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Health Literacy Needs Related to Incontinence and Skin Damage among Family and Friend Caregivers of Individuals with Dementia

Donna Bliss, PhD, RN, FAAN, FGSA,
University of Minnesota, Minneapolis, MN, bliss@umn.edu

Cheri Rolnick, PhD, MPH,
HealthPartners Research Foundation, Bloomington, MN

Jody Jackson, BSN, RN,
HealthPartners Research Foundation, Bloomington, MN

Casey Arntson, BSN, RN,
University of Minnesota, Minneapolis, MN

Jean Mullins, BSN, BA, RN, and
University of Minnesota, Minneapolis, MN

Kenneth Hepburn, PhD
Emory University, Atlanta GA

Abstract

Purpose—The purpose of this study was to describe health literacy needs related to incontinence and skin care among family or friend caregivers of individuals with Alzheimer’s disease and develop supportive and educational materials that address these needs.

Design—Descriptive

Subjects and Settings—The sample included 48 family/friend adult caregivers of individuals who had advanced dementia. Caregivers were spouses (44%), daughters (31%) or extended family members/friends (25%) recruited from community-based agencies, aged 64 (14) years (mean (SD)), and 75% female. Nearly half (48%) had a racially or ethnically diverse background.

Methods—Focus groups, interviews, and written surveys were conducted to assess health literacy needs of AD caregivers related to incontinence and skin care; verbal responses were audiotaped, transcribed, and summarized. To address these needs, a set of educational and supportive materials were developed whose content was directed by caregiver responses and supported by a literature review of current evidence and consultation with clinical and research experts. Study procedures were guided by advisory committee of AD caregivers.

Results—Caregivers had numerous health literacy needs related to incontinence and skin care; areas of need were categorized into knowledge, skills, and attitudes. Caregivers expressed a need to validate the health literacy they possessed. Fourteen educational and supportive documents were developed to address these needs.

Correspondence to: Donna Bliss.

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Conclusion—Materials developed in this study are suitable to incorporate into interventions that support caregivers of persons with Alzheimer’s disease. They offer the potential to raise health literacy and care capacity of caregivers, increase communication with healthcare providers, and improve health outcomes of care recipients.

Introduction

Health literacy affects people’s ability to communicate about their health problems with a healthcare provider, access and navigate the health care system to seek care, and manage chronic health conditions of themselves and their care recipients.^{1–5} Low health literacy is associated with poorer health, more complications and hospitalizations and higher healthcare costs.^{2,6–8} According to the National Assessment of Adult Literacy,^{2,9} which surveyed a nationally representative sample of 19,000 adults, more than one-third (38%) of adult Americans have limited (at or below a basic level) health literacy. The health literacy of older adults^{2,10} and racial and ethnic minorities is lower than younger or white adults.^{2,4} Hispanics have the lowest health literacy scores of any racial/ethnic group.^{2,4,9} Other studies support these findings and show that individuals have limited knowledge about chronic diseases such as asthma,¹¹ diabetes mellitus and hypertension,^{6,11} as well as medical instructions given in the emergency department,⁴ end of life care options,¹² and colon cancer screening.¹³

Patel and colleagues¹⁴ were among the first to demonstrate low health literacy about incontinence. Individuals with incontinence tend to lack terms and words to describe their problem to health care providers. Incontinence, particularly fecal incontinence, is underreported to healthcare providers at clinic visits;^{15–17} one reason for the lack of therapeutic consultation may be low health literacy. Furthermore, low health literacy and incontinence are both associated with social stigma and embarrassment.^{18–20} Disclosure may be especially difficult when the 2 problems are combined.

Incontinence is a problem that can affect the health and quality of life of persons with dementia and threaten their living situations. Whether in persons with Alzheimer’s disease or dementia (AD) or not, skin damage, in the form of incontinence associated dermatitis and pressure ulcers, is a common physical consequence of incontinence. These conditions are costly and decrease well-being; most importantly they can be avoided.²¹ Approximately 15 million informal (i.e., unpaid family or friend) caregivers provide assistance with activities of daily living (ADL) for 5.6 million patients with AD living in the community.²² These AD caregivers report the highest stress levels of any caregivers.^{23–25} Incontinence of urine and/or feces, a known precipitating factor in the movement of persons with AD into institutional care, is an ADL deficit that can occur as AD progresses. Thus, improving health literacy among informal caregivers of individuals with AD may support therapeutic communication with their care recipient’s health care provider as well as raise their capacity for care giving. The purpose of this study was to assess the health literacy needs related to incontinence and associated skin damage among informal caregivers of individuals with AD.

Methods

A descriptive research design within the context of community-based participatory research was used to guide data collection and analysis.³⁵ The aims of study were to describe the health literacy needs of family/friend caregivers related to incontinence and associated skin damage that can occur in AD and develop supportive and educational materials addressing these needs. Study procedures were reviewed and approved by the institutional review boards of the University of Minnesota and HealthPartners Research Foundation.

The theoretical underpinnings of the intervention to be developed in this study relate to stress and coping theory whose constructs are stressors, outcomes, and mediators.^{36,37} Caregivers face multiple stressors, defined as conditions or demands that threaten to overwhelm their ability to provide optimal care. Outcomes include a range of consequences related to the well-being of the care recipient and caregiver. Mediators are resources that influence the relationship between stressors and outcomes. The results of this study have the potential to strengthen mediators that promote the health and well-being of care recipients and caregivers, raise the care capacity of caregivers, and reduce their stress.

