Published in final edited form as:
J Wound Ostomy Continence Nurs. 2016 ; 43(5): 539–544. doi:10.1097/WON.0000000000000263.

Barriers to Communication with a Healthcare Provider and Health Literacy about Incontinence among Informal Caregivers of Individuals with Dementia

Jean Mullins, BSN, RN, **Donna Z. Bliss, PhD, RN, FAAN, FGSA**, **Sharon Rolnick, PhD**, **Casey Arntson Henre, BSN, RN**, and **Jody Jackson, BSN, RN**

Abstract

Purpose—The purpose of this study was to examine barriers to communicating with healthcare professionals and health literacy about incontinence among different types of informal caregivers of individuals with AD.

Design—Descriptive secondary analysis.

Subjects and Setting—The sample included 48 family/friend adult caregivers of individuals who had AD. Seventy five percent were female; their mean age was 64 ±14 years (mean ±SD). Caregivers were spouses (44%), daughters (31%), or extended family members/friends (25%). Nearly half (48%) of caregivers had a racially or ethnically diverse background; 58% of their care recipients had incontinence.

Methods—Data were collected via focus groups, interviews, and written surveys. Verbal responses were audiotaped, transcribed, and analyzed for themes by caregiver type using content analysis.

Results—Caregivers of persons with AD described role-related barriers to improving health literacy about incontinence and its management. Main themes of barriers emerged for each type of role that were emotive in nature for daughters, experiential for both spouse caregivers, system related for husbands, and relational (being perceived as an outsider) for extended family/friends.

Conclusions—Nurse continence specialists have an important role in raising health literacy about incontinence and its management for informal caregivers of individual with AD. Results inform the development of interventions that are tailored to the type of caregiver as recommended by national health literacy initiatives with the aim of for improving outcomes such as incontinence of care recipients.

Introduction

Approximately 15 million individuals in the United States provide informal (i.e., unpaid) care for persons with Alzheimer's disease or dementia (AD) who reside in the community[1]. Health literacy is essential for optimal caregiving and for better health outcomes of care recipients. While health literacy has been defined as "the capacity to obtain, process and

---

Correspondence: Jean Mullins, BA, BSN, University of Minnesota Twin Cities, c/o Donna Bliss, PhD, RN, 5-140 Weaver-Densford Hall, 308 Harvard St, Minneapolis, MN 55455, UNITED STATES, 971-285-6254, jeanhmullins@gmail.com.

understand basic health information and services needed to make appropriate health decisions[2]," a more functional perspective has been recommended[3]. The American Medical Association has proposed that health literacy encompasses the ability to perform clinical tasks, prevention tasks, and health system navigation tasks and having the requisite knowledge and understanding to do so[3]. Caregivers of individuals with AD perform all of these types of tasks. They provide extensive care assistance with activities of daily living as well as interventions for prevention and treatment of health problems. They also advise care recipients on multiple decisions about their health and health care and accompany them to healthcare visits where information for making decisions is communicated. As decision-making ability lessens with progression of AD, informal caregivers also serve as proxy/legal representatives for making health care decisions their care recipients who continue to live at home.

Recognizing the essential role of informal caregivers in the well-being and care of their family members or friend care recipients, the focus of improving health literacy, and the concept itself, is evolving beyond the traditional focus on the individual patient. Our team has joined a group of investigators who assert that health literacy is a priority not only for patients but also for their caregivers in order for patients to achieve the most successful health outcomes[4,5].

Lower health literacy has been reported among racial and ethnic minority groups[2,3] and approximately 15% of informal caregivers are Black, Hispanic or Asian[5,6]. Garcia and colleagues[5] reported that health literacy was low in approximately 30% of Hispanic informal caregivers of older adults. Although about 20% of informal caregivers are non-related friends[6], there are few studies about their health literacy levels, needs, or barriers in relation to their care responsibilities. Informal caregivers have different experiences, care abilities, and resources based on their role in the relationship with their care recipient, (i.e., wife vs. daughter vs. friend), gender, or age[7], which could influence their level of health literacy.

