 (56%) were female; 21 (62%) were widowed, 9 (26%) were married, 2 (6%) had never married and 2 (6%) were divorced: all but three had cognitive impairment at the time of admission (the other three were depressed). Sixteen had previously lived alone, of whom 6 returned, 8 were discharged to a care home and 2 died (a carer was interviewed). Eleven had previously lived with family, of whom 5 returned, 4 went to a care home and 2 died. Seven had previously lived in a care home, three died in hospital, the rest returned to the care home. A further five patients died between discharge and the time of the interview with their carer. The relationship to the patient of 32 of the carers was: wife 9, daughter 8, son 7, niece 2, female friend 2, sister 2, son-in-law 1 and grand-daughter 1 (in two cases the relationship was not recorded). The mean age of carers was 63 (range 46–79) years and 24/34 were female. 15 carers volunteered one or more mental health problems of their own.

Data collection

Seventy two hours of individual patient observations were conducted on eleven acute medical and surgical wards together with thirty-five interviews concerning the experiences of 34 patients. In view of the focus on family carers, this paper presents analysis of these interviews, which were conducted in 2009 and 2010.

Interviews were conducted in the home of the patient or carer and included the patient wherever possible. Interviews took place between 6–8 weeks after discharge, or after 12 weeks if the patient had died. Most interviews involved the patient and carer together and on occasions participants chose to have other family members or friends present.

Interviews began by asking the carer to give an account of the admission to hospital. An interview guide was used flexibly as a prompt to explore the experiences of the person's stay in hospital. Probes were used to elicit more detail on areas where hospitals and staff could improve the care given. Interviews were audio recorded and field notes were made immediately after the interview. Interviews lasted between 20 minutes and 2 hours (average 1 hour).

Interviews were transcribed by an experienced transcriber and were not returned to the interviewees for checking. Transcripts were anonymized by the researcher.

Ethical considerations

Research ethics committee approval was obtained. The main ethical concern in this study related to participant consent where the patient lacked capacity. If the patient had capacity, they gave their own consent. Otherwise consultee agreement was obtained from the carer, along with consent for the carer's own participation. At the start of each interview, ongoing consent to participate was confirmed verbally. A naturalistic approach to interviewing was taken.

Data analysis

Transcriptions and interview notes were uploaded into NVivo 8.0 (QSR International 2008) for data management and analysis. Coding was by two experienced academic nurses (PC and DP). Analysis followed the principles of constant comparison (Glaser & Strauss 1967) and was conducted independently by the two coders who met regularly. Interpretation and naming of codes was agreed by consensus.

Coding became more focused with the organization of codes into categories. These categories represented groups of similar and related concepts. Ultimately a more abstract theoretical framework was developed where it was possible to conceptualize 'how substantive codes...relate to each other as hypotheses to be integrated into a theory' (Glaser 1978, p. 72).

Rigour

Freshwater *et al.* (2010) suggest that rigour is accepted as the means by which integrity and competence are established and a way of demonstrating legitimacy. Strategies to attend to rigour in this study included conducting an inter-rater analysis of basic coding using the NVivo consensus coding command when the first two interviews had been transcribed (QSR International 2008). The coding was compared by setting up basic coding for the main research areas which resulted in high levels of agreement between the researchers (68–98%). With such high level of agreement, independent coding was performed. Regular meetings were held to merge datasets and reach consensus on new codes as they emerged and to discuss interpretation of the data. In addition, none of the researchers engaged in data collection had a clinical role in the acute hospital where the study was conducted. Memos were used to record reflections on emerging concepts in the data analysis.

Results

The findings elaborate a core problem, 'disruption from normal routine' and a core process, 'gaining or giving a sense of control to cope with disruption'. Both the core problem and the core process resulted in immediate, short-term and longer term outcomes. The core problem and core process also applied to the patient, other patients on the ward and staff, whose experiences are described elsewhere (Gladman *et al.* 2012). The word disruption was chosen because of its varied meanings all of which applied to the family carers' experience and to staff and other patients. As a verb disrupt first means to throw into turmoil or disorder and second means to impede or interrupt progress. It can also mean to break apart or split something (Collins English Dictionary Online). These ideas symbolize the experiences both practical and emotional for family carers with a relative with cognitive impairment in an acute hospital.