Study Procedures

Caregivers were recruited from several community sites: a health maintenance organization (HMO), nursing support programs for living at home, an adult daycare center, an African American community group, the state Alzheimer's Association and its support groups, and local conferences focused on Alzheimer's disease. Recruitment strategies were tailored to each site; for example, in the HMO, an administrative database was electronically searched for eligible participants then an invitational letter was mailed followed by a telephone call if necessary. Clinical staff at the living at home nursing support programs mentioned the study and distributed recruitment brochures during contacts with their participants. The Hispanic Advisory Committee member was also instrumental in assisting with recruitment and follow-up of Hispanic caregivers. At support groups and conferences, announcements were made and study brochures were made available. The investigator attended a gathering of the African American community group and explained the study. Study participants could also refer others. Eligibility criteria included being an adult caregiver for someone with Alzheimer's disease or dementia who assisted or would assist with incontinence and perineal skin care and speaking and understanding English. The care recipients of approximately one half of the caregivers were to have urinary, fecal, or dual incontinence while the remaining care recipients were to be free of incontinence.

Data assessing caregiver literacy needs related to incontinence and skin care were collected via focus groups or interviews lasting approximately one hour and via surveys and evaluation forms. Although focus groups for all subjects were initially planned, caregiving, work responsibilities, functional, health, and driving constraints, and weather required that we also conduct multi-person and individual interviews. Focus groups and interviews were audiotaped, transcribed, and summarized. The content of the transcripts was analyzed independently by 2 members of the research team then reviewed by and discussed with other team members on several different occasions so that consensus was reached then refined in an iterative manner.^{38,39} Caregivers answered questions about demographic characteristics and the level of functioning of their care recipient using the Functional Assessment Staging (FAST).⁴⁰ The FAST instrument has been shown to have good validity. In one study of 50 outpatients with AD, Pearson correlations between the FAST and independent clinical assessments of the patients were .83-.94 ($p < .001$).⁴⁰

Development of Data Collection Materials

After health literacy needs of caregivers were identified, the literature was searched for current evidence and best practices related to relevant topics of incontinence management and skin care with specific attention to individuals with AD or their caregivers. Additionally, 2 consultants, a certified WOC specialist nurse and a research expert in incontinence care and caregiving, were consulted and participated in the literature review. The investigators developed a set of educational and supportive materials for the informal caregivers. A specialist in designing health-related materials for lay people from the HMO reviewed the materials and made recommendations regarding language selection, format, and layout. The clinical and research consultants also reviewed the materials for accuracy and currency.

Although we planned to conduct focus groups and interviews so subjects could review and provide feedback about the materials, many caregiver participants requested an option to do so by mail as part of their evaluation of study procedures. This option was offered by developing a set of written instructions and review forms that were mailed with the outcome materials.

Community Participatory Action Research

Investigators consulted with an expert in community participatory action research. This individual has 20 years of experience working with persons of diverse racial and ethnic cultures about procedures throughout the study. The consultant reviewed questions that were planned for the focus groups, interviews and surveys and outcome materials for their readability, inclusivity, and respectfulness of diversity. An Advisory Committee comprised of key informants of caregivers was recruited; 2 were referred by clinicians at the HMO because it was our initial recruitment site and it had the largest number of caregivers. The Advisory Committee guided the investigators at each step of the procedures: they made recommendations about recruitment strategies and scheduling of focus groups and reviewed areas of content as well as questions for focus groups, interviews, surveys and evaluations. They reviewed a summary of study findings and conclusions and the final materials before they were distributed to caregiver participants for review. Caregiver participants also reviewed the outcome materials. They were asked whether the materials reflected their comments during the focus groups or interviews, any information they needed was lacking, and the presentation and format of content was understandable and easily managed, and were provided with opportunity for open-ended comments. Materials were revised as possible in response to the reviews.

Results

Demographic characteristics of caregivers are described in Table 1. The majority of participants were female (75%), middle-aged on average, and married. The sample was highly diverse with nearly half (48%) from a racially or ethnically diverse background. The percentage of caregivers who were working (42%) or retired (39%) was similar. One-third of the sample had a college degree. Most caregivers were spouses (44%) of their care recipients; 31% were children (all daughters), and 25% were extended family members or friends. Caregivers assisted their care recipient with several activities of daily living (ADLs). The highest percentages assisted with instrumental ADLs (e.g., cleaning, meal preparation, transportation, and shopping), and the lowest with ambulation.

Care recipients were mostly female (62.5%), and their median age was 82 years (range 60 to 103 years). More than half (58%) had incontinence, and of those 57% had urinary incontinence and 43% had dual fecal and urinary incontinence; none had fecal incontinence alone. Skin damage was reported as being present in 8% of care recipients. The FAST scores of care recipients were a median of 6 (range 1 to 14) indicating decreased ability to dress, bathe, or toilet independently.

