Continence care for people with dementia living at home in Europe: a review of literature with a focus on problems and challenges

Dianne Gove, Anthony Scerri, Jean Georges, Paul van Houten, Nicole Huige, Daniela Hayder-Beichel, Kai Leichsenring and Vikky Christina Morris

Aims and objectives. To report the findings of a review of literature relating to the continence care of community-dwelling people with dementia in Europe.

Background. More than two-thirds of people with dementia live at home, and many experience continence problems. Incontinence is a significant contributor towards institutionalisation. Care and support is often inadequate or inappropriate, and guidelines are lacking. This represents a failure to respect the human rights and dignity of this group.

Design. A structured review of the literature relating to the continence care of community-dwelling people with dementia in Europe with a focus on problems and challenges.

Methods. Search terms reflecting dementia, continence, care/management and guidelines for community-dwelling people with dementia were applied to four databases. Hand-searching was also carried out. A total of 208 articles were searched for content relating to problems and challenges linked to continence care for this group.

Results. Six relevant articles were fully reviewed. The main difficulties and challenges included the following: (1) perceptions, (2) availability/provision of support and care, (3) financial cost, (4) mobility and the environment, (5) relationships and social inclusion and (6) emotional issues.

Conclusion. Dementia and incontinence have profound effects on quality of life. The dearth of good quality data within this area and the findings of the review confirm the need for expert, consensus-based guidelines and appropriate research to ensure that the rights and dignity of people with dementia are respected.

Relevance to clinical practice. The findings of the review will hopefully raise awareness amongst healthcare professionals in community practice of unmet needs of people with dementia and continence problems, and their caregivers, especially those related to social, financial, emotional and relational issues.

What does this paper contribute to the wider clinical community?

• This article calls for greater awareness amongst healthcare and social care professionals of the unmet needs of community-dwelling people with dementia and continence problems.

• It highlights the importance of health and social care professionals providing a coordinated approach to the continence care of community-dwelling people with dementia, including a sound understanding of the social, emotional, relational and financial challenges associated with the experience of such problems in the community setting.

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review does not provide solutions or guidance but is helpful in highlighting some of the key areas where special attention is needed.

**Key words:** care, challenges, community-dwelling, dementia, incontinence

**Accepted for publication: 3 September 2016**

**Introduction**

Approximately 400 million people worldwide experience some type of urinary incontinence (UI). This may be an underestimate, as only around half of older people with incontinence seek help for their symptoms (Milsom et al. 2012). Older people and caregivers often consider UI amongst older people as part of normal ageing but also as inevitable, irreversible and a sign of incompetence, often resulting in stigma (Mitteness & Barker 1995). Diomede et al. (2008) describe incontinence as the ‘last medical taboo’. There are considerable differences in rates of UI amongst older people living at home in different European countries (Sørbye et al. 2009). Rates of faecal incontinence (FI) are generally lower (Wagg et al. 2013), but there is an association between increasing age and prevalence of both UI and FI, which suggests that age is an independent risk factor for incontinence (Milsom et al. 2012).

A dementia diagnosis (or severe cognitive impairment) is associated with a higher prevalence of incontinence compared to people without such a diagnosis (Byles et al. 2009, Sørbye et al. 2009, Miu et al. 2010). An association has also been observed between incontinence and more severe cognitive impairment and mobility problems (Ouslander et al. 1990, Jerez-Roig et al. 2016) and between incontinence, dementia and institutionalisation (Ouslander et al. 1990, Thomas et al. 2004). The prevalence of UI amongst community-dwelling people with cognitive difficulties or dementia ranges from 1–38%, from 0–9–27% in the case of FI and from 21–34% for UI at night (Drennan et al. 2013). However, dementia is often normalised and/or perceived as a stigma by lay people and healthcare professionals (Vernooij-Dassen et al. 2005, Alzheimer Europe 2013a). Drennan et al. (2013) suggest that the embarrassment and stigma surrounding both incontinence and dementia may well result in underreporting of these conditions in the community setting.