The core problem: disruption from normal routine

Hospitalization caused disruption from carers' established routines at home or in a care home. Disruption was partly caused by the illness itself, with changes in the patient's needs and behaviour, especially when delirium was present. Disruption also occurred as hospital admission necessarily changed routines. These disruptions caused consternation and distress for many family carers. Martha described the change that occurred with her husband Ralph:

Well he completely changed when he was in there: completely. It sent him even more wappy [crazy] than what he was when he went in. He wouldn't let you touch anything, if you went anywhere near his clothes or anything he'd scream at you, LEAVE THEM ALONE, THEY'RE MINE. And you had to...I mean he'd be wet, he'd wet his clothes and everything and to take them home wash he'd be screaming at you...Martha wife of Ralph

Hospitalization and hospital visiting is a disruption to routine experienced by all patients and families but for our participants this was exacerbated for some family members who concluded that visiting was pointless as the patient was unable to interact due to the confusion, acute illness or both:

To be perfectly honest the first couple of times she was in it was a waste of time going because she was asleep all the while. They'd got her out of bed one day...she spoke to us a little while and then all of a sudden she pulls a pillow off the bed and puts it on the arm of the chair and she's away again. And she doesn't know [we] had been up to the hospital at all Evelyn, niece of Gloria

One particular cause of concern for family carers was that community support services might be withdrawn, increasing disruption in the longer term (in the UK these services are usually redeployed after a few days in hospital and have to be re-requested on discharge). This potential for disruption caused worry and consternation for the family carer who anticipated further disruption when her mother had to adjust to new community caregivers:

Another problem was the social services terminated her care package after a fortnight in hospital regardless of what I'd said and I was keeping in very close contact, keeping them informed. I was very concerned that she should stay with the same carers because she had a relationship with them, they're doing very personal things for her and it worked really well and I knew she was on, on the brink of not being able to stay at home...Brenda, daughter of Helen

Hospital processes were perceived as disruptive. The hospital environment did not lend itself well to the management of distressed behaviours. The emergency department was seen as a chaotic place where, despite national targets for swift assessment, treatment and transfer, the process was slow, exhausting and uncomfortable.

..when she went in she was very confused, we stood there for absolutely ages...I got there before lunch...and [we] did not get into the ward until half past 10 at night and that in itself was an experience because she was very tired, very worn and it does take it out of them. Bernice daughter of April

The core process: gaining a sense of control to cope with disruption

Family carers attempted to take control for themselves and for the patient by staying informed, communicating with staff about the patient and planning for the future. This aimed to minimize the impact of hospitalization. Feeling in control was important. Some actions demonstrated self-preservation, whereas others showed a desire to promote control and coping for others. Whatever the motivation, the consequences could be either to reduce or to perpetuate disruption. Strategies to promote control included trying to protect the person with dementia, making judgments about the quality of care being offered and, sometimes, taking steps to monitor the care. Blaming the system and rationalizing care quality problems was another coping strategy.

Protecting the person with cognitive impairment

By trying to protect their relative, family carers were able to feel that they had some control over what their relative

was experiencing. They attempted to do this in two main ways: by acting to counter perceived inadequacies of the system and by trying to maintain what in person-centred care is referred to as the 'personhood' of the patient (a term used in dementia care to describe respect for a patient as an individual with needs, a history and the right to make choices, Brooker 2007).

One strategy used by family carers was that of advocacy, using their knowledge of the person to influence care and getting involved to fill the gaps in care left by the hospital staff and system. Mary found that she was in a position where she had to advocate on behalf of her mother when the hospital system seemed to be slow in working towards encouraging her mobility following a fracture:

I was trying to push everybody to get her on her feet, get her back to the care home, given they weren't going to operate.. Mary, daughter of Gillian

In addition, family carers acted to preserve the personhood of the individual with dementia during their hospital stay. These actions tried to give the person with dementia a sense that they were someone other than just a hospital patient. Bernice found the emergency department a challenging environment for her mother. As a result, she did what she could to comfort her:

The trolleys really are side by side so you really haven't got much room at all...I stroked her hair and made sure that she was alright. Bernice, daughter of April