Health Literacy Needs Related to Incontinence

The health literacy needs of caregivers had 3 major themes: knowledge, skills, and attitudes. Table 2 summarizes the health literacy knowledge and skill needs related to incontinence. Receiving knowledge about the association between AD and incontinence was a common need. Caregivers acknowledged that incontinence may not be able to be eliminated, but stated they wanted to “control” it. They sought information about management strategies including medications, surgery, and modifications in behavior, diet, and fluid intake. Some

had concerns about the adequacy of their care recipient's fluid intake and wanted to know the "right balance" that would prevent both dehydration and urinary incontinence.

Caregivers thought it was important to know a variety of skills and strategies to use at different times and in different situations such as at home or in public. Those trying to reduce the number of incontinence episodes by prompting toilet use were interested in knowing how frequently to ask their care recipient about the need to toilet. They were interested in strategies for managing resistance to toileting, especially before going out in public. Some wanted to know how often to check for soiling in their care recipient. They inquired about devices such as sheaths and a urinal for men and women due to concerns about falls and the care recipient getting "lost" on the way to the bathroom during the night. They had questions and concerns about the cost and insurance coverage of treatments and supplies. Having public bathrooms where both sexes could enter was hailed as an important accommodation that enabled many couples to be able to go out together more often.

Caregivers desired information to help them select among the various types of absorbent products available. One suggestion was for manufacturers to make available a "sampler" of different types of absorbent products to try. Knowing options for using different types of absorbent products for different situations (day vs. night, home vs. public) and about various types of bed pads was a need for some. Caregivers needed strategies for managing resistance by their care recipient (especially men) related to wearing an absorbent product.

Some of the major care problems of incontinence suggested other needs. Caregivers desired ways to reduce the need to change and launder bed linens every morning and their worry about stains on furniture. The time and physical effort needed to undress and redress their care recipient after soiling several times during the day was a challenge. A few caregivers were interested in information about insurance coverage for a home health aide.

Health Literacy Needs Related to Skin Care

Caregivers reported they lacked knowledge about skin problems or skin care related to incontinence. Table 3 summarizes their health literacy needs for knowledge and skills related to skin care. Caregivers desired descriptions and photographs of the types of skin damage associated with incontinence. They wanted to know about the expected course of healing and early signs of worsening. They expressed confusion and frustration about the many over-the-counter skin care products available and stated that having a guide to products, their active ingredients, and indications for use as a real need. They also stated that the variety of locations that skin care products were displayed in retail stores such as a cosmetic counter acted as barriers for locating and comparing products. Women felt they needed to remember knowledge about managing diaper rash in their children and wondered if newer or better products were available for adults. They also expressed a desire for information about preventing skin damage.

A common health literacy need expressed by caregivers was to build skill in skin care, and they sought a set of step-by-step instructions. They wanted information about the best way to cleanse urine or fecal materials from the skin, especially in persons of the opposite sex or a person who is larger or heavier than the caregiver. Some caregivers expressed concerns about the adequacy with which their care recipient cleansed their perineal area, and most noted they did not regularly assess the perineal area of their care recipient for early skin problems (even though they thought doing this was a good idea). Perceived barriers to this practice were lack of knowledge about what to assess in the perineal area, difficulty observing the perineal area in an efficient and unobtrusive manner, the increased modesty of some care recipients. Caregivers also reported hesitancy based on perceptions that assessment of the perineal skin is not something a spouse or daughter usually performs.⁴¹

Caregivers asked about mixed opinions they had heard regarding use of powder to keep skin dry, whether moisturizers should be used on damaged skin, and products that might prevent irritation and alleviate itching and reduce scratching behaviors.

Health Literacy Attitudes

Caregivers acknowledged the public stigma associated with their partner or relative's incontinence. They supported the portrayal of incontinence as a health problem rather than a behavioral or mental problem. Caregivers hoped that this presentation might lessen denial from their care recipients and promote discussion with others in their family and community. Discussing their experiences in managing incontinence with other caregivers was identified as a need and desire so as to not feel alone, validate or acquire management strategies, and reduce frustration.

Caregivers stated that developing incontinence was usually not viewed by the care recipient as warranting a special visit to their health care provider. Caregivers further stated they did not wish to go against their care recipients' wishes, further reducing the likelihood of informing the recipients' healthcare provider. Once incontinence developed and they were managing it, the need to discuss it with a healthcare provider at a future visit seemed less important. Caregivers supported the idea that healthcare providers inquire about the existence of incontinence and skin damage both initially and at follow-up visits if strategies were being used to try to reduce it. They were uncertain about the length of time for improvement to be achieved or reported back to the healthcare provider. None of the caregivers whose care recipient did not have incontinence currently had discussed the possibility of incontinence and skin damage with their healthcare provider; however, they all desired information before their occurrence in order to feel prepared.

Caregivers disagreed on whether the person receiving care should be present when talking to a healthcare provider about incontinence. Those in favor thought that the care recipient would view the healthcare provider as an authority about the topic, rendering the patient more likely to cooperate with management strategies. Those who opposed discussing incontinence with a healthcare professional did not want to upset their care recipient or make them anxious by discussing a problem that they might not fully understand or be able to control. Some caregivers suggested the healthcare provider explain the problem and management options in simple terms when the care recipient was present and then speak separately to the caregiver, providing more details. Caregivers desired "straight talk" about incontinence and its management and relation to AD from a healthcare provider yet they wanted support and reassurance that they were capable of providing the care needed. Most caregivers stated they wanted to continue to care for their family member or friend at home as long as possible. However, anticipating the possibility of a nursing home placement, they desired information about questions regarding policies and programs for incontinence care and pressure ulcer prevention. Caregivers whose care recipients were still continent anticipated needing ways to periodically relieve the work and stress associated with managing incontinence in addition to other problems resulting from AD.