Communication with healthcare providers is one of the main ways to improve health literacy[8]. The low level of communication between patients and healthcare providers about incontinence is well-known[9–12]. In a previous study we reported that informal caregivers of persons with AD have numerous health literacy needs related to incontinence[13] including better communication with healthcare providers. The purpose of this study was to examine barriers to communicating with healthcare professionals and health literacy about incontinence among different types of informal caregivers of individuals with AD.

Methods

This study has a descriptive design; it is a secondary analysis of data collected in a parent study[13]. Study procedures were reviewed and approved by the Institutional Review Boards of the University of Minnesota and HealthPartners Research Foundation.

Parent Study Aims and Procedures

The aims of the parent study that provided data for this analysis were to describe health literacy needs of family or friend caregivers related to incontinence and associated skin damage in caring for individuals with AD and to develop supportive and educational materials that address these needs[13]. 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.

Caregivers were recruited from several community sites: a health maintenance organization (HMO), a block nurse support program 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, at the HMO, an administrative database was electronically searched for eligible participants then an invitational letter was mailed followed by a telephone call if necessary. A Hispanic community advisor in the living at home program was instrumental in recruiting Hispanic caregivers. At support groups and conferences, announcements about the study and study brochures were made available.

Procedures were reported in more detail previously[13]. Briefly, focus groups or semi-structured interviews were conducted to collect data assessing caregiver literacy needs related to incontinence and skin care which lasted approximately one hour. Demographic and health history data were obtained using surveys. Focus groups and interviews were audiotaped and transcribed. All members of the research team reviewed the data. At least two members of the research team conducted the analysis independently then results were discussed with all team members and reanalyzed until consensus was reached. Transcripts were analyzed and coded using content analysis. Themes and subthemes related to the study aims emerged from the analysis. Descriptive statistics (age, sex, etc.) of the sample characteristics were done using SPSS software version 16 (Statistical Package for the Social Sciences Chicago, IL). Results are reported elsewhere[13].

Data Analysis

Data of all subjects collected in the parent study were eligible for this analysis. Data analysis procedures were similar to those in the parent study except that data were categorized by type of caregiver (spouses, children, and extended family or friends), and the content analysis focused on the aims of this study. The transcripts from focus groups and structured interviews were reviewed by all team members. Data were analyzed independently by two members of the research team with the goal of identifying subthemes and main themes. Subthemes and themes that emerged from the data were labeled and coded. Results were discussed with other team members in an iterative manner until consensus was reached. Descriptive statistics (frequencies, percentages, means and standard deviations or medians and ranges) of the characteristics of sample were analyzed by type of caregiver depending on the type and distribution of data using SPSS software version 16.

Results

The characteristics of each type of caregiver are described in Table 1. Most of the caregivers were spouses, and all children caregivers were daughters. One-quarter of caregivers were extended family or friends, and the majority of those were female. More than half of the sample were shared a minority racial or ethnic background. None of the Hispanic caregivers was a husband, and Hispanics had the highest percentage of caregivers who were extended family/friends. Husband caregivers were older on average than wife caregivers. The majority of daughter and extended family and friend caregivers were employed outside the home, while most spouse caregivers were retired. More than half (58%) of all caregivers, regardless of type, were managing incontinence (urinary or dual urinary and fecal incontinence) of their care recipient. One-third of the care recipients had dual incontinence; none had fecal incontinence only.