The proportion of people with dementia living at home ranges from 66% in high-income countries to 94% in low- to middle-income countries, with even higher estimates in rural areas within Europe (Wimo & Prince 2010). However, very few studies have focused on continence problems specifically experienced by community-dwelling people with dementia (Drennan & Cole 2009). Research findings and guidelines for people with dementia and continence problems in residential care cannot simply be transposed into the home setting, and yet, reviews and clinical guidelines often fail to make a clear differentiation between the two settings (Drennan et al. 2012a). Similarly, incontinence guidelines for frail older people are not necessarily appropriate for people with dementia (Drennan et al. 2012a) and guidelines on continence assessment and management for nurses working in the community do not always specifically refer to the needs of people with dementia (Drennan et al. 2012b). Moreover, certain costs related to continence care (e.g. containment products and support) are not covered in the same way across Europe (Alzheimer Europe, 2013b) and even within certain countries (Desai et al. 2008).

Alzheimer Europe is a European organisation which represents the interests of people with dementia and carers across Europe, and is fully committed to promoting the rights, dignity and autonomy of people with dementia: rights which are universal, and guaranteed in the European Convention of Human Rights, the Universal Declaration of Human Rights, the International Covenants on Economic, Social and Cultural Rights and Civil and Political Rights, and the Convention on the Rights of Persons with Disabilities. Over the last 25 years, the issue of providing continence care at home, without adequate and appropriate support and guidance, has frequently been raised at conferences and in meetings of this European organisation. This lack of support, combined with the risk of premature institutionalisation, was considered an important threat to such rights, dignity and autonomy and as inequity in the provision of health care to people with dementia compared to other groups in society. Having recognised a shared interest in improving the continence care of community-dwelling people with dementia, in 2014, Alzheimer Europe met with a team of experts in the field of continence care and policy to address this important issue.

**Aims**

The aim of this article was to report on a literature review which was conducted to inform the development of guidelines to improve continence care for people with dementia in Europe living at home. The authors recognise that people...
with dementia, and their caregivers, do not all experience continence problems (if and when they occur) in the same way. Levels of formal and informal support vary, as do coping mechanisms, personal resources and the impact on their daily life and interaction with others. Nevertheless, it was decided to focus on difficulties and challenges as these suggest aspects of continence care which could be improved. This article highlights areas where the provision of continence care may be problematic for people with dementia living at home and their carers, and focuses on the research question ‘What are the problems and challenges encountered by people with dementia and continence problems living at home in Europe?’

Method

Electronic and hand-searches

A structured search for relevant papers was carried out in four research databases, namely CINAHL plus full text, PsycARTICLES, PsycINFO and MEDLINE. The following search terms were used: (dementia* OR Alzheimer*) AND (continence OR incontinence) AND (guidelines OR recommendations OR care OR management) AND (community based OR at home OR community dwelling). Given the paucity of studies on continence care for people with dementia living at home, no restrictions on time or language were applied. It was possible to review articles in English, German or French. A hand-search for additional articles was also conducted. Again, given the lack of literature on this topic, no restriction was applied regarding methodology. Consequently, all papers were screened for relevance (e.g. those using qualitative or quantitative methods, reviews, opinion pieces) and retained if they met the inclusion criteria. The database search was carried out by DG. All co-authors were involved in the hand-search and were consulted to discuss the suitability of certain articles retrieved from the databases.

Inclusion criteria

The titles and summaries of the abstracts and the additional articles were carefully screened. To ensure the relevance of the articles to continence issues or problems in relation to people with dementia living at home and to avoid drawing conclusions based on the experience of other target groups in other settings, the following inclusion criteria were applied: about people with dementia; about the experience of or issues related to continence problems; focused on people with dementia living at home and the scope of the article covering Europe. Exclusion criteria included the following: having a focus on the residential or hospital care setting, having no reference to dementia and/or covering other continents exclusively, rather than Europe.

Data extraction and analysis

The focus in this literature review was on the areas of continence care of people with dementia living at home which were reported as being either problematic, challenging and/or likely to benefit from improvement. The data extraction and analysis therefore focused on content reflecting these issues and not on topics for which information or guidance was readily available or not reported as problematic or challenging. However, the key characteristics of the papers are presented in the ‘Results’ section and further addressed in the ‘Discussion’ section.

