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Quality in Ageing and Older Adults

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Meeting the needs of older people living at home with dementia who have problems with continence

Abstract

Purpose

This paper discusses the question of how to meet the needs of older people living at home with dementia who have problems with continence. The paper is focused on social care practice in community settings.

Design/methodology/approach

This paper is practice focused and draws on the authors' research and experiences in clinical care and service development.

Findings

This paper summarizes research on incontinence and its negative effects on quality of life and care relationships. It describes the impact of incontinence in terms of social embarrassment, restricted social activity, extra work (such as laundry) and costs, but also distress. It links research with care practice, with a focus on people with dementia who may be at particular risk of both continence problems and of assumptions that nothing can be done to assist them.

Social implications

This paper provides questions that could be addressed in commissioning and provision of services and argues that they need to be informed by care practitioners' experiences. It provides details of sources of support that are available at national and local levels.

Originality/value

This paper draws together research on continence and social care practice to provide a series of self-assessment questions for local services. It focuses on

social care workers who are at the front-line of practice including Personal Assistants and carers.

Key words: continence, dementia, social care, practice.

Paper type – general

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Background

Incontinence is leakage of urine or faeces or both and is a consequence of a bladder or bowel disorder or other problems such as neurological damage, environmental obstacles, medication adverse effects or severely impaired mobility. The prevalence of incontinence rises with age, with estimates of up to 15% of older women and 2-11% of older men experiencing daily urinary incontinence (Milsom et al. 2013). Among people living in care settings the rates are even higher. The risk of women having urinary incontinence increases with factors like having three or more children, obesity, diabetes and moderate to severe dementia. Paradoxically, constipation is also a potential risk factor (Milsom et al. 2013). We know less about factors that predispose men to urinary incontinence but these include urinary tract infections, disability and dementia and other brain disorders, and prostate problems. Among people aged over 60,

rates of faecal incontinence are 5.1% in men and 6.2% in women (Milsom et al.2013), and these increase with age. The risk of faecal incontinence increases with conditions such as a stroke, dementia and also with obesity, although it can also be caused by intestinal disorders including food intolerances, infections and the interplay between loss of mobility and declining cognition (Koebel et al 2013). For some people with physical and/or cognitive impairments incontinence is the result of lack of aids, unadapted environments or lack of timely assistance rather than a physical bladder or bowel problem.

Incontinence impairs quality of life and adversely affects mental health (Newman et al 2013). It can be social embarrassing, restricts social activity, creates extra work (such as laundry) and can mean money has to be spent on replacement clothing and bedding. It can cause conflict between individuals and their family (Brittain and Shaw 2007) and it make caring harder. Other health problems may get even worse, and it can lead to events such as falls and hospitalisation (Brown et al 2000).

There are no UK estimates of the total public expenditure associated with treating or managing incontinence, but there are some indications of the costs of incontinence to the health service. In 2014 in England £52 million was spent on incontinence appliances, e.g. catheters and bags for people living at home (Health and Social Care Information Centre (now NHS Digital) 2014). Reports of National Health Service (NHS) spending on absorbent pads for adults living at home are hard to find but one organisation commissioning services for a

population of 232,00 people reported an annual cost of just under half a million pounds a year (Bexley Clinical Commissioning Group 2013). Commissioning health and social care services that promote continence and prevent incontinence is important not just for the public finances but for the health and well-being of individuals and their family carers (NHS England 2015).

The rates of urinary incontinence for people with dementia living at home are double those of people of similar age without dementia and the rates of faecal incontinence are triple (Grant et al. 2013). The loss of cognitive abilities, as well as behavioural and psychological problems in people with dementia can result in disorientation, lack of concentration, lack of recognition of the urge to urinate or defecate, growing inability to locate the toilet, difficulty in managing their clothes and in emptying bladder or bowels appropriately (Stokes 2000). Incontinence is known to be a significant factor in the decision to move to care home made by or for people with dementia (Caldwell et al. 2014).