Barriers Experienced by Daughter Caregivers

Analysis revealed differences in barriers to communication with healthcare providers and improving health literacy about incontinence by type of caregiver. The main theme of these barriers among daughter caregivers was their emotional struggles with the reversal in roles between parent and child that developed as a result of the parent's AD and incontinence. Subthemes of this barrier were the daughters' awkwardness in assisting with incontinence cares of their father due to gender differences and the unique father-daughter relationship, reluctance to interfere with parents' role domain and privacy, and sadness and distress from feeling empathetic shame for the parent. These emotional barriers stemmed from daughters' awareness that their parents previously performed these types of activities for them. One daughter observed: "I think you hit a point where you become very aware you've switched roles, and in a permanent way, where you're now in the parent sort of role. And that, I think, is difficult…for everybody to adjust to." Another daughter elaborated on this issue that she thought was magnified by the gender difference and role identity of her father: "How does a father accept a daughter's help? In his mind he's the father and I'm a daughter. So fathers always know best… it's very, very different when it's a child caregiving. Very, very different than with a spouse." A wife acknowledged the difference in relationship of a child caregiver and commented that needing to talk to a healthcare provider about incontinence in a parent "adds a whole other dimension."

Daughters reported that they would prefer to discuss incontinence more extensively with their parents' healthcare provider separately from their parent to be sensitive of their parent's privacy feelings. However, time constraints at appointments or inability to meet alone with the healthcare provider often did not allow this opportunity. One daughter stated that although her father knew his daughter wanted to discuss his incontinence during his appointment with the healthcare provider he would not permit it: "I will have to talk separate[ly]. Not with my father in…he won't let me talk about that." Daughters felt caught in a dilemma because they did not want to betray their parent's privacy or go against their wishes by revealing their incontinence to the provider despite wanting to seek advice about its management. One daughter stated, "Even though they have Alzheimer's disease, it is still their body and it is about respect."

Even though some daughters sought more information about managing their parent's incontinence with a healthcare provider, they were conflicted by feelings that the subject was intrusive into a personal part of their parent's life as incontinence was viewed as "a private matter." One daughter commented: "I think it's such a personal issue to the parents that, I think… even as adult children, you feel like it's a more personal issue for the parents."

Daughter caregivers were aware of the social stigma associated with incontinence and felt shame for their incontinent parent. One daughter shared how low health literacy knowledge about incontinence contributed to the family's sense of embarrassment, abnormality, and isolation: "One time, we really didn't know … that this incontinence was a part of Alzheimer's at all….And so we took him and we said, sometimes he has an accident. And the nurse looked right at us and she said, you know, most all of them have it. It's part of the disease. And that was the most comforting thing that I heard as a caregiver…Yeah. I thought it was something, you know, we just kind of have to hide. And here I am a grown woman, and it was—crazy…I just thought it was happening to him. It was just an odd thing, that *he* wasn't controlling his bladder or something."

Another daughter explained how her mother and mother-in-law, who both had AD and incontinence, viewed the stigma of incontinence as being "dirty" and concealed their problem to avoid appearing so when talking to their healthcare providers:, She stated, "Well, my mother-in-law had very similar issues and she thought that it was a dirty topic; it was not something the doctor wanted to know about. And I'm thinking my mom might have been kind of the same, my mom values the doctors and absolutely thinks they are god's greatest gift, and often times would go in there and not tell the truth, she wanted to tell the doctor what he wanted to hear, and that was very frustrating." The daughter-in-law opened communication with her mother-in-law's provider only after the incontinence became a "a big issue."

Barriers Experienced by Spouse Caregivers

The main theme of barriers to improving their health literacy reported by wives was their use of trial and error until their care capacity was exceeded. The subtheme of this main barrier was relying on past experience with providing care. Wives' evaluation of their baseline health literacy about incontinence was greater than that of husband caregivers. Wives said that they would try to manage incontinence in their spouse and delay seeking more information from a healthcare provider until they were unable or unsuccessful manage urinary leakage on their own. One wife explained that she would not immediately make a separate appointment to just discuss incontinence if her husband were to develop it unless her ability for managing it became inadequate: "I probably would only talk about it if we went in for his physical or something…if things start progressing so that I'm having trouble taking care of him."

