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Addressing incontinence for people with dementia living at home: a documentary analysis of local English community nursing service continence policies and clinical guidance

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ADDRESSING INCONTINENCE FOR PEOPLE WITH DEMENTIA LIVING AT HOME: A DOCUMENTARY ANALYSIS OF LOCAL ENGLISH COMMUNITY NURSING SERVICE CONTINENCE POLICIES AND CLINICAL GUIDANCE

Short title: Addressing incontinence for people with dementia living at home

ABSTRACT

Aim and objectives: The aim of this study was to establish whether the problems and issues experienced by people with dementia living at home and their carers were addressed in the clinical guidance for continence management for community nursing services in England.

Background: Internationally, the numbers of people with dementia are rising. Managing incontinence is a significant issue as the presence of incontinence is one of the triggers for people with dementia to move residence to a care home. People with dementia living at home and their family carers report difficulties in accessing knowledgeable professionals and acceptable continence products.

Design: A review by documentary analysis of clinical policies and guidance from a sample of community nursing services in all Strategic Health Authority regions of England.

Methods: A sample of clinical policy and guidance documents for continence assessment and management from up to four community nursing services in each of the ten Strategic Health Authority regions in England was sought. Documentary analysis was undertaken on the relevance of the documents identified for people with dementia living at home.

Findings: Ninety-eight documents from 38 local community nursing services spread across ten Strategic Health Authority areas were obtained and analysed. Only in the documents of three services were nurses offered detailed guidance about the management of incontinence for people with dementia at home. In the documentation of only one service were people with dementia identified as a special case which warranted the provision of additional continence products.

Conclusion: Clinical guidance on continence assessment and management for community nurses in many parts of England does not address the specific needs of people with dementia living at home or their carers.

Relevance for clinical practice: Nurses working in community settings and those providing clinical leadership in continence care should review their clinical guidance and policies to ensure relevance for people with dementia living at home, and their family carers.

KEY WORDS

Continence; dementia; home; incontinence; policy; continence products.

INTRODUCTION

Addressing the needs of the growing and predicted increase in numbers of people with dementia is a major concern to nurses and health care professionals in all countries (Ferri *et al.* 2005, Kalaria *et al.* 2008). Incontinence has been found to be a significant factor in both increasing family carer 'burden' associated with supporting a person with dementia (Georges *et al.* 2008, Ouslander *et al.* 1990) and also in the decision to seek residence in a group care home (Luppa *et al.* 2008). Internationally, policy makers are addressing issues of how to support people with dementia at home for longer (Alzheimer's Association 2010). The National Health Service (NHS) provides community nursing services throughout the United Kingdom to provide nursing care, health education and advice to people in their own homes. A major part of their work is supporting older people with incontinence problems who live at home (National Audit Office 1999). This paper presents the results of research which aimed to establish the extent to which the specific problems of people with dementia, living at home, and their family carers were addressed in the clinical guidance for continence management for community nursing services in England.

BACKGROUND

Dementia has a trajectory of progressive deterioration in cognition, abilities in undertaking activities of daily living such as toileting and physical functioning (American Psychiatric Association Work Group *et al.* 2007). Many people also develop behavioural and psychological symptoms (World Health Organisation 2007), which can manifest in difficult or unusual toileting behaviours (Stokes 1995). The neurological pathways for controlling voiding are affected by the advance of the dementia, resulting in incontinence (Hunskaar *et al.* 2005). The problems experienced by the individual are often made worse by extrinsic factors such as environments un-adapted to the impairments of dementia and attitudes of '*therapeutic nihilism*' (i.e. that nothing can be done to help) in professionals (Kitwood 1997). While there is clear clinical guidance for incontinence in frail older people, most refers to people with dementia and cognitive impairment living in care homes (Dubeau et al. 2010),

which is a very different setting from individual domiciles. Estimates suggest that worldwide about two thirds of people with dementia live at home (Knapp *et al.* 2007, Wimo & Prince 2010). There are no firm data on the numbers of people with dementia living at home in England who have toileting and incontinence problems. However, evidence suggests that up to a third of people with cognitive impairment living at home experience urinary incontinence (Rait *et al.* 2005, Royal College of Physicans 2006). A major part of community nurses' work is supporting older people with incontinence problems who live at home (National Audit Office 1999).

