Healthcare Providers’ Perspectives on Communicating Incontinence and Skin Damage Information with Patients with Dementia and Their Family Caregivers: A Descriptive Study

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Abstract
Communication between healthcare providers and patients/family caregivers about incontinence and associated skin damage is wanting, and information about healthcare providers perspectives on improving this communication is limited. A descriptive study was conducted using semi-structured, tape-recorded interviews with 11 healthcare providers with clinical expertise in geriatrics and dementia working in a large integrated healthcare system. The survey was developed by the authors based on a review of the relevant literature with guidance from a three-member Advisory Committee and consisted of nine open-ended questions related to communication with patients and families about incontinence and skin damage. Specifically, information was obtained about providers’ perspectives on the timing of inquiring about these problems, how best to tailor language and approach the topic, barriers and facilitators to discussion of incontinence, and recommendations for educational and supportive resources. Responses were analyzed using a content analysis approach. Using a purposeful sampling technique, 11 experienced healthcare professionals agreed to participate in the study. Main themes observed included: 1) incontinence issues are not routinely or voluntarily addressed by all providers, 2) caregivers are receptive to discussion if the topic is broached by patient/caregiver, and 3) main barriers to providing information include limited clinician time and patient/family caregiver embarrassment. Participant clinicians expressed interest in readily available, single-topic, printed patient/caregiver-focused educational materials to enhance patient-provider communication and serve as a resource. These materials were subsequently developed. Further research is warranted to test the effectiveness of the recommendations and the materials developed as a result of the study.

Keywords: incontinence, communication, physicians, nurse practitioners, caregivers

Any older adults face urinary and/or fecal incontinence and associated skin damage. These conditions present a further challenge when the patient has dementia and a family member must manage care. Of the 11 million family caregivers of individuals with dementia, nearly one third provide help for loss of bladder and/or bowel control.1 Having the skills and knowledge to manage incontinence can reduce caregiver stress and improve patient quality of life for persons facing this condition.2 Further, effective patient-physician communication is recognized
as an important national health objective in Healthy People 2010.\textsuperscript{3} However, incontinence is not easy to discuss. In examining the epidemiology of fecal incontinence and its severity, Bliss et al\textsuperscript{11} (who surveyed more than 1,300 community-dwelling people) and Johanson et al\textsuperscript{12} (who surveyed 881 patients during physician visits) noted 40\% or fewer patients make their incontinence known to their healthcare provider. Reviews of the literature,\textsuperscript{6-10} a qualitative study,\textsuperscript{11} and descriptive studies\textsuperscript{12-15} involving patients with incontinence offer insight into the various factors that contribute to underreporting the condition. These barriers include social stigma;\textsuperscript{6,7} embarrassment; the notion that incontinence is inevitable due to childbirth, old age, or dementia;\textsuperscript{6,11} concern that advice will not be beneficial;\textsuperscript{12,13} and limited understanding about these topics, referred to as "low health literacy."\textsuperscript{14,15} According to Healthy People 2010,\textsuperscript{3} an individual is considered "health literate" when he or she possesses the skills to understand information and services and use the information to make appropriate health decisions. For many caregivers, lack of information can lead to less-than-optimal health decisions and limit appropriate communication with healthcare providers.\textsuperscript{3}

Moreover, there are limited studies of healthcare providers’ perspectives on improving patient and caregiver knowledge about incontinence. One study of general practitioners observed that even healthcare providers may be reluctant to discuss incontinence when medications are not indicated because of their lack of knowledge of alternate management options: in this large cross-sectional survey (N = 990), conducted to determine the prevalence of fecal incontinence within a community-dwelling population in Sydney, Australia, most participants reported the condition was primarily unrecognized and not discussed by their physicians.

The purpose of this descriptive study was to examine healthcare providers’ perspectives regarding improving communication with patients and their caregivers about incontinence and dementia.

Methods

Participants. A purposive sample of 11 multidisciplinary providers (eight physicians, two nurse practitioners, and one pharmacist) was recruited to be interviewed because of their extensive clinical experience with geriatric patients and their knowledge of issues surrounding incontinence and dementia. All were employed by a large Midwestern integrated health system serving approximately 800,000 patients and were suggested as participants by the head of the health plan’s geriatric division.

In addition, an Advisory Committee was established of three providers — two from the healthcare system and a clinical nurse specialist from a community-based, living-at-home nurse support program — selected for their clinical expertise in the care of patients with incontinence and associated skin problems and/or dementia. The Advisory Committee recommended recruitment strategies and suggested providers to contact as potential participants. They subsequently reviewed the interview questions and questionnaires for a variety of characteristics including clarity, relevance, and acceptability; reviewed study findings; and reviewed the initial draft of the educational materials developed as a result of the study and gave feedback for revisions.

Procedures.