Data of relevance to the research question were extracted, and a descriptive analysis/synthesis of the relevant content was made. This was then discussed by the co-authors in a full-day, face-to-face meeting and led to the identification of six overriding themes. These themes grouped together common, related issues in a meaningful way.

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Journal of Clinical Nursing

Management of incontinence and dementia
Results

The search for literature resulted in a total of 267 papers (208 after removal of duplicates), of which 202 were rejected as they did not meet the inclusion/exclusion criteria, resulting in six papers for full review (Fig. 1).

The six papers consisted of various types of articles from academic and professional journals. As there is limited research on this topic and papers were not excluded on the basis of the methodology adopted, provided that they fulfilled the inclusion criteria, the papers resulting from the search cover a range of methodologies. The papers included one overview/report of policies and guidance on commissioning continence care services in England (Drennan & Cole 2009), three qualitative studies involving informal carers set in England and Germany (Upton & Reed 2005, Drennan et al. 2011, Messer 2012), one opinion piece from Northern Ireland about continence care support for people with dementia living at home (Kyle 2012) and a systematic review (Drennan et al. 2012a).

In addition to the different methodologies covered, the papers also focused on different perspectives and target groups of relevance to the provision of continence care for people with dementia living at home. The overview/report of policies and guidance on commissioning continence care services, for example, drew on an extensive body of work on evidence-based interventions in dementia care for people with dementia and continence problems at home from the perspective of planning and commissioning (Drennan & Cole 2009), whereas the three qualitative studies provided direct insight into the perspectives of carers themselves (Upton & Reed 2005, Drennan et al. 2011, Messer 2012). The qualitative studies involved 5, 32 and 37 carers, respectively (Upton & Reed 2005, Drennan et al. 2011, Messer 2012), for the most part partners/spouses, and none included participants with dementia.

The opinion piece by Kyle (2012) focused on community nursing and informal carers. The systematic review by Drennan et al. (2012a) used the Cochrane method. It covered 14 databases and resulted in 427 records of studies, reported in English but from any country, on conservative interventions (nonsurgical and nonpharmacological) for incontinence for people with dementia or cognitive impairment living at home. Of these, only three studies (from the USA) met the inclusion criteria. None provided sufficient evidence, according to the authors, to support or rule out the effectiveness of any particular strategy. The range of countries covered by the review was limited to England, Northern Ireland and Germany as no relevant papers from other parts of Europe met the inclusion criteria. No papers were found which directly involved or reported the views and experience of people with dementia. An overview of the details of the documents reviewed can be found in Table 1 below, and the possible implications of the specific nature of the papers included are further addressed in the ‘Discussion’ section.

The findings covered six main themes reflecting common issues, namely (1) perceptions of incontinence and dementia, (2) the availability/provision of support and care, (3) financial cost, (4) issues related to mobility and the environment, (5) relationships and social inclusion and (6) emotional issues. These are presented below:

Perceptions of incontinence and dementia

Challenges related to the provision of continence care are sometimes linked to the way that incontinence and dementia are perceived, as well as to personal values and societal expectations. For example, caregivers may experience incontinence in the person with dementia as threatening and even as representing a loss of control over their own living situation (Messer 2012) and not as a separate condition/pathology for which treatment and support may be available. Incontinence may be perceived as running counter to people’s own values and those of society, with the result that continence care is perceived as being somehow dirty, improper, obscene or involving contamination, and thus a taboo topic (Drennan et al. 2011, Messer 2012).