This paper highlights the key actions in seven areas that practitioners working with older people with dementia in the community could consider when helping to promote continence and manage incontinence, in order to minimize the harmful or distressing consequences for the service user, family carers and other people working in health and social care services or beyond. They are potentially relevant to home care workers, personal assistants and day care service staff. Each action point is elaborated by a brief explanation and followed by a range of questions raising key points for managers, funders, and social care workers to

consider. The paper is drawn from work conducted for the EVIDEM- C project (Drennan et al 2015, Box 1) and synthesizes some of its key findings for frontline care workers who wish to provide good care in this often neglected area of practice.

Box 1: A summary of the EVIDEM-C study

EVIDEM-C was a series of studies investigating how to improve health and social care practice for people with dementia and incontinence who lived at home, and for their family carers, In these studies we talked to people with dementia, their family carers, health and social care professionals about what the problems were and their views of how best to address them. We also reviewed the research evidence, investigated the prevalence of these problems, examined local policies and developed and tested some tools to help primary care professionals.

EVIDEM-C was part of a programme of research into improving dementia care (Iliffe et al 2015) <https://www.journalslibrary.nihr.ac.uk/pgfar/pgfar03030/#/s3>)

Assessment before Assumptions

In many cases incontinence can be treated effectively with significant lessening of symptoms but treatment can only start if the person seeks help, usually from their GP or community nurse, who should conduct a thorough assessment.

Assumptions that these symptoms should just be managed by absorbent products, generally termed incontinence pads but sometimes nappies or just

pads, are demoralizing for the person and costly to them, their families and often to health and social care services as noted above.

The key point for social care practitioners is to develop and convey their own confidence that many bowel and bladder problems or other factors related to continence problems can be treated or the consequences reduced. In practice, this means actively encouraging and helping older people to consult their GP or community nurse for an assessment if they have symptoms of loss of continence, or if the symptoms change. Family carers might also need encouragement to seek help, especially if they are caring for someone with dementia who may not recognize their problem. One new group of practitioners to influence is the growing number of Personal Assistants (PAs) who are directly employed by an older person or their carer. There is room for the local authority and NHS to produce accessible information about the subject of continence and locate it in places where PAs and other home care workers meet or visit regularly (such as details of the Alzheimer's Society's factsheets

https://www.alzheimers.org.uk/info/20029/daily_living/13/toilet_problems_and_continence). This could include, for example, the organisations that act as brokers for personal budgets or a community group that offers social events for care and support workers. Older people's groups could also act as 'mystery shoppers' to see if this information is given directly to people and carers by front line information providers, signposting services and other community-facing roles.

The role of mystery shoppers in testing out local information and advice about

residential care has recently been described by Bright, Clarke and Dalley (2013) and about information and advice by Independent Age (2016). This could be extended to other topics, like incontinence.

Other lines of enquiry for older people's groups or representative agencies could be to ascertain if social care workers, older people and families have confidence that problems of continence are addressed by GPs and not seen as ones where nothing can be done because of a person's age. They could ask how the experiences of those making referrals are audited or collated. They might prompt local older people's communications networks or patient representative bodies (HealthWatch (England), Community Health Councils (Wales), the Scottish Health Council and the Patient Client Council (Northern Ireland)) to call for local evidence of concerns and compliments.

One way of encouraging social care staff to think more positively about seeking help to manage continence problems is to report positive stories about the point of consulting NHS professionals. Older people or carers might be very happy to share these, when anonymity can be promised. They could be promoted among staff who may not encounter many professionals (such as PAs or day centre volunteers), or who do not know that the specialism of continence advisor exists or who are worried about being seen as 'interfering'.

