Support for carers of people with dementia during hospital admission

Abstract
The aim of this study was to help develop support services for carers of people with dementia on admission to a district general hospital. Qualitative methodology was used in the form of individual semi-structured interviews. These interviews suggest that service developments need to take into account the individual need of each carer. Identified themes included communication, vulnerability of the carers and the need to develop a therapeutic relationship with the carer as well as the person with dementia. Recommendations for change include a letter introducing the dementia specialist nurse to be given to carers, a poster in wards across the trust to support the letter; and workshops on dementia care for staff with emphasis on the need to work in partnership with informal carers.

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The number of people with dementia being admitted to the acute setting is rising. According to the Royal College of Psychiatrists (2005), ‘older people consume approximately 40 per cent of healthcare resources in England and Wales, occupying two thirds of general hospital beds. A typical hospital of 500 will, at any time, be occupied by 330 older people.’ Two hundred and twenty of these will have mental disorder, of which 102 will have dementia and 66 delirium. It is important to realise that a significant number of these patients will be looked after in the community by relatives.

There are said to be two main sources of difficulty in caring for people with dementia in hospital: hospital systems and the relationship between nursing staff and carers (Walker and Dewar 2001). This article addresses the latter. We have explored the needs of carers for people with dementia when they are admitted to an acute hospital ward with the intention of developing a service around these needs.

Carers of patients with dementia experience high levels of stress that can adversely affect their health and well-being (Argimon et al 2004). Carers may well be isolated by the very act of caring, feel fatigued and have high levels of psychological stress, often with an increased risk themselves of psychiatric and physical morbidity and increased mortality rates (Bruce et al 2002). This high level of stress can be exacerbated by a hospital admission. For people with dementia and their carers, hospital is often an alien environment; the carer often does not know what role to adopt and can feel disempowered (Ashworth et al 1992).

Carer stress should be taken seriously as it is an important issue for public healthcare: negative health experiences can ultimately affect the continuance of the caring role. The emotional health of the carer determines the flexibility of providing care, while physical health determines how much care the carer can safely provide.

By helping carers develop a positive perception of the admission process, the nurse can support carers who may subsequently acknowledge the...
need for help with emotional reactions that admission to hospital can accentuate. Professionals should therefore focus on the carer as well as the person with dementia. The carers’ needs should be included in any care plan for the person with dementia to ensure that adequate family support is continued. The nurse should be proactive in making contact with the carer and develop a therapeutic working relationship. Recognition of the family caregiver rather than the nurse as the expert on the personal care of the person with dementia is fundamental in developing a meaningful relationship between the nurse and the family (Gilmour 2002).

There are a number of useful interventions which may help maintain relationships with close family and friends and would be mutually beneficial for both the carer and the nurse (Nolan and Dellasega 1999). These include creating a welcoming environment which encourages and supports visiting and working with carers, maximising involvement and facilitating a sense of purpose, valuing and assessing the carer’s knowledge and expertise and utilising this as an important part of care planning.

The Carers Act (1995) was the first piece of legislation to formally recognise the carer’s role. It calls for a greater recognition of carers, which includes paying close attention to what they say. However, nurses can find their relationship with carers to be a source of anxiety and stress, causing them to adopt a defensive attitude to complaints which are often regarded as personal criticism, creating a barrier to effective communication (Walker and Dewar 2001). Indeed, many healthcare workers fail to value the knowledge and expertise of the carer and even feel threatened by proactive carers (Keady and Nolan 1994).

We set about identifying the needs of carers of people with dementia in the acute setting with a view to informing service development. A search of the CINAHL and BNI databases using the keywords dementia, carer and general hospital revealed that little research has been done on carer issues and we set about redressing this.

**Study participants**

Carers were identified by going around the ward of the DGH and identifying patients with known dementia who were cared for at home. An introductory letter was passed to the carer describing the research and its rationale. Nine people responded and these were contacted by phone to arrange a meeting once the person with dementia had been discharged so that carers could respond honestly with their view of the interaction with staff. After discharge interviews were arranged in a place to suit the carer.