Health Literacy Possessed by Caregivers

Caregivers identified several strategies used to manage incontinence. The most common were using absorbent products, encouraging use of the toilet prior to going into public, and packing an extra set of clothes and cleansing wipes "for emergencies" while in public. Although some strategies were effective, they were not always desirable and alternatives were sought; one example was laying down plastic-backed pads on chairs. Disruptions in sleep due to soiling required some couples to sleep in separate beds and rooms, which was viewed as a loss of intimacy after sleeping together for years. One caregiver revealed that

they placed a rubber sheet under cloth sheets to protect the mattress. Some caregivers limited traveling with their care recipient. A common need among caregivers who were managing incontinence was validation. They were uncertain whether they were providing proper care and using the best products. They were also interested in the approaches of other caregivers like themselves and their success.

When caregivers were asked how they would describe their care recipient's incontinence to a healthcare provider, responses included the following: "having accidents, leaking, losing control, wetting or messing their pants, having a urine/bowel problem, urgency, diarrhea, loose bowels, being unable to hold it, and not getting there in time." They admitted they did not know the "right" terms to use and were concerned about expressions that would be disrespectful to their care recipient. They did not support use of slang or "baby-like" words. They readily adopted the term incontinence, once made aware of it.

When caregivers were asked to describe the appearance of skin damage due to incontinence that they would expect to see, their responses included the following: rash, pimply, pink or red, blotchy, inflamed or irritated, chapped or chaffed, dry and cracking, thinning, broken skin, bleeding, sore, raw, and excoriated. Individuals with dark-toned skin also described damaged skin as being red or darker or lighter than the normal skin color. Caregivers with dark-toned skin disagreed with descriptions of damage on darker skin as having a "blue" or "gray" color as reported in the literature⁴² and explained that a difference from the normal color is a better indicator.

Educational and Supportive Materials

In response to the needs assessment, several educational and supportive documents were developed. The vast majority of caregivers preferred to receive a printed, rather than an electronic, version of such materials. They perceived the hard copy to be easier and more reliable to store and retrieve when needed. They also recommended a modular format of information rather than one large booklet containing multiple types of information. Caregivers whose native language was Spanish desired written material in Spanish. Only a few younger adult caregivers said they occasionally used the internet as a resource of information. When asked about electronic formats for receiving education, care recipients stated that they would be most interested in watching a short video showing other caregivers of individuals with AD discussing their care.

Attending a face to face training session or a regular support group was not considered feasible by many caregivers. Caregivers also noted that many were responsible for caring for their own children as well as a parent with AD. Other barriers to face to face training included work demands, limited ability to drive, unavailability or unaffordability of respite care, and the need to complete errands outside the home during respite care.

Based on the health literacy needs assessment of this study, 14 documents were developed for caregivers. They addressed the following topics: potential alterations in maintaining continence in AD; managing incontinence; fluid and diet considerations; guide to absorbent products; examples of incontinence dermatitis and pressure ulcers; a guide to and internet resources for skin care products; talking to a healthcare provider about these problems; definitions to common clinical terms; and self-care for the caregiver. These documents are freely available via the *JWOCN* website (<http://journals.lww.com/jwocnonline/pages/default.aspx>).

Discussion

To our knowledge, this is the first study to assess the health literacy needs of informal caregivers of individuals with AD and health literacy in relation to incontinence and skin care. Low health literacy is associated with poor health outcomes in individuals. Few studies have examined the health literacy of caregivers. Due to the increasing number of individuals with AD who require assistance with activities of daily living, such as toileting and incontinence, focusing on the health literacy of caregivers in relation to these topics is important. Our findings reveal that caregivers have numerous needs in the areas of knowledge, skills for caregiving, and attitudes about incontinence and skin care. Low health literacy of informal caregivers has potential to result in poorer health outcomes of their care recipient. Educational and supportive materials that address the health literacy needs of caregivers of individuals with AD were developed in this study. Materials were developed so they can be distributed to caregivers individually or in sets as needed and in print based on the preferences of caregivers in this study. Caregiver needs encompassed a comprehensive set of topics in relation to incontinence and skin care. Caregivers were open to learning new skills to raise their care capacity and ways to improve communication about these problems with other family members and health care providers.

The results in this study support inclusion of a WOC nurse on care teams addressing the needs of caregivers of individuals with AD. Caregivers specifically expressed an interest in discussing skin care with a specialist nurse. The educational and supportive materials developed in this study are available to WOC nurses as resources when interacting with patients with AD and their caregivers (<http://journals.lww.com/jwocnonline/pages/default.aspx>).

Study findings suggest that even when caregivers possessed health literacy about incontinence management and skin damage prevention, they doubted their capabilities and desired validation. WOC nurses can credibly validate the knowledge and skills that caregivers possess as well as teach new information needed.