Promoting continence

There is evidence that simple steps can help avoid some bladder and bowel problems and other factors that may be associated with incontinence. These are steps best summed up as promoting a healthy bladder and healthy bowels as an integral part of person's well-being (Newman et al, 2013). When adapted to the needs of someone with dementia these will include:

- A balanced diet, with sufficient fibre to avoid constipation e.g. 5 or more portions of fruit and vegetables a day,
- Attention to food safety in storage and preparation to avoid food poisoning (illness caused by eating food contaminated with bacteria) e.g. through incorrect storage, poor hand hygiene while preparing or eating food. NHS Choices website (<http://www.nhs.uk/LiveWell/Homehygiene/Pages/Homehygienehub.aspx>) provides up to date food safety advice particularly for foods for people aged over 65 years who are at higher risk of food poisoning than others.
- Adequate liquid to help both the bladder and the bowels: 6-8 glasses of fluids a day (approximately 1.2 litres or 2-3 pints, with more in hot weather),
- Daily walks will help for those that can because physical activity helps the bowels to work and avoid constipation. The national public health recommendations are of at least 150 minutes exercise (e.g. 30 minutes five times a week); this includes those with disabilities for whom exercise will have to be adapted.,

- Opportunities to use the toilet - a person with dementia may need reminding or prompting at regular intervals,
- Attention to hand hygiene after using the toilet needs to be encouraged or made easy,
- Opportunity to use the toilet that allows privacy and adequate time for bowels to open and accords with a person's usual toilet routine. Using the toilet after a meal (after breakfast is a common preference) is likely to be successful as it works with the natural physical response of the body to food. Some people with dementia struggle with locks so attention may need to be paid here such as having a lock that can be opened from outside if necessary.
- In the case of people with impaired mobility or dexterity (skill in using hands), the use of adaptations, aids or assistance (such as raised toilet seats, grab rails, elastic waist trousers rather than zips, and so on) will be important. Occupational therapists, community nurses and disabled living services and shops that sell mobility aids or disability living equipment can advise on these (see also the Disabled Living Foundation <http://www.livingmadeeasy.org.uk/toileting/continence-management-3180/>).
- At home –the person with dementia may be in need of some help to identify where the toilet is, for example having a picture on the door, and have a route that that is clutter/furniture free and well-lit. Movement sensor lights can help light the route at nighttime (occupational therapists may

assist with these as well as being obtainable at disabled living equipment shops or mobility centres). Checking toilet paper is in the sight line while sitting on the toilet and easily reachable can be important. For some people with dementia as their cognition changes having a toilet seat that is a different colour from the surroundings can help identify the 'right' place to go. Men may find it easier to sit to urinate and thus avoid misdirected 'accidents'. Commodes and urinals by the bed at nighttime can be an easier and speedier option and these are generally available from community health services or joint equipment services.

Out and about and using toilets

Many people with dementia will need assistance in maintaining continence and therefore the planning for trips out needs to include identifying the location of accessible toilets. RADAR keys (The National Key Scheme) offers disabled people independent access to locked accessible public toilets around the country (for more information see <https://www.disabilityrightsuk.org>). If the person has been told they have an overactive bladder then they will have also have been told to avoid drinks which may irritate the bladder such as those with caffeine (tea, coffee, cola) and alcohol. People may need reminding or support to replace these types of drinks. Likewise, if being very overweight has been identified as a

contributory factor they may need support in making healthy meal choices and taking exercise.

The key point for social care practitioners is that there are basic steps to promote continence and prevent incontinence. To help them in their work tasks, continence promotion (described above) needs to be understood and put in place in older people's support plans, and promoted in social care contacts with users of services. Such topics also need to be covered in reviews. It is not just up to commissioners to ask for evidence that they are covered in self or facilitated assessments, support planning and reviews; there is a role for sector or care agency led improvements such as peer review and auditing.

Needing the help of other people with managing toileting

Many older people with health problems and disabilities have limited mobility and reduced dexterity. They may need help in acquiring the best adaptations, aids or assistance to maintain independence in toileting. Most people with dementia, as the disease progresses, will only remain continent if they are supported by other people (Wagg et al 2015). This has huge implications for family and other carers and social care workers. Extensive help will very likely be needed if a person becomes seriously cognitively impaired or is at end of life.