Instrument design. Study investigators (two of the authors) are experts and have published extensively on incontinence and associated skin problems and their management\textsuperscript{4,13,17-20} and dementia caregiving.\textsuperscript{21-26} These investigators conducted an extensive literature review using MEDLINE, Cochrane, and the Cumulative Index to Nursing and Allied Health Literature (CINAHL), as well as references in the articles found. Searches were performed for treatments for fecal incontinence and urinary incontinence, including persons with dementia. Their findings were used to draft the first version of the interview guide. The Advisory Committee reviewed the interview questions, and consensus was reached on survey content. With changes incorporated, standardized interviews were conducted with the healthcare providers about several facets of communication with patients and their caregivers regarding incontinence and associated skin damage in dementia.

Survey instrument. Participant demographics were obtained during interviews and included years of experience, certifications (eg, adult medicine, family practice, internal medicine), age, gender, employment (full- or part-time), ethnicity, and highest level of education. The topics of the survey included: 1) deciding when to talk to caregivers about the topics of incontinence and skin care, 2) with whom to communicate, 3) words used in discussions, 4) barriers to discussion, 5) facilitators that promote discussion, 6) interventions recommended to caregivers to help manage patients
with these conditions, 7) current resources used for incontinence, 8) resources used or desired to prevent skin problems in these patients, and 9) additional training or resources desired/needed, including preferred format.

The survey was semi-structured. Responses were open-ended. The same questions in the same order were asked of all participants.

Survey administration. Interviews were conducted by telephone or in person according to provider preference. Interviews were conducted between July and September 2009 by the co-principal investigator and the project manager of the study. All interviews were audiotaped. The interviewer created a written summary of survey question responses after the interview. All participants signed a consent form to participate in the interview and to have the session audiotaped. The recorded tapes were transcribed, and data were analyzed by question using content analysis27,28 to identify common themes from both the transcriptions and response summaries. The study was approved by the internal Institutional Review Boards of the investigators (University of Minnesota and HealthPartners).

Results

Eight participants were interviewed over the phone; three provided responses in person. The specialty areas of the providers were geriatrics (three), internal medicine (three), family practice/primary care (two), neurology (one), urology (one), and clinical pharmacy (one). All participants were board/specialty certified. The providers had a mean age of 53 years (SD 10 years) and average professional experience of 23 years (SD 12 years); seven were female, 10 were Caucasian (not Hispanic), and one was Asian.

Communicating with caregivers. The majority (nine) supported the importance of addressing the topics of incontinence and skin care; two providers did not see these topics as a top priority. The common recommendation (six out of 11 participants) was that communication about these topics was best addressed by the patient’s primary provider versus a referral specialist. All three geriatric specialists stated they routinely inquired if patients experienced incontinence. The other eight providers did not routinely initiate discussion; rather, they waited to respond to caregiver or patient concerns or if symptoms were noted. Similarly, all providers mentioned they often saw redness, skin breakdown, soreness, or incontinence-associated dermatitis in patients with dementia, but varied as to whether they assessed for skin problems routinely or responded to the recognition of symptoms. Geriatricians built this into their routine — all claimed they “routinely ask” about incontinence and interviewers assumed that meant nearly always. All of the providers believed the care recipient should be present (versus only the caregiver) during discussion of incontinence and related skin problems and their management.

Terminology. Providers said patients or caregivers rarely use the term incontinence; as a result, they adopted terms for incontinence used by family caregivers or patients such as “difficulty in getting to the bathroom,” “leaking,” “having accidents,” or “soiling themselves.” Although the topic is sensitive, providers stated that caregivers appreciated when the topic was raised and were usually receptive to engaging in discussion.

Communication barriers and facilitators. The most common barrier to discussing incontinence was time, which was mentioned in all interviews. The provider must cover a great deal of information in an office visit; comprehensively discussing incontinence issues can take far longer than the time typically allotted to spend with patients. Four providers offered suggestions to help circumvent the time restraints — eg, suggest the patient/caregiver return to the clinic for a follow-up visit specifically about these topics or have a nurse specializing in wound and continence care in place for regular referrals to educate and counsel patients and caregivers about these problems, not necessarily in the office setting.
Five providers mentioned embarrassment as an obstacle, and one mentioned that providers who may not be aware of available resources could hinder conversation. Concern about frightening patients/caregivers about potential problems before they occurred was mentioned by two of the providers who do not routinely discuss incontinence. Moreover, one provider, whose patient population is predominantly Southeast Asian, noted this population was uncomfortable discussing incontinence. Seven of the participants mentioned the value of a pre-visit checklist or written materials of some type where patients/caregivers could indicate whether incontinence or skin problems were present; this could alert providers to the need for consultation. Currently, documentation of incontinence and associated skin problems often is not found in the medical record, a situation noted by survey participants and in the literature.29

**Resources.** Although caregivers and patients may obtain information from mass media and websites or groups such as the Alzheimer’s Association website,30 providers thought having readily available handouts geared to patients/caregivers would embellish explanations covered at the office visit and serve as a convenient resource for the caregiver as challenges arise. They recommended that information be formatted not as a large, single brochure, but rather as short, focused handouts that could stand alone and address a singular concern. The modular format would allow providers to give information to caregivers or patients on immediate issues and lessen the risk of overwhelming them. Providers also recommended developing a few standard questions about the presence/status of incontinence and skin problems to be answered in written form by patients and/or caregivers immediately before their visit that could prompt the provider to inquire about these problems and/or whether their symptoms were improving/worsening.