Evaluating the quality of care

Many family carers found that their relative could not be relied on to provide an accurate picture of the care they were receiving. This could leave them feeling out of control. In response they would question staff to obtain a fuller picture. Jill sensed that members of staff would leave family carers uninformed if they were not asked questions:

I asked the questions...and my mum was, 'Oh you shouldn't be asking all these questions, you know.' Yes, I should, because I won't be told anything unless I ask the questions. Jill, daughter of Betty

Dot described the strategy that she used discretely to find out what was happening to her mother Jackie:

She doesn't complain much...the trouble really is, because her memory's so poor that...she couldn't tell you anyway if something had happened yesterday or even the same day...I try and go all sort of different times of the day and...she seems content. Dot, daughter of Jackie

Where such monitoring and evaluation resulted in the family carer reaching the opinion that the quality of care was good, the result was reassurance and satisfaction:

And yeah, quite a good day really that first day...obviously they [nurses] like to make an impression don't they, they'd come in, 'Are you alright Paul?' Giving him his cups of tea and everything and everything seemed to be alright and I felt quite alright leaving that day. Susan, grand-daughter of Paul

Where family carers decided that there were problems with the quality of care, some tried to rationalise what was happening, while others appeared to reach a fixed opinion that care was poor. The former approach may have enabled family carers them to continue to trust staff and feel in control. Tina explained that hospital staff had responsibilities to numerous people not just her and her father:

I mean my dad is the most important person in that room to me, but to them that's working there they've got everybody, not just one. Tina, daughter of Eric

Where family carers felt unable to rationalise what they perceived as poor care, the result was often anger, directed at both members of staff for the decisions that they made, and at the NHS as a whole, for inadequacies in the system. Kirsty expressed anger at the state of the side ward that was allocated to her mother:

The first time she went in...I questioned every time, why she was in a grotty, it was filthy, I took pictures on my phone, the room was dirty. Kirsty, granddaughter of Florence

Some family carers appeared to reach a fixed view on one or more aspects of the service were poor. Frank's wife thought that the staff on the ward seemed to focus on lots of tasks without really delivering quality care:

He was just left on a bed rotting away absolutely rotting away... the sisters they tell you things, but you never saw the same one twice, staff nurses just doing their jobs and machines and bloods or what do you call them, injections and things but then where is the care of getting someone motivated, there isn't any. Muriel, wife of Frank

In such circumstances, family carers tended to feel out of control and might seek to regain it by submitting a complaint:

Erika A letter is not going to put what happened to my mum right.

Kirsty We want closure, don't we? We want somebody to tell us...we did this wrong.

Erika, daughter and Kirsty, granddaughter of Florence

Rationalizing the situation to cope with disruption: supporting hospital staff

Some family carers expressed support for the NHS and its staff, enabling them to feel no less in control than the members of hospital staff. They might sympathize with staff coping with the disruption 'caused' by their relative. If care was thought of poor quality, family carers could rationalise the situation, sometimes blaming the government and other agencies for shortcomings and removing the spotlight from hospital staff:

I mean...they're under pressure to get patients out, aren't they? They've got to reach the government's target and they were making her fit the theory. And I just thought...it's the system isn't it? It's not necessarily the staff. Brenda, daughter of Helen

Some family carers took particular actions with the specific goal of supporting hospital staff. These actions included spending more time with their relative to reduce the demands on the time and attention of nursing staff:

...he was up and down the ward walking around and I think they (the nursing staff) found this quite troubling. So if I could sit with him and try and get him to stay put that was something for them. Felicity, wife of Edwin

Discussion

This study reviewed the experiences of relatives of older people with a range of mental health problems, but predominantly delirium, dementia or both. The findings suggest a variety of issues that family carers experience when their relative is admitted to hospital. The process is disruptive to the family carer; they respond to this disruption proactively; as part of this process, they make judgments about quality of care being offered both to them and their relative; and they emphasise the need for effective communication from members of staff, especially if their relative has dementia.