Some people will only remain continent with aids, adaptations and assistance, all of which needs to be well designed for people with disabilities, including dementia. It is important for social care practitioners to focus on maintaining continence rather than just relying on the premature use of continence pads, which lower self-esteem and are costly. But they do not need to be on their own in trying to maintain continence. Reablement and other prevention services may be called upon as well as local NHS continence services (contact NHS Choices, the subject is under Incontinence, <http://www.nhs.uk/Conditions/Pages/BodyMap.aspx?Index=1>). Information should also be accessible to those people who are paying for their own care and support and to volunteers such as befrienders.

Questions remain about whether frontline care workers are sufficiently well equipped to inform people about sources of information and advice, particularly those older people who do not meet publicly funded social care eligibility criteria and so pay for their own care or just struggle along. Overall, it would be helpful to know if care managers, brokers, dementia advisers and others supporting people with dementia and their carers consider what assistance with continence might be needed, who is responsible for this, and how and where is this recorded?

Managing incontinence

Some people's incontinence cannot be treated or the underlying condition means they are unable to regain continence, for example, teaching pelvic floor exercises may not work for a person with dementia. The aim then is to manage and contain incontinence and minimise distress to all concerned. For some people it may be possible to manage urinary incontinence through pads whilst maintaining bowel continence by assisting the person to sit on the toilet or commode after a meal (often breakfast), or at the time they usually open their bowels. Local health services will have a continence service, which often works in association with community or district nursing services. This service, although varied throughout the UK, will be able to provide expert advice and information on NHS help and provision. However, experience can vary. A review of guidance from different continence services for community nurses found that most did not explicitly address the needs of people with dementia and their carers (Drennan et al 2013). Social care commissioners and those involved in scrutiny through Health and Well-Being Boards may wish to question whether the needs of people with dementia and their carers are explicitly addressed in commissioning continence services.

Absorbent products

The aim for the person, their family carers and for health and social care staff is to ensure that the use of incontinence pads leads to the best possible outcomes in containment, preservation of dignity and prevention of problems such as skin

rashes and pressure sores/pressure ulcers. Points to consider include ensuring that they -

- adequately contain the urine and/ or faeces without leakage (both during the day and at night),
- are changed in ways to preserve dignity and as required to avoid skin damage,
- are of a design that is acceptable and manageable by the person who is changing the pads,
- are used according to the manufacturers' instructions,
- are bagged and sealed before disposing of safely in the household waste.

For many people with dementia, pull-up pant designs (i.e. that mimic underwear) are often more acceptable than other types of designs. Chair and mattress protection may help in promoting hygiene if the best type and size of pad for the individual has not yet been found or, in the case of a person with cognitive impairment who may be unwilling to use pads (dry or wet) or may disturb or take them off.

NHS funded provision of aids, appliances and absorbent pads is based on clinical need (Department of Health 2001) and has developed standards and criteria for continence services (Department of Health 2000). However, the Royal

College of Physicians' national audits show great variation in provision and policies (Royal College of Physicians 2010) and different NHS Clinical Commissioning Groups have set different eligibility and types of provision. In social care services managers may wish to consult these documents if there are disagreements about responsibilities.

Independent sources of advice about continence products include Bladder and Bowel UK (formerly PromoCon) at the Disabled Living Foundation (<http://www.bladderandboweluk.co.uk/>). The International Continence Society's website is another helpful source of information (<https://www.continenceproductadvisor.org/>).