The availability/provision of support and care

Appropriate advice and support

People with dementia sometimes consider attempts from their caregivers to assist with toileting unacceptable and occasionally react aggressively (Drennan et al. 2011). Such behaviour, which is often experienced by caregivers as challenging, may be partly due to embarrassment, aphasia, communication difficulties (Kyle 2012) or an objection to the provision of intimate assistance (Drennan et al. 2011). Other behaviours which can be difficult for caregivers to manage include voiding in inappropriate places, refusing to wipe, putting used toilet paper in inappropriate places, removing a colostomy bag and handling faeces (Upton & Reed 2005, Drennan & Cole 2009, Drennan et al. 2011). Despite difficulties managing, caregivers sometimes feel that it is their personal responsibility to provide care and to manage on their own (Messer 2012). In some cases, providing care and concerns about managing become the focus of daily life and may affect the health of caregivers (Messer 2012). Such
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| **1** Drennan and Cole (2009) – England | Overview/report which draws on background work on evidence-based interventions in dementia commissioned by the National Institute for Health Research (UK) | Challenges facing planners and commissioners in providing integrated care for people with dementia and incontinence problems at home | Under-reporting/low level of recognition  
Difficulties with toileting  
Different views of informal carers of appropriate support  
Numerous care providers, funding sources and eligibility criteria  
Wider public service support may be lacking (public toilets)  
Lack of availability of services due to low priority  
No evidence-based clinical guidance  
Lack of staff training, geographical variations and absence of user involvement in planning or monitoring  
Inappropriate response from professionals  
Access to continence products  
Concerns about causing harm and distress |
| **2** Drennan et al. (2011) – England | Qualitative study (interpretive tradition, involving thematic analysis) | Semistructured Interviews with 32 carers (all but one spouses or adult children) of community-dwelling people with dementia and continence problems | Difficulties providing support for independent toileting  
Dealing with inappropriate behaviour  
Delaying seeking help  
Inappropriate response from professionals  
Access to continence products  
Concerns about causing harm and distress |
| **3** Drennan et al. (2012a) | Systematic review | Conservative interventions for incontinence in people with dementia or cognitive impairment living at home | Insufficient evidence from any studies to recommend any strategies  
Need for clinical guidance for health professionals in community settings  
Mobility and dexterity issues  
Managing resistance to care and behaviour  
Sensitivity of outside carers  
Challenges related to the environment and symptoms of dementia  
Emotional issues |
| **4** Kyle (2012) – Northern Ireland | Opinion piece | Psychological and behavioural problems associated with dementia that impact on continence care at home; targeted at community nurses and informal carers | Mobility and dexterity issues  
Managing resistance to care and behaviour  
Sensitivity of outside carers  
Challenges related to the environment and symptoms of dementia  
Emotional issues |
| **5** Messer (2012) – Germany | Qualitative study (descriptive; qualitative content analysis) | Perspective of five spousal caregivers’ of the experience of providing incontinence care to a partner with dementia at home | Challenge to own values and perspective of life  
Impact (changes) on relationship with partner  
Responsibility/having to cope alone  
Withdrawal from social life  
Overriding focus of daily life  
Impact on carers’ health and issues related to smells |
Concerns include whether care strategies adopted by caregivers are appropriate (Drennan et al. 2011).

Nevertheless, caregivers suggest the need for a better understanding amongst healthcare professionals of issues related to the continence care of people with dementia at home (Drennan et al. 2011). Often, when advice and support is provided by GPs and other service providers, it is not considered helpful, appropriate, acceptable or effective by people with dementia and their caregivers (Drennan et al. 2011). This is because it is reportedly too brief and does not take sufficient account of the person’s situation (including physical demands and the exhaustion of the caregiver) or of dementia (including behavioural challenges and decreased attention span) (Upton & Reed 2005, Kyle 2012). Healthcare professionals have also been criticised by caregivers for focusing on caregiving tips, on the documentation of toileting activities and on the primary consequences of dementia whilst failing to address how continence care is experienced and taking it for granted that caregivers will provide such care (Messer 2012). Some caregivers perceive healthcare professionals as merely passing on people with dementia and their caregivers to other professionals who are equally unhelpful, sometimes proposing solutions which are potentially harmful and distressing for the person with dementia (Drennan et al. 2011). The issue is perhaps further complicated by the fact that continence care services are often provided by a range of different public and private service providers with different funding and eligibility criteria (Drennan & Cole 2009) and the lack of evidence-based information about effective interventions (Drennan et al. 2012a).