Husbands' viewed their health literacy about incontinence as low. The main theme of the barriers that resulted in this low level was their lack of experience and confidence in providing cares for their wives in general. Subthemes were unawareness of the link between incontinence and AD, healthcare providers' lack of initiating discussion about incontinence, fear of no longer being able to live with their wives, and healthcare system barriers regarding clinic visit schedules. In contrast to wife caregivers, husbands tended to communicate with their wife's healthcare provider almost immediately. Husband caregivers indicated they often felt anxious and overwhelmed from their lack of preparedness to manage their spouse's incontinence. One husband said, "I wouldn't hesitate to do whatever has to be done in order to make the situation better. Whatever it is. But, I don't know." One husband admitted that he did not know what to do if his wife with AD developed incontinence he would need to call his doctor: “My first step would be calling up the regular physician.” Another husband explained that even after he had a discussion with his wife’s healthcare provider about her incontinence and how to manage it, he still needed information and more basic information -- “more information for husbands, like us. Cleaning a woman. I think we could have more information on that.” Another husband in his group supported his comment. Because they were often unaware of the possibility that their wives might develop incontinence, husbands viewed the lack of inquiry about this problem by healthcare providers as a barrier to their health literacy. One husband caregiver concluded: “it might be easier if doctors brought it up, instead of me having to bring it up with them.”

Husbands feared the consequences of being judged as having low health literacy and inadequate caring ability. They were afraid that they would be told that they needed to place their wife into a nursing home, which they did not want to do. One respondent expressed concern that if his wife developed incontinence, she would no longer be able to live with him at home and feared the logistical and emotional repercussions that would have: “She may have to take another residence and I don’t drive… I just dread seeing it coming.”

Husband caregivers described additional barriers such as the brevity and focus of routine clinic appointments when attempting to bring up a new or potential problem such as incontinence. As one respondent explained, “Other than that [the reason for which an appointment was made], he’d [the physician], never ask. I mean, he doesn’t ask about anything else either. You bring in a problem. You tell the doctor, and then he reacts, I think.”

Husbands described feeling a need for consultation and assistance for managing their wives’ incontinence in an immediate way. One husband said that when he calls his clinic and asks for assistance on managing his wife’s incontinence, he values the ability to obtain an appointment with his wife’s healthcare provider the same day he called or within a few days. Others commented that longer wait times for clinic visits were a barrier to communication with healthcare providers.

Extended Family or Friend Caregivers

The major theme of barriers to health literacy of extended family and friend caregivers was being looked upon as outsiders and not valid caregivers. Extended family and friends said that they were rarely invited to participate in clinic visits of their care recipient with a healthcare provider and often had less access to providers for questions because they are not closely related to the care recipient. When they were present during a clinic visit, the healthcare provider did not ask them about the presence of incontinence in their care recipient; some thought that the provider likely thought that they would not know about the problem. One extended family caregiver whose aunts had incontinence and which she helped them manage said, “A doctor never asked me about the issue of incontinence, and I went to the doctor with my aunts all the time.”

Caregiver Recommendations for Improving Health Literacy

In addition to describing their barriers to health literacy about incontinence, the caregivers identified ways that the healthcare provider and health care system could improve their health literacy. The recommendations were voiced by all types of caregivers and were not role specific. One major theme of their recommendations was to present information in a simple understandable way. As one daughter put it, information about incontinence from healthcare providers be “simple… simple writing for families.” Another daughter gave an example illustrating the need for providers to use terms for treatments that informal caregivers can understand. She said that knew that her mother, who had “leakage,” received “medication for a problem, but didn’t know what the medication was actually for” because the doctor said it was for incontinence but she “didn’t know what incontinence was.” Although most caregivers, regardless of their role, were unfamiliar with terms such as “incontinence,” or “fecal,” they said that they readily adopted them once they were informed.