Community nursing services are usually provided by a local Community Health Service (CHS), which also has specialist continence nurse services. These specialist continence nurses work closely with a lead medical consultant, and across primary and secondary care services and into non-NHS arenas such as care homes. Their remit usually includes:

a) Providing specialist services to a defined patient population;

b) Development of continence policies and clinical guidance for community nursing services (amongst others) based on available evidence, (e.g. National Institute of Clinical Excellence [NICE] 2006, 2007) for agreement with those who commission care in the local NHS and also their employing CHS;

c) Providing education and training on all aspects of continence assessment and management for community nurses (amongst others); and

d) Overseeing and managing the budget for NHS provided absorbent continence products.

Local continence policies and guidance include not only clinical aspects but also the detail regarding the provision of NHS funded absorbent continence products (e.g. incontinence pads) to people living in their own homes. This will usually include eligibility criteria, mechanisms of provision, availability of types, and ordering and delivery processes. NHS guidance states that continence products should be available to all in quantities appropriate to the individual's clinical needs (Department of Health 2002). The delivery and provision of the continence products is usually tendered and outsourced from the NHS. Two recent surveys identified the variation in the provision of NHS funded incontinence

pads and lack of clarity about entitlements related to managing incontinence generally across local NHS organisations in England (Desai 2008, Royal College of Physicians 2010).

A qualitative study exploring the issues and strategies for managing toileting problems and incontinence with people with dementia and their family carers (authors reference 1 2011) found that two issues were repeatedly raised:

a) Concerns about lack of access to knowledgeable health professionals for advice on managing toileting and incontinence problems for people with dementia; and
b) Difficulties in access to NHS supplies of effective and acceptable absorbent continence products.

This study (authors reference 1 2011) raised questions about whether local level CHS continence policies and clinical guidance for community nurses addressed the needs of people with dementia and their family carers. This paper reports on research we undertook to investigate the extent to which local level policy produced by continence services for community nursing services explicitly addresses the toileting and incontinence needs of people with dementia and their family carers. The research addressed two questions:

1. To what extent do clinical guidance and continence policies specifically address the needs of people with dementia living at home, and their family carers, with regard to toileting and incontinence?
2. Are there examples of good practice in the clinical guidance that specifically address the toileting and incontinence problems of people with dementia living at home?

STUDY METHODS

A documentary analysis (Silverman 2005) of a sample of local CHS continence policies and clinical guidance documents, from across each region of England, was undertaken. The sample of documents was obtained from both public domain availability through the Internet and from written requests to all CHS continence nurse specialists. The internet search was carried out between November 2009 and May 2010 to identify public domain policies and guidance produced by continence services in

England. Key words used were – *continence service, incontinence, bowel and bladder care*. Individual local NHS organisations' websites were also searched. In July 2010 written requests for documents, together with an explanation of the research and in particular the aim of identifying good practice examples, were sent to continence specialist nurses in local CHS for whom no documentation had been accessed online. These were identified using the *Directory of Community Health Services 2009/10* (Fermor 2009). Reassurances were given in the request that no service would be identified or direct quotes used in subsequent reports or publications without seeking permission first.

The continence policy and clinical guidance information identified by these methods was then reviewed using documentary analysis (Silverman 2005). Key issues to be investigated in the documents were identified from the authors' previous study (authors' reference 1, 2011). In addition, our ongoing research advisory group, which comprised former family carers of people with dementia and professionals, was consulted to ensure the analytical approach was relevant to patients and practitioners, and important issues were not left uninvestigated. Results of the documentary analysis were subsequently fed back to the advisory group. The key issues were used to focus on three elements for analysis. The first element was to identify any references in the documents specific to addressing the needs and problems of people with dementia and their family carers using key word searches e.g. (dementia, Alzheimer's, cognitive impairment). The second element was to identify examples of detailed good practice guidance on any aspect of supporting people with dementia and their family carers. The third element was to identify references to people with dementia and their carers and the provision of absorbent continence products.

The study was reviewed by the NHS research ethics service and deemed service evaluation not requiring NHS local ethic committee review. The study conformed to all university requirements for the ethical conduct of research.