Continence aids and containment products
Healthcare professionals’ initial response to incontinence amongst older people is often to provide continence pads only, rather than to assess and treat underlying causes (Drennan & Cole 2009). The provision of containment products is, nevertheless, a valuable form of support for many people with continence problems but may be problematic for some people with dementia who do not understand their purpose, have difficulty handling them and using them appropriately due to agnosia, aphasia, arthritis and tremor and have difficulty organising and managing supplies (Drennan et al. 2011, Kyle 2012). This suggests the need for greater flexibility on the part of suppliers for people with dementia, especially those living alone (e.g. allowing people to choose products which they find easiest to use, ensuring that the packaging is easy to open, permitting last minute orders). In addition, the aesthetics of certain continence equipment may be off-putting to people with dementia and caregivers at home and the stigma of continence may lead to embarrassment obtaining and disposing of pads (Drennan & Cole 2009).

Financial cost
Providing continence care at home can be costly (e.g. in terms of laundry, especially water and electricity, containment products and cleaning materials) and has been described by some caregivers as the most expensive aspect of care (Drennan et al. 2011, Messer 2012). Where household waste disposal by the state is organised on the basis of quantity, people with dementia who use containment products may face higher charges (Messer 2012). The cost of continence care may have implications for the dignity of people with dementia and reflects a lack of equity in the provision of continence care across Europe. Even within countries, wealthier people with dementia may benefit from better care and support compared to those with less financial means who are often largely dependent on the state for supplies and support (Drennan et al. 2011).

Table 1 (continued)

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<tr>
<td>6 Upton and Reed (2005)</td>
<td>Qualitative study (interviews and case studies; phenomenological approach)</td>
<td>Experience of informal carers (mean age 77.3) cope with incontinence care of a person with dementia (mean age 73.9) living at home (37 cases)</td>
<td>Difficulties of managing inappropriate voiding Behaviours carers find challenging Inappropriate response from professionals Continence aids/products and need for carer respite Cost and time considerations, physical exhaustion Impact on relationships</td>
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Issues related to mobility and the environment

Problems with mobility, sometimes associated with disturbed gait, lack of coordination and jerky movements, may prevent people with dementia from reaching the toilet in time and result in functional incontinence (i.e. incontinence which with appropriate and adequate support would not have occurred) (Kyle 2012). Similarly, nocturia, which is very common in older people (see Wagg et al. 2013), may in the case of dementia result in the need to find the toilet during the night and disrupt the sleep of caregivers if assistance is needed (e.g. due to mobility problems and disorientation). Whilst signage may help, this is not always well accepted in people’s own homes (Drennan et al. 2011). Home modifications and various aids may contribute towards better mobility and a home environment that is more suited to managing continence, but eligibility to such support may vary, also depending on funding sources (Drennan & Cole 2009).

Relationships and social inclusion

Constant vigilance and round-the-clock continence care may contribute towards the exhaustion of the caregiver with possible implications for the ability to carry on providing care and for the relationship with the person with dementia (Messer 2012). Within families, the gender of the carer and of the person with dementia sometimes raises problems, with some sons and/or husbands/male partners being unwilling or considered unsuitable by other relatives to provide care to a mother or wife/female partner (Drennan et al. 2011).

Continence problems may contribute to people with dementia and their caregivers withdrawing from social life or feeling socially excluded by other people (Messer 2012). Some caregivers have expressed concern about people outside the immediate family knowing about their relative’s need for continence care (Drennan et al. 2011). The problem is often hidden from outsiders and sometimes even from close relatives (Messer 2012).

The provision of intimate care to people with dementia may result in changing roles, provoking feelings of infantilisation (Drennan & Cole 2009), but also, in some cases, leading to closer ties and togetherness (Messer 2012). However, behavioural and psychological behaviours (such as verbal threats, physical aggression, hurtful comments, screaming and shouting) by the person (Upton & Reed 2005) may take a toll on relationships. Some couples report a negative impact of continence care on their relationships, involving loss of physical attraction, affection and sexual contact (Messer 2012).

Emotional issues

People with dementia sometimes experience embarrassment and shame in relation to continence problems and may fear what they perceive as humiliating and degrading procedures linked to toileting support (Kyle 2012). Physically attending to the continence care of a person with dementia has been described by caregivers as resulting in feelings of disgust, contamination, frustration, embarrassment and uncertainty about the ability to cope (Drennan et al. 2011, Kyle 2012, Messer 2012). Caregivers also report feeling ashamed, either personally or on behalf of the person with dementia, during social interactions (Messer 2012). Embarrassment may also result in reluctance to seek help (Drennan et al. 2011), as well as to oversights and omissions in integrating services linked to mental and physical well-being (Drennan & Cole 2009). Prolonged lack of sleep and the physical exhaustion of caregivers have also been linked to psychological stress (Messer 2012).