A literature search revealed studies considering family carers of people who were critically ill (Eggenberger & Nelms 2007, Söderström *et al.* 2009, Van Horn & Tesh 2009, Verhaeghe *et al.* 2010), who have had a stroke (Qiu & Li 2008, Van der Smagt-Duijnsteet *et al.* 2009) and who were near the end of life (Spichiger 2008, Cohen *et al.* 2010, Donnelly & Battley 2010). One study was of the care of people with dementia at the end of life (Thune-Boyle *et al.* 2010). This literature suggested experiences and concerns that are common to many family carers, but also some distinct differences.

Where illness is perceived as being severe the patient becomes the focus of life during the early stages of admission (Van der Smagt-Duijnsteet *et al.* 2009, Verhaeghe *et al.* 2010). Such a focus is unsustainable over the long term

because of a combination of exhaustion, a re-emergence of the demands of daily life and an awareness of own and other family members' emotional needs (Eggenberger & Nelms 2007). Family members spending prolonged time in hospital often have disrupted sleep, poor diet and inadequate exercise, making them irritable (Van Horn & Tesh 2009) and they may become depressed (Qiu & Li 2008). Our own data aligns with the findings of these studies. The family carers in our study had concerns that the person with cognitive impairment is more distressed than other patients without cognitive impairment because they did not understand why they were there, what was happening and were anxious about being abandoned. Staff need to be more alert to the needs of the family carer when a patient has such impairment, providing not only verbal reassurance but demonstrating their care and concern to help the cognitively impaired person feel safe in the hospital environment.

A sense of disruption could be compounded by hospital rules. In a study from South Asia, Vydelingum (2000) found that the ward was perceived as an 'English place' subject to unwritten rules and expected conformity. This perception extended to other patient groups and influenced the ease with which family members were able to visit (Spichiger 2008, Verhaeghe *et al.* 2010) and get involved in providing care themselves (Higgins & Joyce 2007). This contribution by family carers appears to be underestimated by most healthcare professionals (Quattrin *et al.* 2009). Acute hospitals are recognized as disempowering places for older people and carers (Tadd *et al.* 2011).

While the admission to acute hospital of someone with cognitive impairment does not necessarily entail the sense of shock that accompanies someone being admitted with a stroke or critical illness (Van der Smagt-Duijnsteet *et al.* 2009, Verhaeghe *et al.* 2010), the disruption caused by juggling life and supporting the person in hospital remains. The perception that hospitals are not equipped to meet the needs of a person with dementia and that care will be poor, leads some carers try to avoid hospital. Family carers may view services on a continuum from facilitative to obstructive (Nolan *et al.* 1996) with the specific position on the continuum being determined by: the extent to which service providers actively engaged carers as partners; taking account of the expertise of carers and use of effective caregiving strategies. Gilmour (2002) identified a similar range of perceptions of hospital-based respite care: acceptance, qualified acceptance and marked ambivalence.

Previous work has not much discussed carer reactions to hospital (Vydelingum 2000, Qiu & Li 2008). Our study found strong evidence of proactivity in trying to deal with disruption. Some family members tried to fill in gaps in care,

What is already known about this topic

- Cognitive impairment is common among older people admitted as an emergency to acute general hospitals.
- Acute care settings are very challenging to older people with cognitive impairment.
- Working with family members has been identified as key to provide appropriate care for people with cognitive impairment.

What this paper adds

- An insight into the potential disruption experienced by family carers when their older relative with cognitive impairment is admitted to acute care.
- An understanding of some strategies used by family carers to gain a sense of control in the face of the disruption associated with the admission of their relative to hospital. Strategies to gain a sense of control include trying to work in partnership with members of staff.

Implications for practice and/or policy

- Healthcare professionals need to be triadic rather than dyadic when communicating issues related to the care of older people with cognitive impairment.
- Healthcare professionals need to be more consistent in working in partnership with family carers, recognizing them as a source of expertise in the specific needs of a person with cognitive impairment.

especially during the early stages of admission where the unfamiliar environment, stress of the emergency department and the admission ward seemed to cause most distress to the patient. In addition, they tried to help members of staff and other patients as well. However, as noted by Quattrin *et al.* (2009), there was little evidence that this was recognized by staff, which left carers feeling used and exhausted. Relatives who spent prolonged periods of time in hospital, often made judgments about the quality of care (Donnelly & Battley 2010), distinguishing between 'good' and 'less good' members of staff (Verhaeghe *et al.* 2010). Qualities that were valued included good listening skills, being available, being engaged and able to respond to unspoken signals (Spichiger 2008) and 'competence' (Thune-Boyle *et al.* 2010). Where members of staff were task orientated or failed to acknowledge family members, the result was distress (Buttery *et al.* 1999, Eggenberger & Nelms 2007) and concern about what might be happening when no visitors were present (Higgins & Joyce 2007). Where family members had concerns about

individual members of staff they are aware that they have to continue to deal with them, which could leave them feeling impotent and frustrated (Verhaeghe *et al.* 2010).

