



# Newsletter

## Management of urinary incontinence in people with dementia: an occupational therapy perspective

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### Introduction

Management of urinary incontinence (UI) for persons with dementia can be a real challenge. Incontinence contributes to caregiver stress<sup>1</sup> and can be a significant factor in the decision to move into a care home.<sup>2</sup> Local study has shown that UI commonly occurs in people with dementia,<sup>3</sup> with the prevalence increasing as the severity worsens.<sup>4</sup> The syndrome of dementia result in progressive deterioration of cognitive and physical functioning, that impacts upon the ability of the individual to maintain continence. Besides, behavioral and psychological symptoms of dementia can manifest in socially inappropriate voiding and toileting behaviors.<sup>5,6</sup>

Enhancing the abilities of individuals with dementia to engage in activities of daily living is the core occupational therapy services. Occupational therapists address a wide range of the patients & their care-givers' concerns and help them to increase the sense of competence by facilitating them to develop strategies for managing UI.

### Assessment

Continence status in persons with dementia may be affected not only by lower urinary tract functions, but also by cognitive-perceptual functioning, physical and hand function, environmental factors, psychological distress, and motivation etc. A comprehensive occupational therapy assessment (Table 1) becomes the basis for tailoring treatment to individual's needs .

Cognitive-perceptual domain:	◇ the severity and nature of cognitive-perceptual deficits e.g. attention, memory, orientation, problem-solving, body scheme, spatial relations etc
Sensory-motor domain:	◇ visual skills, tactile sensation, range of motion, manual dexterity or upper limb strength to reach and clean after toileting etc
Functional domain:	◇ abilities in toilet transfers, manipulating clothing and managing flushing system etc
Psychosocial domain:	◇ the patients and their care-givers' attitude towards incontinence as well as the effects on quality of life
Environmental domain:	◇ the existence of environmental barriers that could limit access to the toilet and the need for assistive devices e.g. commodes and urinals
Behavioral domain:	◇ any behavioral disturbances (e.g. depression & apathy) that may affect volition to maintain continence and co-operation with toileting assistance

Table 1. Occupational therapy assessment: incontinence in people with dementia

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## Intervention

### **Functional skill training**

The symptoms of dementia have a significant impact on a person's ability to complete daily activities independently.<sup>7c</sup> Functional skill training for people with dementia has been routinely conducted in different clinical settings to enhance functional performance in self-care activities and minimize the risk of excess disability. Most self-care activities are over learned behaviors,<sup>8</sup> that may be regained through the intensive practice and repetition.<sup>9</sup> Physical demonstration, prompting, positive reinforcement and graded assistance are regarded as a crucial element of functional skill training.

### **Cognitive and perceptual training**

Deficits in cognition and perception experienced by people with dementia have an effect on the ability to manage the personal activities of toileting e.g. difficulty in locating, recognizing the toilet. Cognitive-perceptual remedial trainings place an emphasis on enhancing and maintaining impaired cognitive-perceptual skills e.g. attention, memory, spatial relations. Interventions take place in a variety of formats and with varying content e.g. computer-based practice. Occupational therapists utilize various guiding principles (e.g. errorless learning) in training sessions. As implicit memory function remains relatively intact in Alzheimer's dementia, interventions using implicit learning methods may promote improvements in the performance of everyday functions.<sup>10</sup>

### **Environmental Modifications**

Physical environment (e.g. distance to the toilet and toilet height) can impact on the ability of individuals with dementia to maintain continence. It has been found that environmental hazards may increase the prevalence of UI.<sup>11</sup> Occupational therapists conduct home evaluation to identify potential environmental risk factors, and suggest adaptations according to the needs of the patient. Home modifications (e.g. installation of handrail, design of toilet door and reconstruction/relocation of water closet) may also help to facilitate the safety and accessibility in toileting. The toilet can be made more recognizable with clear signposting, while adequate lighting and easy access toilet are essential.

### **Prescription of toileting aids & Clothing Adaptation**

Toileting aids would be crucial in enabling a person with dementia to continue living at home safely and may also minimize the burden on family care-givers. Occupational therapists recommend a suitable assistive device for the patients and provide adequate training so as to promote proper usage of the device. Grab bars and raised toilet seats are provided to facilitate independent toileting in a person with physical deficits. A study demonstrated that UI is a significant risk factor for falls among older people with dementia.<sup>12</sup> They may be considered a high risk of falls while hurrying to try to get to the toilet in time. It is suggested using a urinal at night instead of getting out of bed to use the toilet.

In addition, clothing could be an important determinant for toilet behavior. It can be difficult for patients to manage tights and zipped or buttoned trousers when they are in a hurry. Occupational therapists provide advice on type of manageable cloths e.g. elasticated pants and trousers, pull-up pants. Simplifying clothing by using velcro straps instead of buttons and zippers can help persons manage their garments more easily.