The experience of caregiving for a family member or friend with AD is paradoxical; it was described as simultaneously negative and positive, taxing yet self-affirming.^{25,43} Caregivers may experience emotional distress resulting in depression, sleep disturbances, family discord, and interference with their work and social activities. They often forego exercise and other healthy lifestyle practices.^{25,31,32,44} Nevertheless, many caregivers have both positive and negative responses to their caregiver role and describe feeling depleted yet self-affirmed.⁴³ Several studies report that incontinence, especially fecal incontinence, is a deciding factor to admit their care recipient into a NH.^{45,46} Although NH placement reduces direct care obligations of caregivers, it does not necessarily alleviate caregiver distress or burnout. Admission to a NH paradoxically introduces new stressors such as guilt, worry about adequate care, and conflicts with NH staff.³² Depression, anxiety, and burnout scores were not significantly different between caregivers of persons with AD living at home or in a NH.^{25,31,47} The high rates of incontinence (50–60%),^{48,49} pressure ulcers (10%) and incontinence associated dermatitis (5–6%) in NH residents^{48,50} suggest a lack of capacity for substantial increases in NH admissions with these problems.

Educational and supportive interventions aimed at strengthening the care giving capacity of and perceived benefits for informal caregivers of persons with AD have been shown to ameliorate a number of adverse effects of care giving. For example, The Savvy Caregiver program, which consists of 6 two-hour learning sessions that are portable for use by a variety of groups or organizations,⁵¹ has improved the sense of mastery and lowered the distress and sense of loss of caregivers of individuals with AD in several

investigations.^{34,52,32,34,52} Another psychoeducational intervention for spouse caregivers of persons with AD reduced NH placement 28% for a median delay of 557 days.³² The intervention comprised 6 sessions of individual and family counseling, support group participation, and continuous availability of ad hoc telephone counseling. Benefits of the intervention to caregivers were higher satisfaction with social support, less reactivity to a care recipient's negative behavior, and less depression.^{32,52} Lower depression severity was sustained in caregivers who received the intervention for up to three years in one study.⁵² The health literacy materials developed in this study can augment established psychoeducational interventions for caregivers of individuals with AD.

The results of this study show that caregivers of individuals with AD have an interest in increasing their health literacy related to the management of incontinence and prevention of skin damage. Clemesha and Davies⁵³ reported that caregivers of persons with AD in the United Kingdom had knowledge about the association of cognitive factors and fecal incontinence but lacked information about ways to manage incontinence. An educational program increased the incontinence related knowledge of the caregivers including their awareness of factors that might be contributing to fecal incontinence severity. Findings in this study also indicate that caregivers need more knowledge about the association about AD and incontinence than those in the study of Clemesha and Davies.⁵³ Other studies show that training caregivers in specific interventions to reduce urinary incontinence improved outcomes of the care recipient. In one study, training caregivers of homebound elderly with AD to implement a prompted voiding intervention reduced daytime urinary incontinence episodes of care recipients 22%.⁵⁴ Caregivers of frail elderly who were trained to perform a toileting intervention reduced incontinence associated dermatitis in 19% of care recipients and the frequency and volume of urinary incontinence.⁵⁵

Despite a lack of communication about incontinence among healthcare providers, patients, and caregivers, and likely missed opportunities for treatment, we found no systematic investigations of ways to improve these problems. We therefore developed a guide for caregivers that promotes initiation of discussion pertaining to these sensitive health conditions with healthcare providers. A glossary of terms commonly used in reference to incontinence and skin care was also developed to increase health literacy. Whether use of these materials will improve communication between caregivers and health care providers about these problems is unknown and needs further study.

A noteworthy finding of this study was the description of skin damage on dark toned skin. Although the nursing literature describes the appearance of stage I and II pressure ulcers on dark-toned skin as a bluish or gray color,⁴² the caregivers with dark-toned skin in this study refuted that description. They maintained that skin damage, either from a less severe pressure ulcer or incontinence associated dermatitis, would appear as red or pink or as a lighter or darker color than the usual skin tone. Our team is in process of examining the appearance of these types of skin damage on dark-tone with these revised descriptions in mind.

Study Limitations

There are limitations of this study. Incontinence and AD are sensitive topics and some AD caregivers may not have expressed all of their needs even though the investigators are experienced in inquiring about them using focus groups and interviews. The study included a diverse sample of AD caregiver participants to increase generalizability of findings but there may be race or ethnicity-specific needs that this study was not designed to evaluate. Recruitment procedures did not identify male children caregivers to be included.

Conclusion

Informal caregivers of community-living individuals with AD identified multiple health literacy needs related to incontinence and skin care. There is opportunity for the WOC nurse to address these needs as part of their practice. Interventions that raise health literacy offer the potential to improve health outcomes and care giving capacity. Educational and supportive materials were developed in this study to support interventions to increase health literacy to incontinence and skin care in AD patients.