Concern for quality of care is greater when a patient has dementia as it was difficult for family carers to ascertain what had been happening outside of their visiting times. In a sense this could be interpreted as a sense of losing control over the care of their family member. When the patient was perceived to be an unreliable historian, who was unable to remember what was happening and keep family carers informed about it, family carers control was disrupted. We found that some family carers tried to address this by being present on the ward as much as possible and trying to monitor the quality of care while others took a decision to trust nursing staff. A key support for this was communication with staff. However, as reported previously, reassurance was lacking if communication was poor (Van der Smagt-Duijnsteet *et al.* 2009, Thune-Boyle *et al.* 2010). Another key strategy was to provide the care for the person directly. This was done either as a necessity, which seemed to be the case in the emergency room, or later in the ward as a way of helping the nurses and providing comfort to the person with dementia.

Quality of care was perceived to be poor if the family carer said that staff were not listening to them or taking their information seriously; this often served as an indicator that staff really did not know enough about the care of a person with dementia. Listening to family carers and using the knowledge they have of the person with dementia is probably the single most practical recommendation to be made from this data. Information needs include details about the hospital, the illness and its consequences (Higgins & Joyce 2007, Spichiger 2008, Thune-Boyle *et al.* 2010). Being recognized as someone who has expertise in the needs of the patient was important (Eggenberger & Nelms 2007, Söderström *et al.* 2009, Dougherty 2010). When it occurred, such recognition could lead to better 'access' to the patient to be involved in care delivery (Buttery *et al.* 1999).

Limitations

There are several limitations with this study. Only a third of carers invited to be interviewed agreed. The relatively low response rate might be because the carers had a wide range of relationships, backgrounds and competing priorities on their time. Some carers were recently bereaved; others had negotiated transitions to new care arrangements or care homes. At the point where potential participants indicated their willingness to be contacted to be interviewed (near the time of admission), it is possible that they did not fully realize other demands that they would face. However,

this study was larger than any previous work in this area. The cohort from which the interview sample was selected was systematically assembled and we are confident, however, that data saturation occurred. As with any qualitative work findings are open to different interpretations. Interviews took place some weeks after the hospital admission, which will have permitted reflection on events and this may have changed opinions. Events may not have actually occurred as reported, or they may reflect misunderstandings, ongoing difficulties or problems outside the hospital.

Conclusion

Family carers are not passive in the face of the disruption of hospitalization and respond both by trying to involve themselves in the care and support of their relative and by trying to work in partnership with members of staff. For patients with dementia communication must be 'triadic' rather than 'dyadic'. Patients often had difficulty communicating and the family carer needs to be constantly updated and involved in decision-making. We found some examples of good communication, but many family carers considered the communication that they received to be poor, demonstrating a lack of insight on the part of healthcare staff.

It is unlikely that family carers will report better experiences of care unless staff know 'where they are coming from', what they are thinking and why, appreciate their special relationship with a person with dementia (or other mental health problem or cognitive impairment) and recognize the emotional, psychological and practical needs of many family carers themselves. Family carers of such patients have different concerns and needs from other family carers. Healthcare professionals need to be more consistent in working in partnership with these family carers, recognizing them as a source of expertise in the specific needs of a person with dementia, as a source of direct care for their family member and also as a partner who needs to be welcomed, supported and kept informed.

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Conflict of interest

No conflict of interest has been declared by the authors.

Author Contributions

All authors have agreed on the final version and meet at least one of the following criteria [recommended by the IC-MJE (http://www.icmje.org/ethical_1author.html)]:

- substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
- drafting the article or revising it critically for important intellectual content.

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