### **Toileting program**

An individual toileting program is a behavioral technique used to promote urinary continence and reduce the number of incontinence episodes.<sup>13</sup> In general, the less severely demented and more mobile patients are more likely to benefit from toileting programs.<sup>14</sup> One of the essential aspects of toileting program in those with dementia is providing constant verbal reminders to establish a routine. In timed voiding, the toilet visits take place at predetermined times. Prompted voiding is used to teach people to initiate their own toileting through requests for assistance,<sup>15</sup> and it is usually combined with positive reinforcement for appropriate toileting requests. Timed voiding in combination with additional interventions (e.g. incontinence aids and staff training) and prompted voiding are the available evidence-based interventions for UI.<sup>15</sup>

### **Occupational Lifestyle Redesign Program (OLSR)**

UI in dementia can have a detrimental effect on social well-being of patients and their care-givers, and also places varying limitations on occupational activities and lifestyle. It may cause patient and their care-givers to stay at home most of the time and avoid social contact because they have a fear of a urinary accident in public, contributing to a decline in their quality of life. OLSR seek to provide patients and their care-givers with strategies and opportunities to increase in engagement in purposeful and meaningful occupations for life satisfaction. Lifestyle redesign utilizes occupational therapy principles of client-centered engagement in personally meaningful occupations to empower people to set individual goals and to facilitate them to develop personal strategies to achieve such goals.<sup>16,17</sup>

## Care-givers education and empowerment program

Incontinence is reported as the most problematic symptom to manage by family care-givers of persons with dementia.<sup>1</sup> Influenced by cultural norms and personal beliefs, family care-giver always feels embarrassed when they are involved in intimate care. Family care-givers have described in some instances only seeking assistance from health professionals about incontinence problems at the point of crisis.<sup>2</sup> Occupational therapists need to encourage care-givers to express their concerns and worries about incontinence problems, and provide psychological support for them. It is necessary to train care-givers to recognize nonverbal cues that may signal the need to toilet e.g. restlessness, unexplained agitation and tugging on trousers.

### Conclusion

Occupational therapists play a unique role in the management of UI in people with dementia. Given the multifactorial nature of UI, collaboration with other members of the multidisciplinary team is necessary. Treatment of dementia-related incontinence must be always reviewed as continence related problems change over time. Maintaining dignity of our patients and their family care-givers is paramount in continence management.



**Simplifying clothing**

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# *Strategies from Occupational Therapists for patients with urinary incontinence in special needs*

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## **Introduction**

Urinary incontinence is a common health problem amongst elderly population. A survey conducted in 2010 showed that around 54% elderly people aged above 60 years old have urinary incontinence<sup>1</sup>. Urinary incontinence is a concerning issue for people especially in Chinese culture, since many incontinent people are too embarrassed to seek help and they denied the existence of the problem. Thus, the number of people who have the urinary incontinence problem is underestimated in many studies.

People normally associate urinary incontinence to “leaking” or “wetting diaper” but in fact there are some cases that the patients are unable to pass urine. One typical example is those patients with spinal cord injury with supraconal lesions (above conus medullaris), it often leads to simultaneous activation of parasympathetic neurons innervating the detrusor and somatic neurons innervating the external urethral sphincter. The dyssynergia may result in unable to void urine.

The strategies for “wetting” type of urine incontinence are more widely discussed and applied as they are more commonly seen in the clinic for the elderly or post labor mothers. The aim of this article, however, is to focus on the patients who need to use catheter for urine incontinence.

Although permanent catheterization is a kind of effective remedy for people with bladder disorder, it can have a serious consequence on the psychosocial health for patients. Therefore, it is difficult for users and their family to accept the use of long term foley, they may feel troubled and vulnerable to use the device.

## **Psychosocial influences on permanent catheterization**

Permanent catheterization is not only associated with many medical complications (e.g. catheter-associated urinary tract infections, encrustation, and tissue blockage<sup>2</sup>) but also includes the emotional disturbances of users. People with incontinence have psychiatric disorders is a common phenomenon, such as somatization, anxiety and depression<sup>3</sup>. It is more serious for the users of permanent catheterization because their lives are irreversibly altered. They need to continuously self-mange the device. Some studies revealed that the lifestyle of people who are living with a long-term urinary catheter could change dramatically due to the negative experiences. They treat catheter as "foreign subject" and they are too concerned about the catheter presence at all time. Sufferers expressed that catheter messing up their lives instead of helping their health. They are uncomfortable to live with the device<sup>4</sup>.

In summary, the quality of life for patients with permanent catheterization is compromised. Patients with catheterization have to face discrimination in community. They may experience great embarrassment and shame. Therefore, the stigma of alienation forces them to avoid social interaction and activities<sup>5</sup>. At personal level, there are also other effects for patients with permanent catheterization. The practical inconvenience and restricted activities increase their disability and dependency. They may have the feelings of worthlessness, fear, loss of dignity, low self-confidence and loss of autonomy<sup>6</sup>. From the family caring point of view, the tendency of choosing long-term caring placement is increased because the catheter use is a burden for family<sup>7</sup>.