Topics of most concern to patients and caregivers are detailed in Table 1 and include the relationship between incontinence and Alzheimer’s Disease and dementia, strategies for managing incontinence, preventing skin problems, talking to a healthcare provider, caring for yourself, and questions to ask when considering nursing home care. Handouts based on these topics were developed; electronic copies of these handouts can be obtained by contacting the author.

Providers who want to keep up-to-date on incontinence and associated skin problems suggested making educational forums (eg, lunchtime meetings or webinars) available. Suggested topics included conservative (nonpharmacological) therapies for incontinence, adverse effects on cognition/dementia of medications for urinary incontinence, and indications for various topical products for skin damage prevention.

Discussion

This study is among the first to explore healthcare providers’ perspectives for improving communication about incontinence and associated skin damage with patients and their family caregivers. Communication with a healthcare provider is an important aspect of improving the caretaking capacity and health literacy of family caregivers and health outcomes of patients. Increasing the percentage of people whose healthcare providers have satisfactory communication skills is a national objective carried forward into the Healthy People 2020 initiative from 2010.3 Others who have written about the subject encourage all providers to inquire routinely about incontinence.31-33 In a review article about assessing for incontinence in the primary care setting, Kōilmann34 found that having a provider ask directly is the single-most important approach to help patients with this problem. Review and opinion publications31,32,35-37 reiterate that if providers do not ask about incontinence, it is likely to go undetected and untreated. In a study examining the development and evaluation of a continence educational package on patient awareness and management preferences, O’Connell et al35 found fewer than 25% of patients received information about incontinence even though they had incontinence problems. Similar to the current study results, lack of time to address a sensitive topic is a communication barrier,33,34 along with reluctance to bring up the topic.3,35

The current study obtained providers’ perspectives on ways to improve communication. One of the main requests was access to informational patient handouts about incontinence and skin care. The literature shows educational materials are successful in building awareness,33,37-39 increasing communication, and in some instances, leading to actions that help with the problem.40-42 In one study from Australia (N = 111),40 two thirds of participants bothered by incontinence sought help from a professional after reading a brochure on the topic. Tannenbaum et al41 studied the impact of an interactive workshop to evaluate attitude and behavior changes among older women; following workshop participation, 43% reported being satisfied with their self-treatment and 42% consulted a health professional. In a randomized trial42 of a medication combined with or without an educational intervention (which included printed information about bladder problems, behavioral treatments such as Kegel exercise, and fluid regulation), those in the education group were more likely to persist with their medication (P <0.05), report starting behavioral treatment, and see an improvement in the bladder symptoms. Patient education materials on incontinence also have been shown to be well-received.37 In one study43 that followed patients given a brochure, more than 85% reported they kept it. Although keeping a brochure does not provide evidence of actual use, the fact patients did not
discard the materials is encouraging, and many patients reported finding it a valuable resource long after receiving it. Information promoting incontinence is available in a computerized format,29,43 but seven of the 11 providers in the current study preferred focused, readily available written materials on topics of importance to patients and caregivers they could use to embellish discussions and provide as reference material.

Although some patients and family caregivers may readily respond to a provider directly asking about incontinence, according to a prevalence study44 and additional research,45 others are more likely to report incontinence using an indirect (written) format. Incontinence is stigmatized,7 and some patients may feel embarrassed when confronted.15 Offering patients and caregivers an opportunity to make known the presence/change in status of incontinence in written form, as recommended in this study, can be a less threatening and more effective way for providers to introduce discussion about this condition.

Providers who interact with caregivers and patients with other similar health problems might resonate with some of the current findings, but these results are limited to the patients with dementia treated by the participants. Studies that comprise larger, more diverse populations and studies to test the effectiveness of the materials developed to increase the frequency and quality of communication about the under-discussed topics of incontinence and skin care are warranted.

Limitations

A limitation of this study is the small and culturally limited group of healthcare provider participants. Ten of the 11 who participated were white; the small, non-diverse sample may not be representative of all who care for patients with incontinence and dementia. Nonetheless, all of the participants had extensive experience with patients with these conditions.

Conclusion

Increased communication between healthcare providers and patients/caregivers about incontinence and related skin problems is essential, particularly in the growing group of individuals with dementia who are at risk for these conditions. Because healthcare providers are key participants, their perspectives for improving related discussions are valuable. Additional examination of ways to engage healthcare providers with their patients and caregivers is warranted.

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