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References

1. Sudore RL, Mehta KM, Simonsick EM, et al. Limited literacy in older people and disparities in health and healthcare access. *Journal of the American Geriatrics Society*. 2006; 54:770–776. [PubMed: 16696742]
2. White S. Assessing the Nation's health literacy key concepts and findings of the national assessment of adult literacy (NAAL). American Medical Association Foundation. 2008
3. Williams MV, Davis T, Parker RM, Weiss BD. The role of health literacy in patient-physician communication. *Family Medicine Journal*. 2002; 34(5):383–389.
4. Williams MV, Parker RM, Baker DW, et al. Inadequate functional health literacy among patients at two public hospitals. *Journal of the American Medical Association*. 1995; 274(21):1677–1682. [PubMed: 7474271]
5. Nutbeam D. The evolving concept of health literacy. *Social Science and Medicine*. 2008; 67:2072–2078. [PubMed: 18952344]
6. Williams MV, Baker DW, Parker RM, Nurss JR. Relationship of functional health literacy to patients' knowledge of their chronic disease: A study of patients with hypertension and diabetes. *Archives of Internal Medicine*. 1998; 158:166–172. [PubMed: 9448555]
7. Weiss BD, Palmer R. Relationship between health care costs and very low literacy skills in a medically needy and indigent medicaid population. *Journal of the American Board of Family Practice*. 2004; 17(1):44–47. [PubMed: 15014052]
8. Howard DH, Gazmararian J, Parker RM. The impact of low health literacy on the medical costs of medicare managed care enrollees. *American Journal of Medicine*. 2005; 118(4):371–377. [PubMed: 15808134]
9. Kutner, M.; Greenberg, E.; Jin, Y.; Paulsen, C.; White, S. NCES 2006-483. U.S. Department of Education; Washington D.C: 2006. The health literacy of America's adults: Results from the 2003 national assessment of adult literacy.
10. Baker DW, Wolf MS, Feinglass J, Thompson JA, Gazmararian JA, Huang J. Health literacy and mortality among elderly persons. *Archives of Internal Medicine*. 2007; 167(14):1503–1509. [PubMed: 17646604]
11. Gazmararian JA, Williams MV, Peel J, Baker DW. Health literacy and knowledge of chronic disease. *Patient Education and Counseling*. 2003; 51:2–275.
12. Volandes AE, Paasche-Orlow M, Gillick MR, et al. Health literacy not race predicts end-of-life care preferences. *Journal of Palliative Medicine*. 2008; 11(5):754–762.
13. Davis TC, Dolan NC, Ferreira MR, et al. The role of inadequate health literacy skills in colorectal cancer screening. *Cancer Investigation*. 2001; 19(2):193–200. [PubMed: 11296623]
14. Patel K, Bliss DZ, Savik K. Health literacy and emotional responses related to fecal incontinence. *Journal of Wound, Ostomy, and Continence Nursing*. 2010; 37(1):73–79.
15. Bliss DZ, Fischer LR, Savik K, Avery M, Mark P. Severity of fecal incontinence in community-living elderly in a health maintenance organization. *Research in Nursing and Health*. 2004; 27(3): 162–73. [PubMed: 15141369]

16. Leigh RJ, Turnberg LA. Faecal incontinence: The unvoiced symptom. *Lancet*. 1982; 1(8285): 1349–51. [PubMed: 6123650]
17. Johanson JF, Lafferty J. Epidemiology of fecal incontinence: The silent affliction. *American Journal of Gastroenterology*. 1996; 91(1):33–6. [PubMed: 8561140]
18. Wolf MS, Williams MV, Parker RM, Parikh NS, Nowlan AW, Baker DW. Patients' shame and attitudes toward discussing the results of literacy screening. *Journal of Health Communication*. 2007; 12(8):721–732. [PubMed: 18030638]
19. Garcia JA, Crocker J, Wyman JF, Krissovic M. Breaking the cycle of stigmatization: Managing the stigma of incontinence in social interactions. *Journal of Wound, Ostomy, and Continence Nursing*. 2005; 32(1):38–52.
20. Peden-McAlpine C, Bliss DZ, Hill J. The experience of community-living women managing fecal incontinence. *Western Journal of Nursing Research*. 2008; 30(7):817–835. [PubMed: 18270314]
21. Reddy M, Gill SS, Rochon PA. Preventing pressure ulcers: A systematic review. *Journal of the American Medical Association*. 2006; 296(8):974–984. [PubMed: 16926357]
22. Alzheimer's Association. 2011 Alzheimer's disease facts and figures. *Alzheimers & Dementia*. 2011; 7(2):1–66.
23. Cassells C, Watt E. The impact of incontinence on older spousal caregivers. *Journal of Advanced Nursing*. 2003; 42(6):607–616. [PubMed: 12787234]
24. Upton N, Reed V. The meaning of incontinence in dementia care. *Int J Psychiatr Nurs Res*. 2005; 11(1):1200–1210. [PubMed: 16268229]
25. Almborg B, Grafstrom M, Winblad B. Caring for a demented elderly person--burden and burnout among caregiving relatives. *Journal of Advanced Nursing*. 1997; 25(1):109–116. [PubMed: 9004018]
26. Selden, C.; Zorn, M.; Ratzan, SC.; Parker, RM. [Accessed December, 28, 2008] Health literacy [bibliography online]. current bibliographies in medicine. no. 2000–1. <http://www.nlm.nih.gov/floyd.lib.umn.edu/archive//20061214/pubs/cbm/hliteracy.html>.
27. Sela-Katz P, Rabinowitz I, Shugaev I, Shigorina G. Basic knowledge of the medication regimen correlates with performance on cognitive function tests and diagnosis of dementia in elderly patients referred to a geriatric assessment unit. *Gerontology*. 2010; 56:491–495. [PubMed: 20339299]
28. Bevan JL, Pecchioni LL. Understanding the impact of family caregiver cancer literacy on patient health outcomes. *Patient Education and Counseling*. 2008; 71:356–364. [PubMed: 18372142]
29. Yap P, Tan D. Urinary incontinence in dementia - a practical approach. *Australian Family Physician*. 2006; 35(4):237–241. [PubMed: 16642241]
30. Shamliyan T, Wyman J, Bliss DZ, Kane RL, Wilt TJ. Prevention of urinary and fecal incontinence in adults. *Evidence Report/Technology Assessment*. 2007; (161):1–379.
31. Almborg B, Grafstrom M, Winblad B. Major strain and coping strategies as reported by family members who care for aged demented relatives. *Journal of Advanced Nursing*. 1997; 26(4):683–691. [PubMed: 9354978]
32. Mittelman MS, Haley WE, Clay OJ, Roth DL. Improving caregiver well-being delays nursing home placement of patients with Alzheimer's disease. *Neurology*. 2006; 67:1592–1599. [PubMed: 17101889]
33. Hepburn K, Lewis M, Tornatore J, Sherman CW, Bremer KL. The savvy caregiver: The demonstrated effectiveness of a transportable dementia caregiver psychoeducation program. *Journal of Gerontological Nursing*. 2007:30–36. [PubMed: 17378189]
34. Ostwald SK, Hepburn KW, Caron W, Burns T, Mantell R. Reducing caregiver burden: A randomized psychoeducational intervention for caregivers of persons with dementia. *Gerontologist*. 1999; 39(3):299–309. [PubMed: 10396888]
35. Olshansky E, Sacco D, Braxter B, et al. Participatory action research to understand and reduce health disparities. *Nursing Outlook*. 2005; 53(3):121–126. [PubMed: 15988448]
36. Lazarus, RS. *Psychological Stress and the Coping Process*. New York: McGraw-Hill; 1996.
37. Antonovsky, A. *Health, Stress, and Coping*. San Francisco: Jossey-Bass; 1979.