Challenging or distressing behaviour and 'matter out of place'

Assistance in toileting and providing intimate personal care can seem particularly insulting or threatening for someone with dementia and may be a flash point for the person to resist help or become aggressive. Other challenges for carers and care workers may include faeces wiped in inappropriate places (sometimes referred to as smearing), and lack of hygiene. Visitors may misinterpret care practice and the subject may lead to conflict between carers and care staff. Both older people and care workers may have cultural, gendered, or sexuality-related preferences that need to be considered. The Mental Capacity Act 2005 (England and Wales) provides a framework for acting legally and in a person's best

interests in this area of making decisions – as it does in other areas when a person lacks capacity to make decisions. Some situations may give rise to concerns about safeguarding so advice should be sought on these from supervisors or safeguarding staff in accordance with local policy and procedures.

Some questions for older people's groups to explore themselves or to suggest to their political representatives are whether social care practitioners have received training in working with people with dementia and are they skilled in communicating and supporting people with dementia to reduce fear, anxiety and resistance? What advice is available to staff and carers in written but also through face-to-face learning? .Are there opportunities for staff to discuss intimate care in group or personal supervision? How well are interventions, information and support meeting the needs of diverse groups of older people, carers and care workers? Is care informed by the principles and guidance of the Mental Capacity Act 2005? This could apply when carers and care workers are making decisions about supporting people lacking capacity, such as carrying out care tasks when a person is saying no or resisting assistance.

Similarly questions arise about whether social care practitioners are aware of behavioural management techniques that may help to identify potential causes of challenging behaviours around continence care. Do social care workers know who to either refer the person to and do they need to encourage the person and their family to approach experts for assessment and strategies to manage or

lessen behavioural and psychological disturbances? What is the local referral pathway and is there evidence that it leads to positive outcomes? Are there any examples that can be used to assure care staff and carers that this is worth the trouble?

Incontinence is humiliating, distressing and embarrassing for almost every adult. Denial and concealing this problem from others are common responses (Drennan et al. 2011). In people with dementia this can sometimes mean inappropriate activities, e.g. hiding soiled clothing and forgetting it, wrapping up faeces and hiding them. As the dementia progresses, identifying the correct place to urinate or defecate can also become a problem, as can apathy, both resulting in spillage of urine or faeces. Attempts to clear up leakage and 'matter out of place' can also be ineffective or they may seem to make matters worse, from a carer's or care worker's point of view. If a person has faeces on their hands and tries to remove them then this can cause great distress. This can occur when the person can no longer manage personal hygiene after defecating or the person has tried to manipulate the pelvic floor or rectum to help defecation or in severe dementia as an innate response of curiosity to the sensation of faeces exiting the body. These types of behaviours can place additional stress and distress on family carers and care workers, as well as visitors and others living in close proximity. Such subjects are sensitively addressed in the Alzheimer's Society factsheets as noted above.

There is a series of 'links in the chain' for social care practitioners: when urine and faeces are 'out of place'. These include being confident that care managers and care providers are aware of contact points when seeking to have an assessment or to obtain advice on preventing and managing these situations. And advocacy may be a way to ensure that people can have their dignity protected, so details of local advocacy services and their remit should be available (these will be listed on the adult services site of the relevant local authority).

Conclusion

We have focused above on direct care practice with older people, especially people with dementia, and with their family or other carers. Summarising these points, four questions could be addressed in overall commissioning and provision of services and they need to be informed by care practice:

What do older people with dementia and their carers say about local information and continence management services? What information is available to carers and to direct care workers and is this accurate, sufficient and accessible? Do HealthWatch and Health and Wellbeing Boards (in England) have the opportunity to consider their views?

How are local responsibilities for information, equipment, advice and professional interventions to manage continence divided or managed jointly? Do they take explicit account of the needs of people with dementia?

Would it be helpful to undertake an audit of assessments, support plans and reviews covering continence and incontinence for people with dementia?

If managing continence and incontinence are to be part of the outcomes framework in local commissioning for people with dementia, what needs to happen locally for this to be successful?

Everyone working with older people and their carers will encounter questions about continence, and those working with people with dementia will do so regularly. This paper has suggested ways in which paying attention to frontline knowledge, skills and attitudes may all help improve older people's quality of life in this respect.

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