How nurses can support informal carers of people living with dementia

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Abstract

There are 7 million carers in the UK, of whom 11% care for people with dementia. One in five people aged 50-64 are carers. This article explores the difficulties faced by informal carers, and highlights the need to support and care for them, as well as the person living with dementia. It suggests how nurses working in hospital settings can recognise and understand the physical and emotional health needs of informal carers through appropriate engagement, assessment and inclusion.

Keywords

carers, dementia, neurology, older people, patients, professional

The context of carer burden

Carer burden is a consequence of the demands made of informal carers, and the financial, physical, social, psychological and emotional...
stressors they experience (Kasuya et al 2000). Perhaps unsurprisingly, informal carers can find carer burden oppressive and worrisome (Hunt 2003), even though caregiving is often rewarding. Reinhard et al (2008) suggest that, because informal carers often need help and support, they can be referred to as ‘secondary patients’. Nurses must be aware of such situations, and should be able to act on them in a proactive and timely manner.

There is little research into informal carers’ lives and carer burdens from before the 1950s, when people with dementia were deemed to have mental health problems and often sent to asylums (Kuipers et al 2010). Today, the effects of a dementia diagnosis on carers are better understood. Carers who are older or who have co-morbidities can experience particular difficulties, and may feel overwhelmed by what is expected of them. The long hours spent providing care may have a negative effect on carers’ health, well-being and quality of life (Butcher et al 2001, Etters et al 2008, Lewis et al 2014, Manteau-Rao 2016).

Cuijpers (2005) suggests that disease progression relates to high stress levels in carers, specifically the ways in which the nature of advancing dementia transforms the relationship between the carer and the person (Schulz and Sherwood 2008). For example, although a person with dementia may appear the same physically, they are different in mind and personality. They may no longer be the same person who led an active social life, enjoyed meals out with friends, holidays with family or worked hard to provide for their family. They no longer remember the person they were. Such changes can generate considerable distress and symptoms of bereavement, which Boss (2007) describes as ‘ambiguous loss’. This loss is felt, not when a loved one dies, but when there is a change in the person caused by the disease process. The ambiguous loss theory explores how these life events can be understood and how nurses can aid in the process of transition for the spouse, who is now the carer for a person who may not recognise them.

It is also important to be aware of the financial implications. While informal caring may lead to time out of the workplace and even unemployment, it may also involve additional expenditure to support the caring role, for example to purchase appropriate furniture, or fund respite care or even carers (Nguyen 2009, Carers UK 2014, Gordon 2016). All of these will add to the stress experienced by the spouse who may be coming to terms with the dementia diagnosis and the realisation that the condition is progressive.

As healthcare professionals, nurses should be aware of the potential burden of spousal caring and identify carers’ stressors. The nurse’s role is to gain a clear understanding of the carer’s needs, provide effective communication about the patient’s condition and care management while hospitalised, and signpost them to agencies that provide help and assistance.

**Engagement with carers**

During an acute hospital admission, it may be identified that a person’s dementia is progressing. The person may be becoming increasingly frail, or physically and cognitively presenting with agitation and confusion. Holistic assessment may reveal that continuing homecare may no longer be feasible and long-term care must be sought (Yaffe et al 2002, Brodaty and Donkin 2009). At this point the family will have to make, or be involved in, decisions about future care, for example about transitions to institutionalised care (Livingston et al 2010, Bahrampour 2016). In making these decisions carers may experience feelings of guilt and anxiety, especially if the person with dementia does not want to go into care. Good communication is vital, therefore, to ease informal carers’ stress.

Nurses should introduce themselves at the earliest opportunity in a friendly, professional and competent manner because informative and empathetic communication can help relieve the carer’s stress and anxieties. Clissett et al (2013) suggest that families respond positively when they are actively involved with healthcare professionals during hospitalisation. Ensuring that carers are fully aware and involved with medical management and discharge planning can therefore prevent carer dissatisfaction and unnecessary complaints (Whittamore et al 2014).

The use of professional language, especially nursing jargon, can be an added stressor and should be avoided. Core terms and phrases, such as deprivation of liberty, capacity and best interests, may mean little to carers and, if used, should be explained. According to Rosa et al (2010) families who care for their relatives with dementia need psychological support due to their carer burden. However, Wills and Soliman (2001) assume that a ‘need’ should be considered as individual to the person requesting it. In relation to dementia, ‘needs’ can change as a result of the deteriorating process. Nurses can identify carers’ needs by referring to Bradshaw’s (1972) taxonomy of needs (Table 1).