38. Krueger RA. Analyzing focus group interviews. *Journal of Wound, Ostomy & Continence Nursing*. 2006; 33(5):478–481.
39. Lincoln, Y.; Guba, E. *Naturalistic inquiry*. Thousand Oaks, CA: Sage Press; 1985.
40. Reisberg B. Functional assessment staging (FAST). *Psychopharmacology bulletin*. 1988; 24(4): 653–659. [PubMed: 3249767]
41. Mullins J, Bliss DZ, Rolnick C, Jackson J, Arntson C, Hepburn K. Health literacy needs related to incontinence and skin damage among different types of caregivers of individuals with dementia. *Midwest Nursing Research Society*. 2011
42. Bennett MA. Report of the task force on the implications for darkly pigmented intact skin in the prediction and prevention of pressure ulcers. *Advances in Wound Care*. 1995; 8(6):34–35. [PubMed: 8696575]
43. Narayan S, Lewis M, Tornatore J, Hepburn K, Corcoran-Perry S. Subjective responses to caregiving for a spouse with dementia. *Journal of Gerontological Nursing*. 2001; 27(3):19–28. [PubMed: 11915254]
44. Lieberman MA, Fisher L. The impact of chronic illness on the health and well-being of family members. *Gerontologist*. 1995; 35(1):94–102. [PubMed: 7890209]
45. Armstrong M. Factors affecting the decision to place a relative with dementia into residential care. *Nursing Standard*. 2000; 14(16):33–37. [PubMed: 11209437]
46. Tsuji I, Whalen S, Finucane TE. Predictors of nursing home placement in community-based long-term care. *Journal of the American Geriatrics Society*. 1995; 43(7):761–766. [PubMed: 7602027]
47. Schulz R, Belle SH, Czaja SJ, McGinnis KA, Stevens A, Zhang S. Long-term care placement of dementia patients and caregiver health and well-being. *Journal of the American Medical Association*. 2004; 292(8):961–967. [PubMed: 15328328]
48. Bliss DZ, Savik K, Harms S, Fan Q, Wyman JF. Prevalence and correlates of perineal dermatitis in nursing home residents. *Nursing Research*. 2006; 55(4):243–51. [PubMed: 16849976]
49. Nelson R, Furner S VJ. Fecal incontinence in Wisconsin nursing homes: Prevalence and associations. *Diseases of the Colon and Rectum*. 1998; 41(10):1226–9. [PubMed: 9788384]
50. Bliss DZ, Zehrer C, Savik K, Thayer D, Smith G. Incontinence-associated skin damage in nursing home residents: A secondary analysis of a prospective, multicenter study. *Ostomy Wound Management*. 2006; 52(12):46–55.
51. Hepburn K, Lewis M, Tornatore J, Sherman CW, Bremer KL. The savvy caregiver program: The demonstrated effectiveness of a transportable dementia caregiver psychoeducation program. *Journal of Gerontological Nursing*. 2007; 33(3):30–36. [PubMed: 17378189]
52. Mittelman MS, Roth DL, Coon DW, Haley WE. Sustained benefit of supportive intervention for depressive symptoms in caregivers of patients with alzheimer's disease. *Am J Psychiatry*. 2004; 161(5):850–856. [PubMed: 15121650]
53. Clemesha L, Davies E. Educating home carers on faecal incontinence in people with dementia. *Nursing Standard*. 2004; 18(34):33. [PubMed: 15151022]
54. Engberg S, Sereika SM, McDowell BJ, Weber E, Brodak I. Effectiveness of prompted voiding in treating urinary incontinence in cognitively impaired homebound older adults. *Journal of Wound, Ostomy, & Continence Nursing*. 2002; 29(5):252–265.
55. Colling J, Owen TR, McCreedy M, Newman D. The effects of a continence program on frail community-dwelling elderly persons. *Urologic Nursing*. 2003; 23(2):117–122. [PubMed: 12778826]