FINDINGS

Ninety-eight documents were located from 38 local CHS in England. Continence polices and clinical guidance were obtained from at least two organisations in each of the ten Strategic Health Authority areas in England, giving the sample a broad geographical spread.

The documentation included different types of information and ranged from single page leaflets to policy documents over 100 pages long. The documents were classified into one of three types:

A. Policy documents detailing continence services (including community nursing service contribution) and NHS provision of absorbent continence products, including audit review
B. Detailed clinical guidance (including clinical information, assessment forms, care pathways and associated patient leaflets)
C. Referral forms for access to NHS funded continence products

Table 1 reports the number of documents within each type.

Table 1 here

The authorship and target audience of these documents was not always easily identifiable. The documents were generally authored by a senior continence nurse or service manager and frequently ratified by someone higher up in the organisation such as the executive director. Information was often provided on the version number of the document, when it had last been updated and was due for review. Some policies stated they had been written with the support of other continence services located nearby or known for their good clinical practice (e.g. Bayliss *et al.* 2000).

In some areas, the clinical care pathways, assessments and leaflets were included as part of the policy documents and in other areas these were available as standalone guidance. Most policy and guidance documents referenced national policy documents, for example the relevant NICE e.g. NICE 2006,

2007. Referral forms for access to NHS funded incontinence pads and products were generally not authored, and many continence services used the same forms, suggesting that they originated from a contracted organisation supplying the items. Likewise, the continence promotion leaflets for patients tended not to give authorship, and the same leaflet was often used by many CHS.

Evidence of addressing the needs of people with dementia and their carers

Of the 38 local CHS organisations for which we located polices and guidance, only 13 (34%) specified dementia as a condition to be aware of, or record the diagnosis of in the assessment process. In addition, documentation from six more (16%) CHS organisations made reference to cognitive dysfunction, Alzheimer's, neurological dysfunction or confusion. Although the assessment forms required that these conditions were recorded, there was very little evidence of any subsequent advice or mechanism for producing specifically tailored care plans (such as a dementia care pathway) to support people with dementia living at home and their family carers. Documents from the remaining 19 (50%) made no mention of dementia or cognitive impairment.

For individuals using continence services and in receipt of NHS funded absorbent continence products, documentation from 12 local CHS organisations indicated that a reassessment should be offered after a fixed time period, but of these, in only one CHS organisation did the documentation specify the need for reassessment with regards to people with dementia. In this case reassessment was usually held after 12 weeks unless there was 'no treatment' in which case reassessment was not undertaken; 'severe dementia' was given as an example of when no treatment was appropriate along with 'end of life'.

Only three (8%) of the local CHS organisations provided documentation with detailed information for community nursing staff about incontinence and dementia. In the first of these, the clinical guidance documentation included a copy of a detailed presentation for the education of community nursing staff, providing both clinical advice and a sample care management plan for people with incontinence and dementia. The documents from the second CHS included tailored care plans and clinical guidance

for people with dementia, including directions on prompted toileting techniques. Documentation from the third CHS contained a large section of clinical guidance on 'functional' incontinence, which included information and advice specific to people with cognitive impairment. Figure 1 provides examples from these documents of good practice guidance for community nursing staff in relation to people with dementia living at home who have toileting and incontinence problems.

Documentation in ten (26%) of the 38 local CHS organisations incorporated or referred to a leaflet entitled *Continence in the Confused Elderly,* which was to be given to family carers of people with dementia. The study advisory group reviewed this leaflet and concluded there could be a number of improvements in its content, level of information and style. Another area of interest to the study advisory group was whether people with dementia and their carers received a hard copy of their continence assessment or care plan. Only one local CHS organisation mentioned this issue in their documentation, however this was in relation to confirming the provision and delivery of incontinence pads, rather than helping a person with dementia, or a family carer, to remember the details of their consultation, or of the advice or aids they had been offered.

