Incontinence and dementia: providing innovative family care

The prevalence of incontinence among people diagnosed with dementia

The prevalence of incontinence for Australians has been approximated as 800,000 in 1995\(^4\), while in 2005 the condition is thought to affect approximately 2 million Australians\(^7\). The rate of incontinence for people who also have dementia is unknown\(^6\), although Ouslander\(^8\) identified two studies that revealed a prevalence rate of 23-53% of older people living in the community as also reporting incontinence.

There are approximately 18,200 people newly diagnosed with dementia annually, with around 9,900 people aged 60 years or less also having the condition\(^9\). During 2005, it is estimated that 200,000 people diagnosed with dementia will also report symptoms of incontinence\(^9\).

Dementia care in Australia is provided in a range of different settings, the most frequent being community home settings (80%) and nursing home or residential aged care environments (20%)\(^9\).

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The combination of cognitive impairment and incontinence may be one of the eventual predictors for institutionalisation of people with dementia\(^6,5\). The focus of this paper is to discuss evidence based considerations, techniques and insights on how to support caregivers of people living in the community with dementia and incontinence.

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Thirty percent of Royal District Nursing Service South Australia – RDNS (SA) – clients, approximately 800 individuals, have a diagnosis of dementia\(^10\). The severity of the dementia can vary; of these 800 individuals, 40% have mild dementia, 46% have moderate dementia and, most interestingly, 14% have severe dementia but are able to remain in their home. Ninety percent of RDNS clients diagnosed as having dementia live alone.

Dementia is a decline in intellectual ability to the point that it interferes with social or occupational functioning. The medical diagnosis of dementia denotes a cluster of symptoms or disorders that are evidence of a cumulative and degenerative effect on the normal neurological pathways of the body\(^11\).

Incontinence is not an inevitable result of dementia\(^12\) but may occur due to the inability of the person to interpret normal bodily cues, the loss of the ability to recognise toileting facilities and inappropriate social behaviours\(^5,13,8\). However, dementia and functional impairment are frequently associated, and the link between dementia and incontinence has been demonstrated in many studies and professional papers.
The issues for caregivers

Each person’s coping ability is different and there are sometimes cultural taboos that prohibit caregivers from expressing that a problem exists or from accepting help, as to do so would be to admit failure.

The social implications and stigma attached to incontinence are often the reason that people seek help. A high standard of personal hygiene is expected in our society and adults are expected to have control over elimination. For people caring for a person diagnosed with dementia who is also incontinent, the mundane routines for managing continence take on a greater importance as incontinence intrudes into their lives. Caregivers are confronted with a range of physical and psychosocial demands that challenge them as spouses, human beings and caregivers, often with minimal professional assistance.

A term commonly used is caregiver burden 6, 14, referring to a person’s emotional response to changes and demands that occur as they help and support the person they care for. Some challenges that caregivers have reported are economic burden, adverse health effects for themselves, quality of life and social isolation, loss of sleep and the burden of other co-morbidities or new illnesses and behavioural issues.

Economic

Families will often try to ‘go it alone’ and often purchase inappropriate and costly products from supermarkets and pharmacies without the benefit of a holistic and multifocal assessment to determine need and appropriate products. Within South Australia there is no scheme to assist those people aged 65 or older to purchase disposable pads; this is a significant impost on the limited and often fixed finances of older people.

The increased housework, laundry, need for additional clothing and linen and possibly the need to replace household furniture and floor coverings due to repeated soiling is unreported. Statistics reveal that containing incontinence for older people is big business. In 2001, continence costs for America and Italy accounted for 2% of the total health budget; Italians spent approximately US$1000 per year, per person aged over 65, on incontinence pads alone 15.

Adverse health effects

Spousal caregivers are generally of the same age as the person that is being cared for and therefore often suffer from their own health issues; these may be exacerbated by the additional burden of containing incontinence. A variety of studies 1, 4, 15 during the last 2 decades reveal that this factor contributes as much as incontinence to perceived caregiver burden and often leads to caregivers to look to alternative care provision.

Quality of life

The caregiver is often embarrassed by the person’s behaviour, and may be reluctant to accompany the person in public. Hence, both of them can become prisoners in the home. Social isolation, decreased finances, adverse quality of familial relationships (associated with the shift of care to younger members of the family who are unable or unwilling to provide assistance to the primary caregiver), and adverse health outcomes for the caregiver all impact on the quality of life of the carer 12, 16, 17.

The relationship between caregiver and the person with dementia may also change, particularly when the caregiver is a spouse. A significant loss of intimacy can result from both the physical manifestation of incontinence and the pathology of dementia as the sufferer can misinterpret normal sexual advances and the caregiver may be repulsed by the actuality of intercourse because of incontinence. However, one report demonstrates that hugging and kissing may increase as sexual intimacy decreases 16.

Loss of sleep

Loss of sleep rates highly in the caregiver burden scale, with many carers stating that they seem never to escape the burden over a 24 hour period as they are woken multiple times during the night to toilet or change the linen of the care receiver. A loss of rest and sleep can lead to an increase in the other areas of burden. Spouses and family members giving care to a person with dementia are nearly twice as likely to have symptoms of depression compared with caregivers of people who do not have a dementia illness. They also have higher rates of chronic illness and are twice as likely to be using psychotropic medications for depression or anxiety as people who are giving care to someone without dementia 18.

Physical complications

Often the incontinent individual will also have urinary tract infections, sleeping difficulties, depression, skin problems and pressure sores. All of these complications may compound the caregiver burden and may singly or collectively add to the decision to institutionalise the individual.