Table 1

Demographics Characteristics of Caregivers

n = 48		% (n)*
Sex	Female	75 (36)
Age mean (SD)		64 (14)
Race	White, not Hispanic	52.1 (25)
	Black/African American, not Hispanic	10.4 (5)
	Other/More than One Race, not Hispanic	6.3 (3)
	Hispanic, White	25 (12)
	Hispanic, Black	2.1 (1)
	Hispanic Other/mixed race	4.2 (2)
Relationship Status	Always Single	1.2 (1)
	Widowed	4.2 (4)
	Married	66.7 (32)
	Divorced/Separated	20.8 (10)
	Partnered	4.2 (2)
	Missing	2.1 (1)
Living situation	Lives Alone	18.8 (9)
	Lives with Spouse	66.7 (32)
	Lives with Partner	4.2 (2)
	Lives with Child	16.7 (8)
	Lives with Grandchild	2.1 (1)
	Lives with Sibling	6.3 (3)
	Lives with Son/Daughter	6.3 (3)
	Lives with Parent	12.5 (6)
	Lives with Other	4.2 (2)
Employment	Currently Employed	39.6 (19)
	Retired	41.7 (20)
	Unable to work or Disability	14.6 (7)
Highest level of education	Grade School	8.3 (4)
	Some High School	8.3 (4)
	High School degree	10.4 (5)
	Some college/Vocational Training	35.4 (17)
	College degree	33.3 (16)
ADLs Assisting with**	Bathing/Showering	45.8 (22)
	Grooming	45.8 (22)
	Dressing	54.2 (26)
	Toileting	41.7 (20)
	Ambulation	35.4 (17)
	Meal Preparation	79.2 (38)
	Shopping	72.9 (35)

Transportation	77.1 (37)
Medication Set-Up	62.5 (30)
Managing Finances	66.7 (32)
Cleaning	79.2 (38)

* Unless noted otherwise;

** More than one could be selected so %s are >100%

Table 2

Health Literacy Needs of Informal Caregivers of Individuals with Alzheimer's Disease or Dementia Related to Incontinence

Knowledge	<ul style="list-style-type: none"> • association between incontinence and Alzheimer's disease or dementia • incontinence during sleep • clinical terms to discuss incontinence with healthcare provider • therapies for incontinence <ul style="list-style-type: none"> ◦ medications ◦ types of device aides: condom catheter, urinal, commode ◦ surgical options ◦ behavioral strategies to manage • diet and fluid changes to reduce incontinence • absorbent products to use for containing incontinence • ways to obtain supplies cost-effectively • where to go to obtain resources and information • validation of knowledge possessed
Skills	<ul style="list-style-type: none"> • scheduling toileting to prevent incontinence • managing at home, including protection and care for furniture, rugs etc. • managing in public • how to deal with resistance from care recipient <ul style="list-style-type: none"> ◦ related to wearing absorbent products ◦ related to prompts to toilet • how to keep up physically with care e.g., changing and laundering clothes, bed linens, etc. • validation of skills possessed

Table 3**Health Literacy Needs of Informal Caregivers of Individuals with Alzheimer's Disease or Dementia Related to Skin**

Knowledge

- types of skin damage that can occur
- causes of skin damage
- time to heal
- identifying/recognizing different skin problems
- how to prevent and treat skin damage
- consequences of not treating
- treatment products/ointments to use – are they the same as for infants?
 - availability and sources of products
- any changes in nutrition advised
- interest in discussing information with a skin specialist nurse
- validation of knowledge possessed

Skills

- step by step instructions for skin care
 - explain product ingredients for normal and damage skin
 - best way to cleanse and care recipient - especially of opposite sex of care giver and larger size
 - how to keep skin dry
 - use of powder
 - how to minimize irritation
 - managing scratching
 - validation of skills possessed
-

Table 4**Health Literacy Attitude Needs of Informal Caregivers of Caregivers of Individuals with Alzheimer's Disease or Dementia**

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- desire for incontinence to be framed as a health problem
 - more public awareness and information to reduce stigma
 - important to feel not only one dealing with these problems
 - when to communicate with health care provider; would appreciate health care provider to inquire about these problems first
 - want to prepare for occurrence of these problems
 - want "straight talk" from healthcare providers
 - general support from health care provider for managing these problems along with other dementia problems
 - mixed opinions about discussing problems with health care provider with care recipient present
 - inquiries after initial one should be considerate of treatment selected and potential for improvement (e.g., if only using pads, incontinence would not improve)
 - when to consider a nursing home and what to look for in a nursing home to manage these problems
 - Hispanic care givers desire resource materials in Spanish
-