Participants included two husbands, one wife, five daughters and one daughter-in-law. Four of these carers lived with the person with dementia whilst the other carers lived within a five mile radius.

Information (in letter form) on complaints procedures and how to access the Patient Advice and Liaison Service (PALS) was also given to participants in the introductory letter. Consent forms were signed at interview and each interview was taped and transcribed. Each carer was interviewed in a quiet room in the hospital with the exception of two participants who were interviewed at home. The length of the interview varied between 60 minutes and 90 minutes.

**Ethical issues**

Ethical approval was sought from the local Research Ethics Committee: South Devon LREC. This consent was continually negotiated throughout the study and participants were informed that they could withdraw at any time during the process. The participants were assured that their confidentiality and anonymity would be respected. Participant well-being was monitored throughout and participants were made aware in the initial letter of where to find further emotional support or to make a complaint about procedure during hospitalisation. Interviews were arranged post discharge to remove any bias that might occur in the responses of the interviewees.

**Results and discussion**

From the interviews it became obvious that failure to develop a therapeutic relationship impacted not only on the well being of the person with dementia but also on the emotional wellbeing, and consequently the continuation of the caring role, of the carer. As the person with dementia becomes more distressed, the emotional effects on his or her physical recuperation begin to have an effect on outcomes, such as increased chance of institutional care and loss of skills which increase the ‘burden’ on the carer. Six themes emerged from the data. These were:

- Communication
- Nurses’ poor understanding of dementia
- Carer vulnerability
- The need for advocacy
- Long term effects of being in hospital
- Therapeutic relationship

**Communication**

One of the most enduring themes was poor communication from the admission process through to discharge. Carers often had invaluable insight into the needs of the person with dementia and this...
information though shared with the healthcare professional was often felt to be ignored. Carers often felt that they were excluded from decision-making and discussion on prognosis and diagnosis especially when the person with dementia was unable to recall information due to short-term memory loss.

‘You do expect to be told what is going on, especially when it’s someone like Dad who cannot discuss it himself with the doctor.’

Communication is basic to the development of relationships, poor communication often gives rise to greater misunderstanding and conflict. Part of being responsive to another person is to listen; this requires attending to that person and attempting to understand the message being given (Grover 2005).

**Nurses’ poor understanding**

Themes that constantly emerged were markers for concern and improvement. There was a general feeling that the carer acknowledged that the nurse was busy, expressing support and concern. The carer was usually happy about the general care received but felt that nurses lacked an understanding of dementia on the whole even though reassurance was given to the contrary. In some cases the ‘business’ of the nurses impinged on the quality of care.

‘I cannot praise the staff highly enough, they were unceasingly kind and gentle with her but they did not understand her condition or her specific needs, and they were totally at a loss to understand how to treat her.’

In one case the nurse had obviously not understood that the family would be aware of the father’s dementia and went out of her way to prove a point that actually showed her lack of understanding of the condition.

One family member said: ‘We know Dad is muddled up. But she was telling us this as if it was something new, I said we know he’s muddled and he’s going to be even worse because he’s in hospital. He’s not very well. She said to Dad – I think she probably was thinking that this would demonstrate how muddled he was – “Who is the prime minister?”’, and I knew that my Dad would know who the prime minister was. He said, “Tony Blair”.’

**Carer vulnerability**

One of the most enduring themes was the feeling of vulnerability of the older carers in particular.

‘When you go into hospital it is one of the most vulnerable times of your life. You walk in and you are terrified of everything and you listen to every burp and murmur that nurses give you. I suppose you pick up on every thing nurses tell you. It’s the time when you need someone to be nice to you, a little bit of tender loving care I suppose.’

‘I think it would be good if the nurses had an understanding of how stressful it was for you when you came in. You might not be in the right frame of mind to pursue seeing a doctor. I was just trying to keep everything together and really needed support especially when having to seek information.’