## **Intervention**

By using holistic perspective, Health care professionals should be sensitive to patient individual needs. It is indispensable to acknowledge the difficulties and negative adjustment on patients' lives with permanent catheter<sup>8</sup>. The positive support for people with chronic illness is highly suggested that enable to reinforce their self-management<sup>9</sup>. Occupational therapists thus act as a strong role in reducing the severity consequences of urinary incontinence that is related to environment factors and specific needs for aids and adaptation<sup>10</sup>.

## 1) Clothing adaptation for permanent catheterization

A study found that the visibility or invisibility of the situation is one of the essential factors for stigmatization. Patients living with a permanent catheterization receive discrimination in the community because of the drainage bag's visibility. Users hope that it can be kept invisible, then their health condition will not display in public unwillingly<sup>11</sup>.

Occupational Therapists help patients with permanent catheterization to build up self-esteem and self-autonomy by modifying the clothing for better self-management and minimize stigmatization. There are three main suggested modifications for trousers. First, the hook and loop fastening can be set at the side of the trousers. User can put out the catheter tubing and drainage bag from inside of trousers through this open area (picture 1). Second, the side bag made in same color of fabric was added at the lower part of the trousers. It is easy to conceal the drainage bag in the side bag and keep it below the level of the bladder. Third, the hole could be opened at the bottom of side bag for the outlet port of drainage bag. It is convenient for users to drain the urine if needed to prevent the drainage bag become bulky and make sure users can ambulate freely and naturally (picture 2).

In reality, some male clients with leaking urinary incontinence may use Pauls' tube (external collective device) daytime instead of diaper if they want to have whole day out, which may reduce the trouble of changing diaper. The above mentioned adaptive clothing is also applicable in this situation.



Pic 1 illustration with adapted trousers



Pic 2 illustration with adapted trousers

Trousers can be modified to side opening with Velcro or zip for paraplegic clients (Picture 3 & 4) who need to do intermittent self-catheterization but has difficulties to pull down trousers.



Pic 3 Side opening with Velcro



Pic 4 Side opening with zip

## **II) Adaptive Equipment for Intermittent Self -catheterization**

Intermittent catheterization is an effective method for people who have got bladder dysfunction, especially for neurogenic bladder (spinal cord injury, stroke and Parkinson's disease). It is a widely advocated management because there exist no environmental limitation. Users can perform catheterization at home or public washroom. By inserting and removing the catheter several times during the day to empty the bladder, so no drainage bag is needed. Patient's self-esteem and autonomy would be enhanced when they have enough capability to self manage the device<sup>12</sup>.

Self-catheterization is a complex technique. Therefore, the determinant factors for adopting this technique are patients with good cognitive function, motivation, eye-hand coordination and finger dexterity<sup>13</sup>. For those with normal sensation, hand function and eye sight, nursing colleagues will be able to teach patients to learn this skill. However, problem may arise for various causes and Occupational Therapists can work closely with our nursing colleagues to solve these problems.

Women may have difficulty to palpate the urethral meatus with different postures. A handy finger mirror made by occupational Therapist can facilitate women to locate the structures in the perineum correctly for self-catheterization (picture 3 & 4). For male patients with poor hand functions, a USA designed holder is helpful to stabilize the penis to perform the intermittent catheterization (picture 5). Patients with strong adductor spasm may have difficulties to perform self-catheterization. The leg spreader assists them to separate the legs by placing it between the thighs (picture 6). The enlarged handle (picture 7) and the catheterization clip with adapted cuff (picture 8) are other options for patients with poor finger dexterity and in-hand manipulation to hold the catheter.

## **III) Hand function and skill training**

Aids prescription is helpful for patients. However training is also a crucial element for them. Train up of the pincer grip and use of simulated set-up for patients to rehearse the process of self catheterization before perform on their body directly is also a good strategy lead to success. For finger dexterity training, using simple tools to simulate the process of inserting catheter (Picture 9). Finger mirror acts as a training tool; women can use it to practice until they can palpate the location correctly without mirror. One successful example is that a C7 level tetraplegia wants to achieve self IMC with tendon transfer done to gain lateral pinch. After operation with further hand function training, he can finally use IMC instead of keeping a long term foley.

## **Conclusion**

Physical issue is only a part of problems relate to continence care. Patients are also concern about the environment, clothing, psychosocial acceptance, self-competence for management and functional ability. Therefore, the ultimate goal of occupational therapy intervention for patients with urinary incontinence is to alleviate the psychosocial distress and improve their quality of life.



Pic 5 & Pic 6 Handy finger mirror



Pic 7 commercial penis holder



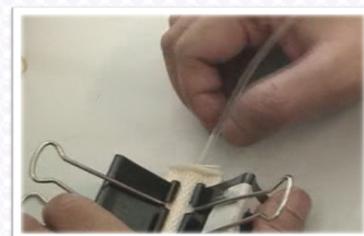
Pic 8 leg spreader



Pic 9 Enlarged handle



Pic 10 catheterization clip with adapted cuff



Pic 11 Finger dexterity

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