All types of informal caregivers included in this study identified their care recipient’s healthcare provider as a major trusted source of information for improving their health literacy about incontinence and it management. As one husband stated, information coming from the healthcare provider “would be more authoritative, for me.” Although a few caregivers sought additional information about incontinence from the Internet, many did not feel proficient in web searching, and were concerned about not being able to understand or discern the accuracy of information found. As one daughter caregiver stated, “I’m sure that there’s tons online… but I would say probably only about 20% of [the] time I get information on the Internet.” A wife who had searched online for some information about her husband’s AD said, “We really are finding that computer sources or online sources are not the first choice.” For caregivers whose care recipients did not have incontinence, they wanted providers to discuss information about possible future problems and any ways they might be prevented.

Hispanic caregivers, regardless of their caregiver role, noted that they experienced language barriers to better health literacy about incontinence. One Hispanic friend caregiver who spoke English as a second language said that he does not always fully understand the treatment procedure for his care recipient that the doctor gives because he “doesn’t explain…in a way you can understand.” Hispanic caregivers stressed that it was essential for providers to discuss incontinence using language that those with English as a second language can understand. They strongly supported having written materials about incontinence in AD and treatment plans available in Spanish.

Lastly, responses from the caregivers support the inclusion of caregivers in efforts to promote health literacy. All types of informal caregivers were cognizant of their essential role in assisting their care recipient with healthcare decisions. One wife caregiver described her husband’s ability in this way, “There’s a lot … he’s still very good at. But making decisions, he’s not as good at making decisions anymore.” Their steps to improve their health literacy were made to assist them in meeting this responsibility. Because AD is characterized by changes in cognitive status and physical function over time, informal caregivers voiced concerns about needing to increase their health literacy regarding clinical tasks and health system navigation tasks in an ongoing manner. One wife summed up his idea, “Our situation will change too, as we have to give more and more caregiving. And we don’t know what’s up ahead…It’s just a whole unknown.”

Discussion

This study is first to our knowledge to describe barriers to communication with healthcare providers and health literacy about incontinence experienced by different types of informal caregivers of individuals with AD. Studies of caregivers of patients with AD show that different types of caregivers differ in their experience and response to care responsibilities[7,14]. The findings of this study extend those results by showing role-related barriers to health literacy that need to be eliminated. Higher health literacy improves health outcomes of patients with multiple chronic conditions, including incontinence.[4,15] Results of this study illustrate that informal caregivers are involved in assisting their care recipients in making health care decisions and performing all three types of health literacy tasks: clinical, prevention, and healthcare system navigation. Findings show that informal caregivers are interested in improving their health literacy about incontinence and value communication with healthcare providers as a primary method for achieving this goal. The importance of raising the health literacy of informal caregivers of these patients is now becoming evident[5], yet it is not well studied. The new information about the unique barriers experienced by different types of caregivers related to incontinence care in AD is an important contribution to this emerging body of knowledge.

The barriers to health literacy identified by the caregivers can be used to develop more tailored interventions by nurse continence specialists and other healthcare providers; this strategy is recommended by the National Action Plan for Health Literacy[8]. For example, our findings suggest that daughter caregivers are likely to benefit from emotional support when discussing their parents and the parent-child role reversal they perceive. Based on study findings we further recommend that healthcare providers allow time during clinic visits for caregivers (and especially daughter caregivers) to ask more questions about incontinence and its management separately from their parent. Making a referral to continence nurse for follow-up education and counseling about incontinence care in AD might facilitate these objectives. Daughters also might derive emotional support from participating in a nurse-led support group or caregivers of individuals with incontinence and AD.

Study findings suggest that husband caregivers would benefit from education about incontinence and management options by a continence nurse. Resources are available for improving health literacy in general[16]. Evidenced-based educational and supportive materials specifically about incontinence in AD and its management which were developed as part of parent study[13] are freely available online via this journal's website (http://www.journals.lww.com/jwocnonline/pages/default.aspx) or from one of the authors (DZB) to share with patients and caregivers. Bliss and colleagues[13] reported that caregivers welcomed information about possible problems that their care recipients might experience in the future, such as incontinence, and ways to prepare for their management. Previous studies have shown that incontinence is stressful for caregivers and influences the decision to place a family member in a nursing home[17–21]. We found that husbands especially dreaded placing their family member in a nursing home. Providing accurate information to caregivers has been shown to decrease anxiety and stress, increase caregiving skills, and delay nursing home placement[18,20–27].