Provision of incontinence pads for people with dementia

Documentation in 19 local CHS organisations provided details on the provision of NHS funded absorbent continence products. This included information on eligibility criteria, for example, the numbers of products to be allocated per person, per product type and over specific time periods. Documents in two local CHS organisations required the use of frequency/volume charts (which contained advice on weighing incontinence pads using domestic scales within the home) as part of the decision-making process for pad allocation. Only one set of documents referred specifically to the needs of people with dementia, noting that: a) 'pull up pant' designs of incontinence pads would be available if the need could be demonstrated with a client (for example, if they could not tolerate the more commonly used 'insert' designs); and b) dementia was included as an 'exceptional' circumstance when additional incontinence products could be provided. In only one other local CHS

organisation did the documentation mention dementia, citing it as an example of when additional products should *not* be offered, and specifying instead that a thorough needs assessment should be undertaken and a new care plan implemented.

Documents from 12 local CHS organisations discussed the delivery of incontinence pads. There was wide variation in the elements of local systems including:

- whether or not patients were allowed to have a 'stop' in deliveries to avoid stockpiling;
- the length of time between deliveries (ranging between five days and a 12 week cycle); and
- whether deliveries were made automatically or a 'ring-back' service was available to request a delivery, again to avoid stockpiling.

However, only one local CHS organisation's documentation addressed these issues with reference to people with dementia, acknowledging the difficulties they might face in remembering about the delivery system. This document stated that individuals living in their own homes were required to give seven days' notice when new supplies were required, but that in the case of patients with memory impairment, automatic delivery could be arranged if a third party could not be found to do this.

DISCUSSION

This documentary analysis of a national sample of CHS policy and clinical guidance on continence assessment, care planning and provision of NHS funded continence products, found that only half the CHS made any reference to the specific needs of people with dementia and their family carers, and of those that did, the reference was very perfunctory with little detailed consideration. This suggests that, in many areas, clinical leaders in continence and community nursing services are giving little explicit consideration to the needs of people with dementia living at home, and their family carers. This lack of regard for people with dementia and their family carers was evident in the documentation at all levels – policy, assessment, care plans and guidance.

Examples of good practice were found, but these were in the minority. These good practice examples focused on person-centred assessment and responsiveness to the described problems, an approach advocated for some time in the care of people with dementia, see for example Kitwood (1997). While specialist nursing for older adults, whether gerontological or dementia-specific, has advocated person-centred approaches to care (see for example Adams & Clarke 1999), these findings question whether generalist nurses in community and primary care settings are being enabled and encouraged to do the same. There is a need to disseminate the examples of good practice identified here more widely, and for each community nursing service to consider whether their clinical guidance encourages and enables particular attention to be given to the needs of people with dementia living at home, and their family carers.

The clinical guidance in a quarter of the CHS organisations recommended a leaflet for family carers, *Incontinence in the Confused Elderly (no author or date given*). However, for the ex-carers on our advisory group, this leaflet lacked tailored advice and was problematic in appearance, and in the tone of language used. The Royal College of Physicians (Royal College of Physicans 2006, 2010) has noted that continence services rarely involve service users; we would suggest that the development of patient and carer resources is one area where service-user / carer input could be invaluable.

The variation in polices regarding the provision of NHS funded incontinence pads has been well documented (Desai *et al.* 2008), most recently through a national audit by the Royal College of Physicians (Royal College of Physicians 2010). This analysis indicates that few CHS organisations had policies that pay explicit attention to the needs of people with dementia living at home and their family carers, who might face additional challenges due to relatively sudden changes in their abilities, with consequences for managing both incontinence and continence product delivery systems. With NHS spending on continence related prescription products (e.g. urinary catheters and sheaths) and incontinence pads at over 150 million pounds a year (Royal College of Physicians 2010), this may be an area that will be examined in financial efficiency savings. A debate has also started about whether service users would benefit from being given their own budget or vouchers to spend on the continence

products of their choice (Fader *et al.* 2008). Recent proposed changes to the organisation of the NHS in England (Department of Health 2010) include the recommendation that patients should be offered more choice in the provision of continence services and specialist nurses (Department of Health 2011). Some continence specialist nurses have questioned whether the public purse should be funding continence products at all (Nursing Times 2010). The implications of any major changes in policy such as these would need to be considered very carefully in the case of people with dementia and their family carers. Potential savings provided by greater rationing of continence products could be counter-productive if they were to trigger greater numbers, and earlier entry, of people with dementia into care homes, with all the consequent distress and costs.