Caregivers have expressed distress and difficulty getting used to smells associated with incontinence (although some eventually do not notice it), and of this contributing towards concerns about being labelled as dirty (Drennan et al. 2011, Messer 2012), which is again linked to shame and embarrassment. On the other hand, daily continence care is to some extent normalised in that caregivers describe suppressing their feelings (Messer 2012) and ‘just getting on with it’ (Drennan et al. 2011, p. 4).

Discussion

The literature review draws attention to some of the key problems and challenges faced by people with dementia and their caregivers linked to the way that dementia and incontinence are perceived, the availability/provision of support and care, financial costs, mobility and the environment, relationships and social inclusion, and emotional issues. It suggests that continence care at home is often experienced as inappropriate and inadequate, all too often failing to address the broader social, emotional, environmental and relational issues, as well as cost (Upton & Reed 2005, Drennan & Cole 2009, Drennan et al. 2012a, Kyle 2012, Messer 2012).

Personal perceptions and societal expectations surrounding incontinence and dementia may further hinder access to appropriate support (Drennan & Cole 2009, Drennan et al. 2011, Messer 2012). Much of the information identified in the literature review relating not only to perceptions but also to the availability of support and care, relationships, social inclusion and emotional issues can
also be understood in terms of stigma (Mitteness & Barker 1995, Vernooij-Dassen et al. 2005, Drennan et al. 2011, Milsom et al. 2012, Alzheimer Europe 2013a), which as Drennan et al. (2013) point out may also result in the underreporting of both conditions. Goffman (1963, p. 12) described stigma as an attribute which is deeply discrediting in that it reduces someone in other people’s minds from a ‘whole and usual person to a tainted, discounted one’. This can be detected in statements from caregivers about the need to protect the person’s dignity, about embarrassment and shame, and about hiding problems from outsiders and even close family. The discrediting nature of the attribute is not inherent but dependent on the meanings people attach to it (i.e. it is socially constructed). Efforts must therefore be made to address such stigma by challenging the way both dementia and continence problems are perceived and portrayed. Discrimination, in the form of lack of appropriate and adequate services for this group, is also a key component of stigma (see Link & Phelan 2001) and must be urgently addressed by policymakers.

Reports of the unmet needs highlighted in this review suggest that an integrated and holistic approach to the continence care of people with dementia living at home has yet to be achieved. This results in many people with dementia and their informal caregivers having to manage continence problems and dementia at home without appropriate support. In some countries, even access to basic containment products is problematic, with restrictions on the number or type of products being provided or reimbursed by the state (Alzheimer Europe 2013b). A comparative study involving 11 European countries revealed that continence pad use by older people (not necessarily with dementia) ranged from 29–52%, with the cost of pads being fully covered by health insurance in some countries and only partly or not at all covered in others (Sorbye et al. 2009). Another recent study revealed that in the UK, Germany, Poland and Spain, 75% of people with incontinence incur out-of-pocket expenses to buy additional containment products (SCA and Age Platform Europe 2016). Such lack of care, support and supplies may have a negative impact on quality of life (Cassels & Watt 2003, Sorbye et al. 2009) and contribute towards premature institutionalisation (Ouslander et al. 1990, Thomas et al. 2004), which represents a higher cost to society (Wimo & Prince 2010).