Our results also suggest that healthcare providers initiate discussion about the possibility of incontinence with husband and other caregivers proactively rather than wait for the caregiver to raise this subject. This approach is recommended as part of the National Action Plan for Health Literacy[8] and is expected to result in husbands being better prepared to manage incontinence in a partner with AD. Rolnick and associates[28] suggested a simple and feasible intervention of asking caregivers to answer a few questions about the presence of incontinence in their care recipient when they check into the clinic, which could be reviewed by providers to prompt discussion during the visit.

The trial and error approach to managing incontinence of their spouse taken by wives and their delay in seeking help from a healthcare provider until they were unable to deal with it, is consistent with the results of Perry[14]who noted that wife caregivers tended to feel more competent to provide care for their husbands with AD due to the experience they gained as caregiver for children in the family. We hypothesize that wives might benefit from increased health literacy about incontinence so they could more effectively intervene as AD progresses. Prior studies have shown that formal training programs for caregivers not only increases their health literacy, care capacity and confidence; training also improves health outcomes of the family members they care for[18,24,27,29,30]. Findings also suggest that scheduling periodic follow-up appointments and discussions with wife caregivers about incontinence management for their spouse by a nurse continence specialist is an important activity that should be planned.

While some caregivers occasionally used other resources, such as the Internet, study findings suggest that nurses and physicians are valued as sources of accurate information and for being able to interpret sometimes confusing clinical information for caregivers. Further research is needed to evaluate the effectiveness of educational strategies such as online discussions or health literacy training using a mobile device. Caregivers are known to appreciate support groups as sources of emotional support and information[31,32]. For child caregivers who are also employed and care for their own children, for example, online or mobile educational/support resources may be a convenient way to raise health literacy.

Provision of information to extended family and friend caregivers is a challenge given current laws and policies designed to protect patient privacy. Extended family and friend caregivers may also benefit from nurse-led education sessions about incontinence in AD and its care.

Obtaining information is vital to achieving health literacy. A next important step for caregivers is to learn to incorporate that information into problem-solving processes[7,14,33–35]. Findings of this study encourage utilization of nurse continence specialists to guide caregivers in using available evidenced-based information about incontinence management effectively.

Limitations

Because of the sensitive nature of AD and incontinence, subjects may not have been forthcoming when discussing barriers or experiences. We focused on communicating with healthcare providers as a means for improving health literacy about incontinence among caregivers; we acknowledge that other barriers to health literacy may exist that this study was not designed to detect. In addition, we did not evaluate the views of son caregivers.

Conclusion

Results of this study describe the unique barriers experienced by different types of caregivers of individuals with AD related to communication with healthcare providers and health literacy about incontinence. Study findings raise awareness of the need to assess these role-related barriers. They highlight the important role that continence nurses can fulfill in promoting literacy related to incontinence management in persons with AD. Findings also offer a foundation for tailoring interventions to increase the health literacy of informal caregivers.

Acknowledgments

This study was funded by grant from the Undergraduate Research Opportunities Program at the University of Minnesota and the National Institute of Nursing Research, NIH, Partnerships in Research Program, R03NR011243 and R03NR11244.