This is a small-scale study which may have limited reliability and generalisability. The representativeness of the 98 documents from the 38 CHS organisations is unknown, as the reasons why individual services chose to post documents on the Internet (other than for enabling access to service user leaflets and guidance) are unclear. It is possible that these documents were uploaded as their authors felt they were useful examples of good practice, or alternatively their dissemination could be part of a local CHS open access, patient and public involvement policy. It is also unknown to what degree these documents should be viewed as collective, organisational artefacts, ratified by senior staff but not necessarily influencing the professional practice of the community nurses. The degree to which the guidance is implemented, and thus reflects the actual service people with dementia receive, can also be questioned (Bero *et al.* 1998). However, these documents do provide an insight into whether clinical leaders in continence and community nursing services actively address the needs of people with dementia and their family carers. The wide geographical spread of the retrieved documents indicates that the analysis presented here is not confined to specific geographical areas. The written requests to named continence specialist nurses produced very few documents, which suggests there are unlikely to be more examples of documents particularly tailored to the needs of people with dementia. This provides some confidence that the study findings are indicative of the situation in many parts of England.

To our knowledge there has been no other investigation into the degree to which these types of local continence policy and clinical guidance documents address the needs of people with dementia and their family carers at home. We were unable to identify any similar studies in other countries. As such, this study provides insight into the opportunities for increasing the awareness of, and responsiveness to, the needs of people with dementia and their family carers in remaining at home. Following this documentary analysis, the authors have gone on to establish an expert group to develop a template for community nurses of best clinical practice in assessment and management of toileting and incontinence problems for people with dementia living at home and their family carers.

CONCLUSIONS

Supporting people with dementia and their family carers is a major issue for all health and social care practitioners in the context of projected growth in numbers of people with dementia. This study has focused on the documentary evidence available from CHS organisations on continence policies and clinical guidance, and its consideration of people with dementia. A focus on local CHS organisations' documentation is unusual as it is more common to look at the gap between national recommendations (e.g. NICE 2006, 2007) and surveys of what practitioners say they are doing (e.g. Royal College of Physicians 2010). Examination of the documentation uses a different lens to investigate this issue. From this perspective, it is clear that there is scope in many areas of England for policies and clinical guidance for nurses in primary care to be more sensitive and tailored to address the problems experienced by people with dementia and their family carers. This study also provides evidence that there is scope for joining up knowledge from generalists and specialists in clinical practice and in the provision of NHS funded absorbent continence products.

RELEVANCE TO CLINICAL PRACTICE

Nurses working in community settings and those providing clinical leadership in aspects of continence care should review their clinical guidance and polices on continence assessment and management to consider whether they could be more sensitive and tailored to address the problems of

people with dementia living at home, and their family carers. Local policy and guidance about NHS funded continence products could also be tailored to address the needs of people with dementia living at home and their family carers.

CONTRIBUTIONS

Study concept and design (VMD, LC)

Data collection and analysis (CN, SD, VMD, LC)

Manuscript preparation (VMD, CN, SD, LC)

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Table 1. Spread of Type of Documents

Document Classification	Number of documents retrieved and analysed
A	14
B	64
C	4
A & B	4
B & C	6
A & C	3
A, B & C	3
Total	98

Figure 1

Examples of good practice guidance for community nurses in assessing and care planning with people with dementia and their family carers living at home found in three sets of continence clinical guidance and policies

Fig 1. Examples of good practice guidance for community nurses in assessing and care planning with people with dementia and their family carers living at home found in three sets of continence clinical guidance and policies

- Development of incontinence should not be seen as inevitable – people should be given encouragement and opportunity to be dry, following a holistic, person-centered approach
- A comprehensive assessment should be carried out to identify reversible or underlying continence problems
- Review medications
- People with dementia's capabilities should be assessed – Consider referral to other therapists:
  Psychology (memory clinics, psychometric testing, behavioral assessment)
  Occupational therapy (dressing apraxia, modifying clothes)
  Physiotherapy (mobility/dexterity)
  Sensory handicaps (impaired vision, hearing)
  Pain assessment
  Podiatry needs
- Treat urinary tract infections and continence often returns
- Toileting programme – routine, time of day, allow time, respect privacy/dignity – clean comfortable toilets
- Review nutrition - drinks readily available, finger foods?
- Review the patient´s environment - consider toileting aids/equipment, using prompt signs, colour codes or picture markers on the toilet