Carers who express a need that is unmet are more likely to believe that they can no longer
cope. Ultimately, their loved ones will either be admitted to hospital or a long-term care environment (Anderson and Gaulger 2006). There is a burden of guilt, especially if they have promised to never put their loved ones in a home, and fear of what will happen.

Identifying the level of care a person requires may help to plan appropriate support for the carer after the loved one is admitted to hospital. The Bayer Activities of Daily Living Scale (Hindmarch et al 1998) rates the ability to perform an activity of daily living (ADL). A score of 1 indicates that a person can undertake ADLs independently. Nagaratnam et al (2013) explain that the scale measures functional impairment objectively by use of a questionnaire completed by either the principal carer or close family member.

The General Health Questionnaire (GHQ) (Goldberg and Williams 1988) is useful in understanding sources of distress and predisposing factors, and can be used to detect depression, anxiety, somatic symptoms and withdrawal (Jackson 2007). Questions include: ‘Have things got on top of you?’ and ‘Are you getting edgy and bad tempered?’ Stirling et al (2010) state that a score of more than 3 may suggest the presence of a non-psychotic mental health problem that requires further investigation. Ill health in informal carers is not uncommon with presentations ranging from minor to life-threatening conditions (Stirling et al 2010).

Health professionals working with people with dementia should be able to prevent this level of stress from occurring. Nurses should help carers make sense of changing situations and form ‘meaningful partnerships’.

Even though carers appear stressed they may resist or refuse support services, for example, care home respite. There may be two reasons for this: the financial cost, and guilt and worry that the person may not receive the same level and quality of care that they would at home. In some areas of the UK there are a small, but expanding, group of Admiral Nurses who have extensive experience in working with people with dementia, and whose role is to help and support those living with dementia and their families practically, clinically and emotionally (Dementia UK 2019). Such services are invaluable where patients and carers wish to continue care in their own home. The Dementia UK (2017) Strategy 2017-2020 indicates that Admiral Nurses have a positive effect and are cost effective.

**Caring for the carers**

Clear communication is essential when caring for people with dementia and when interacting with their carers. Negative language can have a detrimental effect. Critical media stories about the care of those with dementia in hospitals can exacerbate family carers’ stress and anxiety. Expressing empathy and clarifying understanding is essential to ensure good rapport is maintained between nurse and carer (Thompson 2015).

Much work has been done to make hospitals more dementia-friendly environments, including the creation of shared care wards where mental health and general medicine staff work together. These environments have been beneficial to family carers as well as those with dementia (Whittamore et al 2014). Specialist clinical environments are more suited to meeting patients’ physical needs and the effects of dementia, such as confusion and agitation, can be managed in them more appropriately (Harwood 2013, Whittamore et al 2014, Thompson 2015). Staff in these environments have been appropriately trained, which leads to better care and more involvement with families about treatment options.

**Conclusion**

When patients with dementia are admitted to hospital it is essential that nurses develop the ethos ‘we are about our carers’. Recognising the role of the carer for patients with dementia is fundamental because they are integral to the patient’s life and ongoing support after they are discharged from hospital. The ward-based nurse is in a prime position to communicate effectively with carers, and to ensure they are consulted and involved in patients’ care plans and management during their stay.

Hospital nurses must also recognise that carers need emotional, physical and financial support to continue in their caring role, and must strive to refer carers to relevant support services. Such interventions ensure families are confident that support services are available and can therefore support earlier hospital discharge.

### Table 1. Taxonomy of needs

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<thead>
<tr>
<th>Type of need</th>
<th>Description</th>
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<tr>
<td>Felt</td>
<td>Individual perceptions of variations from normal health</td>
</tr>
<tr>
<td>Expressed</td>
<td>Individual seeks help to overcome variation from normal health (demand)</td>
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<tr>
<td>Normative</td>
<td>Professional defines interventions appropriate for the expressed need</td>
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<tr>
<td>Comparative</td>
<td>Comparisons between needs for severity, size, range of interventions, cost</td>
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(Bradshaw 1972)
nursingolderpeople.com

References