References

1. Alzheimer's Association. 2011 Alzheimer’s disease facts and figures. Alzheimer's & Dementia. 2011; 7(2):1–66.
2. National Institutes of Health. [Accessed September 22, 2012] Clear communication -- health literacy. http://www.nih.gov/clearcommunication/healthliteracy.htm. Updated 2012
3. White S. Assessing the nation's health literacy: Key concepts and findings of the national assessment of adult literacy (NAAL). [Accessed January, 2011] www.ama-assn.org/ama1/pub/upload/mm/367/hl_report_2008.pdf. Updated 2008.
4. Bevan JL, Pecchioni LL. Understanding the impact of family caregiver cancer literacy on patient health outcomes. Patient Education and Counseling. 2008; 71(3):356–364. [PubMed: 18372142]
5. Garcia CH, Espinoza SE, Lichtenstein M, Hazuda HP. Health literacy associations between Hispanic elderly patients and their caregivers. Journal of Health Communication. 2013; 18:256–272. [PubMed: 24093360]
6. Family Caregiver Alliance. Selected caregiver statistics. [Accessed March 23, 2011] http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=439.
7. Siriopoulos G, Brown Y, Wright K. Caregivers of wives diagnosed with Alzheimer’s disease: Husbands' perspectives. American Journal of Alzheimer's Disease & Other Dementias. 1999; 14(2):79–87.
8. U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. National action plan to improve health literacy. http://health.gov/communication/initiatives/health-literacy-action-plan.asp. Updated 2010
9. 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 & Health. 2004; 27:162–173. [PubMed: 15141369]
10. Leigh RJ, Turnberg LA. Faecal incontinence: The unvoiced symptom. Lancet. 1982; 1:1349–1351. [PubMed: 6123650]
11. Johanson JF, Lafferty J. Epidemiology of fecal incontinence: The silent affliction. American Journal of Gastroenterology. 1996; 91:33–36. [PubMed: 8561140]
12. Milsom, I.; Altman, D.; Cartwright, R., et al. Epidemiology of urinary incontinence (UI) and other lower urinary tract symptoms (LUTS), pelvic organ prolapse (POP) and anal incontinence (AI). In: Abrams, L.; Cardoso, S.; Khoury, S.; Wein, A., editors. Incontinence. Fifth. The Netherlands: ICUD-EAU Publishers; 2013.