**Advocacy**

During the interview, one carer said: ‘It seems to me that in embracing the technology which we all need and love because it saves far more lives than it did ten to 20 years ago, the treatment of the person as an individual has somehow been lost’

The need to advocate for the person with dementia was a common theme running through the interviews. Carers felt that they needed to be with the person with dementia in order to ensure that their needs were met especially for those patients where communication had become difficult. Carers acknowledged the emotional impact that being in hospital had on the person with dementia.

‘She was very frightened and very confused but she was fine as long as I was with her.’

Individual carers need to have the opportunity to establish with health care professionals the level of involvement they want (Waterworth and Luker 1990. Dewar et al 2003). It also needs to be recognised that informal carers may need to learn how to be involved.

**Long term affects of hospitalisation**

Care staff frequently fail to recognise and draw upon the expertise of family caregivers when planning and implementing care for the older person with dementia.

‘At the time when she came to the ward she was fully mobile, able to take herself to the toilet and eating and drinking normally. I told the nurse that my mother had a history of refusing to eat or drink if she was frightened, lonely, confused and somewhere where she didn’t know the people. I gave them the name of her psychiatrist.’

A strange environment and unfamiliar faces can have a negative effect on people with dementia. Refusing to eat and drink is common and can lead to further deterioration in well-being.

‘She was virtually unrecognisable as my mother. She had lost a tremendous amount of weight, and she couldn’t walk and wasn’t eating and drinking. It was doubtful whether she could actually go back to the residential home.’

This person with dementia eventually responded
To be being back in her own familiar environment. Her appetite improved and she began to put weight on.

**Therapeutic relationship**

Developing a relationship with the carer as well as the person with dementia ensures that the wellbeing of the person with dementia is at the forefront of care.

‘I felt that if I had seen and spoken to somebody then perhaps we could have made a plan of her care needs and her treatment, not of the chest infection but of her Alzheimer’s and her needs.’

A therapeutic relationship can be defined according to Peplau (1991) as ‘a relationship that develops in predictable ways with behaviour changes from stage to stage’. In addition to growth and self maintenance the goals to attaining an effective therapeutic relationship have been identified as the forming and maintaining of a supportive relationship that enables patients/carers to express concerns and feel that they have been understood. In turn, such a relationship maintains and preserves quality of life thereby reducing stress and frustration and the feeling of being isolated (Williams and Tappen 1999).

‘It wasn’t until about two days before he came out that one of the nurses came and sat on the bed with me because she realised I was upset. She did take the time to speak to me then and said, “you know you have got to think about how difficult it will be looking after him”. She was the first person to acknowledge this.’

**Conclusion**

This study highlights the need to develop a therapeutic relationship with the carer as well as the person with dementia. The person with dementia and their carer should be seen as one unit as anecdotal and observational evidence suggests that any behavioural changes in the patient may be partly due to separation anxiety from their carer which in turn leads to frustration and anger at being abandoned. The study also highlights the need to recognise that older carers in particular are themselves vulnerable. Stress from caring accumulates and may interfere with the carers’ ability to cope with hospitalisation of their loved one, not to mention the added burden of an empty house and travel. This stress, together with prolonged hospitalisation, can have an impact on the caring relationship.

**Implications for practice**

This study set out to determine how to develop a service for carers of people with dementia while in a general hospital. Staff needs to feel empowered to take a more proactive approach to changing practice. What constitutes an effective level of involvement with the person with dementia and their carer will also depend on the individual’s needs. The challenge is to develop a service that effectively supports and informs carers of people with dementia, moving towards working in partnership. From the small study, we are able to make recommendations as to how this relationship can be improved:

- A letter introducing the dementia specialist nurse to be given to carers of people with dementia on admission, giving the carer the opportunity to discuss any concerns
- Posters in all the wards to support the introductory letter
- Workshops on various aspects of dementia, to include the biological, psychological and social perspectives with an emphasis on the need to work in partnership with informal carers

**References**

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