The review also highlights the lack of evidence-based knowledge and hence of suitable guidance about appropriate care and support available to healthcare professionals (Drennan et al. 2012a,b), many of whom operate within systems of care which are perhaps not geared towards meeting the needs of people with dementia and of informal caregivers, whose involvement in continence care is often taken for granted (Messer 2012). Informal dementia care has traditionally been provided by women (Ford et al. 1997, Ramford 2011), but there is some evidence of the increasing role of men in providing dementia care (Baker & Robertson 2008). The gender issues related to the provision of continence care raised by Drennan et al. (2011) are in keeping with the reported lack of information about the experience and needs of male carers (especially sons) of people with dementia (Sanders & McFarland 2002, Mc Donnell & Ryan 2011). Moreover, lack of specific reference to the needs of people with dementia living at home in continence assessment guidelines (e.g. for community nurses in England) and of awareness of appropriate guidelines for people with dementia and continence problems has been reported (Drennan et al. 2012b), with very few national Alzheimer associations in Europe having reported being aware of guidelines on continence care for people with dementia living at home (Alzheimer Europe 2013b).

Limitations

The findings of this literature review reflect the situation in a small number of countries. Moreover, they are for the most part based on qualitative studies and opinion pieces which do not, by definition, seek to provide generalisable knowledge based on statistical analysis. However, this does not necessarily rule out the transferability of the findings to the parent population based on symbolic representation covering the diversity of experience at the level of categories and explanations (Lewis & Ritchie 2003). The qualitative studies reviewed were particularly valuable in providing meaningful, in-depth knowledge about the range of experience of continence care (albeit mainly from the perspective of caregivers). At the same time, it must be acknowledged that the problems and challenges faced by this population in other European countries may in some respects differ due to different social, cultural, economic and political influences.

The carers involved in the qualitative studies provided valuable information about the experience and perceived difficulties faced by people with dementia and continence problems. It is unfortunate that no studies were found which directly involved people with dementia even though the difficulties addressing this sensitive topic must be acknowledged. Their involvement might have shed light on different priorities, problems and issues based on their unique experience, perspective and values.
Further work

The literature review confirms the need for more research into the experience of continence care across Europe, as well as for evidence-based research into care and treatment for people with dementia and continence problems, and into support for them and their caregivers. This will inevitably take time, and meanwhile, measures must be taken to promote their well-being by improving the experience of continence care at home. Following their systematic review of nonpharmacological and nonsurgical interventions for people with dementia or cognitive impairment and incontinence living at home, Drennan et al. (2012a,b, p. 9) conclude that ‘there is a gap that urgently needs to be addressed by an expert group, including carers, to develop guidelines based on consensus methods’. The literature review reinforced the authors’ belief in the necessity to take immediate action and served as a useful starting point for the development of expert, consensus-based guidelines targeted at people with dementia, caregivers, healthcare professionals and policymakers. The findings of the review served as the basis for discussion within a multidisciplinary working group involving experts in dementia care, continence care, healthcare policy, general practice and psychology, together with people with dementia from different European countries and carers to produce such guidelines. These can be consulted at http://alzheimer-europe.org/Research/Continence-care. The guidelines are perhaps unique in that they address the key stakeholders, namely people with dementia and continence problems living at home, their caregivers, healthcare professionals, producers and suppliers of continence products (separately but in the same document) with a dedicated section directed at service providers and policymakers.

Conclusion

Continued failure to address inappropriate continence care and to support people with dementia living at home represents a form of structural discrimination which must be urgently addressed by policymakers in order to ensure that the human rights and dignity of people with dementia and their caregivers are respected. The literature review brought together the findings from a small number of relevant studies. The qualitative studies in particular (by Drennan and colleagues, Messer, and Upton and Reed), whilst small in number, provided a wealth of information and should ideally be replicated in other countries and extended where possible to include also the experience of people with dementia. Meanwhile, it is hoped that the consensus-based guidelines which build on the findings on this literature review will be helpful in improving the continence care of people with dementia living at home.

Relevance to clinical practice

The literature review, in focusing on problems and challenges faced by both people with dementia and continence problems and their caregivers, offers healthcare professionals a broader perspective of the kind of support and care needed in the community setting for people with dementia and continence problems and their caregivers. Increased understanding and awareness of the experience of people with dementia and caregivers by all actors in the field, combined with a greater understanding of the specific issues related to providing continence care at home, will hopefully contribute towards the gradual development of more appropriate and adequate support within the community healthcare setting.

Contributions

Study design: DG, AS, PVH, DH, NH; Data collection and analysis & manuscript preparation: DG, JG, AS, VM, PVH, DH, KL, NH.

References