Disruptive behaviour

The nature of dementia can mean that the caregiver may be confronted by disruptive or aggressive behaviour when assisting the person they care for with toileting 11. A full assessment of the person requiring care can help to determine the cause of this behavioural change, as it may not be the dementia that is causing the behaviour. In the event that the behaviour is directly related to the dementia, the general practitioner will be able to refer the caregiver on to an aged care mental health agency that can
provide the appropriate support and interventions to deal with the behaviour issues. Being unable to cope with behavioural changes may be a reason that carers seek alternative care such as residential aged care 19.

There are other factors that may help reduce the carer burden. These include:
- Help from other family members,
- The ability to use problem-focused coping strategies,
- Support from community agencies.

While there is a focus in the literature on the negative consequences of care giving, there is also evidence that there may be benefits which can be achieved using strategies to improve the relationship between caregiver and care receiver, and those that empower the carer such as recognition of their usefulness 19,20. Nolan 20 focused on the positive aspects of family care giving and found that family relationships can be enhanced through expressions of appreciation, love and affection, a sense of dignity and achievement, reduction of guilt, development of personal qualities such as tolerance and patience, development of skills and abilities in caring and existential satisfaction.

**Nursing interventions**

The management plan for those with a cognitive impairment and symptoms of incontinence should encompass realistic aims that can be implemented within the environment 21. The level of cognitive ability will be a significant predictor of success with scheduled training programmes. For individuals with a greater degree of impairment, other methods will need to be employed.

Comfort and dignity must rate highly in any management plan 13,22, and the caregiver is generally the best judge of the care receiver’s capabilities and limitations. A primary health care approach of working ‘with’ people to plan care becomes profoundly important. To set an individualised management plan, it is vital to have a thorough nursing, medical and pharmacological, holistic and multifactorial assessment. Some innovative nursing care considerations that may help to minimise caregiver burden include a review of modifiable risk factors that may exacerbate incontinence such as recurrent urinary tract infections, constipation, poorly controlled diabetes, hypertension, pain and functional mobility issues.

It is important to support and develop knowledge of the care receiver’s toilet cues such as fidgeting, getting up and down multiple times, repeating the same word, attempting to remove clothing, agitation and wandering. Providing the caregiver with voiding, bowel and food journals to appropriately map input and output over a designated period of time can assist the nurse to predict when incontinence occurs in relation to other daily events, such as time of taking medicines, bedtime, change of carer, food and drink intakes and exercise or exertion.

Physical assessment should be undertaken to determine pelvic floor strength and eliminate or ameliorate other co-morbidities that could impact on toileting programmes such as haemorrhoids, vaginal or rectal prolapse, thrush, vaginitis, poor pelvic floor muscle function or hernias.

The management plan should be developed and regularly reviewed in consultation with the individual, their caregivers and, if possible, include the wider family unit. The plan should include key factors such as ensuring adequate daily fluid intake. Approximately 5-8 glasses of a variety of fluids 22 should be consumed; those fluids can include jelly, ice cream and custard. People with dementia are often reluctant to drink and gentle encouragement at favourable times of day and a greater variety of fluids can be explored. A review of the caffeine intake in both food and fluid and an endeavour to avoid caffeine intake in the late afternoon to reduce nocturia is possible; a trial of decaffeinated tea and coffee could also be of benefit.

A trial toileting routine for bowel management could be established – make use of the morning gastro-colic reflex following this effective routine for bowel evacuation 23,24. For example, encourage the individual to eat an orange after getting up in the morning, followed shortly after by breakfast and a warm drink. Twenty minutes later, encourage the person to sit on the toilet for no more than 10 minutes.

The community nurse can advise carers what resources and supports are available in their community. Aids to functional incontinence may assist in allowing the care receiver to regain a greater degree of continence than previously thought possible. Aids can be obtained through independent living centres, aids and equipment suppliers, wholesalers and domestic care organisations. Typically, equipment may consist of grab rails, toilet raise, walker, urinals and bedpans 25.

Falls are considered a potential risk of dementia and incontinence 4 and may be secondary to other health complications such as urinary tract infection, loss of mobility, urge incontinence, disorientation, loss of spatial awareness and hypotension. To ensure the safety of individuals, it is important they have regular health and medication checks and for the carer to be aware of signs and symptoms that are indicative of an impending fall. This could include agitation, dizziness or being over eager to get to the toilet. To minimise falls, it is also prudent for those individuals who use recognition cues that the route to the toilet is clear, signposted and well lit.
In developing the management plan, the nurse should allow time and space for carers and family to regain control of a situation. A strategic management plan may indeed ameliorate carer stress and postpone institutionalisation. Carers and family members should be provided with written, oral and visual information whenever possible to guide and support them towards achieving improved lifestyle outcomes for the person with dementia and themselves. The role of the nurse can be to provide encouragement and support to help the caregiver and the individual to see and celebrate the ‘wins’ rather than continually focus on the problem.

Conclusion

Embarrassment, frustration, fear and social stigma prevent many people from discussing incontinence. People often fail to seek information and immediate help for the problem. Individuals and caregivers, therefore, miss out on opportunities for an early assessment and diagnosis. Incontinence, in many instances, can be successfully treated, managed or even cured.

It is important to consider the impact of a dementia diagnosis on the structural, physical and psychological wellbeing of any family unit. Incontinence compounds the turmoil that a family experiences and it is a testimony to caregivers that they surmount the burdens.

Contidence management, including toilet assistance, can be a major cause of caregiver burnout. Therefore nursing interventions need to be clinically effective and should take account of what carers need and not what nurses think they need. Nurses have a duty of care to examine each situation individually and develop innovative, creative and enlightened health care plans to contain the consequences of incontinence and dementia.

References