13. Bliss DZ, Rolnick C, Jackson J, Arntson C, Mullins J, Hepburn K. Health literacy needs related to incontinence and skin damage among family and friend caregivers of individuals with dementia. Journal of Wound, Ostomy, and Continence Nursing. 2013; 40(5):515–523.
14. Perry J. Wives giving care to husbands with Alzheimer's disease: A process of interpretive caring. Res Nurs Health. 2002; 25(4):307–316. [PubMed: 12124724]
15. Etters L, Goodall D, Harrison BE. Caregiver burden among dementia patient caregivers: A review of the literature. Journal of American Academy of Nurse Practitioners. 2008; 20(8):423–428.
16. Center for Disease Control and Prevention. Education and community support for health literacy. http://www.cdc.gov/healthliteracy/education-support/index.html. Updated 2015
17. Mittelman MS, Ferris SH, Shulman E, et al. A comprehensive support program: Effect on depression in spouse-caregivers of AD patients. Gerontologist. 1995; 35(6):792–802. [PubMed: 8557206]
18. Mittelman MS, Ferris SH, Steinberg G, et al. An intervention that delays institutionalization of Alzheimer's disease patients: Treatment of spouse-caregivers. Gerontologist. 1993; 33(6):730–740. [PubMed: 8314099]
19. Mittelman MS, Haley WE, Clay OJ, Roth DL. Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease. Neurology. 2006; 67(9):1592–1599. [PubMed: 17101889]
20. 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]
21. Mittelman MS, Ferris SH, Shulman E, Steinberg G, Levin B. A family intervention to delay nursing home placement of patients with Alzheimer disease. A randomized controlled trial. JAMA. 1996; 276(21):1725–1731. [PubMed: 8940320]
22. Mittelman MS. Psychosocial intervention for dementia caregivers: What can it accomplish? International Psychogeriatrics. 2003; 15(Suppl 1):247–249. [PubMed: 16191248]
23. Mittelman MS, Roth DL, Clay OJ, Haley WE. Preserving health of Alzheimer caregivers: Impact of a spouse caregiver intervention. American Journal of Geriatric Psychiatry. 2007; 15(9):780–789. [PubMed: 17804831]
24. Hepburn K, Lewis M, Tornatore J, Sherman CW, Bremer KL. The savvy caregiver program: The demonstrated effectiveness of a transportable dementia caregiver psychoeducation program. J Gerontol Nurs. 2007; 33(3):30–36. [PubMed: 17378189]
25. Hepburn KW, Tornatore J, Center B, Ostwald SW. Dementia family caregiver training: Affecting beliefs about caregiving and caregiver outcomes. J Am Geriatr Soc. 2001; 49(4):450–457. [PubMed: 11347790]
26. Hepburn KW, Lewis M, Sherman CW, Tornatore J. The savvy caregiver program: Developing and testing a transportable dementia family caregiver training program. Gerontologist. 2003; 43(6):908–915. [PubMed: 14704391]
27. Bartfay E, Bartfay WJ. Quality-of-life outcomes among Alzheimer's disease family caregivers following community-based intervention. Western Journal of Nursing Research. 2013; 35(1):98–116. [PubMed: 21415243]
28. Rolnick SJ, Bliss DZ, Jackson J. Healthcare providers' perspectives for promoting communication with family caregivers and patients with dementia about incontinence and skin damage. Ostomy Wound Management. 2013; 59(4):62–69.
29. Winslow BW. Effects of formal supports on stress outcomes in family caregivers of Alzheimer's patients. Res Nurs Health. 1997; 20(1):27–37. [PubMed: 9024475]
30. Ostwald SK, Hepburn KW, Burns T. Training family caregivers of patients with dementia. A structured workshop approach. J Gerontol Nurs. 2003; 29(1):37–44. [PubMed: 12596336]
31. Drentea P, Clay OJ, Roth DL, Mittelman MS. Predictors of improvement in social support: Five-year effects of a structured intervention for caregivers of spouses with Alzheimer's disease. Soc Sci Med. 2006; 63(4):957–967. [PubMed: 16616406]
32. Smith TL, Toseland RW, Rizzo VM, Zinoman MA. Telephone caregiver support groups. J GERONTOL SOC WORK. 2004; 44(1):151–172.

33. Cassells C, Watt E. The impact of incontinence on older spousal caregivers. J Adv Nurs. 2003; 42(6):607–616. [PubMed: 12787234]
34. Duffy LM. Helping caregiver cope: Managing urinary incontinence associated with Alzheimer's disease. Journal of Entrostomal Therapy. 1990; 17:87–93.
35. Hogan VM, Lisy ED, Savannah RL, Henry L, Kuo F, Fisher GS. Role change experienced by family caregivers of adults with Alzheimer's disease: Implications for occupational therapy [corrected] [published erratum appears in PHYS OCCUP THER GERIATR 2003;22(2):80]. PHYS OCCUP THER GERIATR. 2003; 22(1):21–43.

Table 1

Characteristics of Informal Caregivers of Individuals with Alzheimer's Disease or Dementia

n (% within type of caregiver)*		**Spouse n = 21**	**Children n = 15**	**Extended Family or Friend n = 12**
Gender	Male	9	0	3
	Female	12	15	9
Age (mean (SD))		75 (10)	52 (9)	60 (10)
Race	White	18 (86)	13 (87)	6 (50)
	Black or African American	1 (5)	0 (0)	5 (42)
	More than one race	1 (5)	2 (13)	1 (8)
Ethnicity	Latino	2 (10)	6 (40)	7 (58)
Employment	Currently Employed	2 (10)	10 (67)	7 (58)
	Retired	17 (81)	1 (7)	2 (17)
	Disabled or not working for other reasons	2 (10)	2 (13)	5 (36)
Already managing incontinence	Urinary Incontinence (UI)	7 (33.3)	6 (40)	3 (25)
	Dual Incontinence (DI)	5 (23.8)	3 (20)	4 (33.3)

[*] unless noted otherwise