Assistive devices caregivers use and find helpful to manage problem behaviors of dementia

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L.N. Gitlin, L. Winter, M.P. Dennis. Assistive devices caregivers use and find helpful to manage problem behaviors of dementia. Gerontechnology 2010; 9(3):408-414; doi:10.4017/gt.2010.09.03.006.00 **Purpose** Use of assistive devices in caring for individuals with dementia has not been systematically examined, particularly as it concerns managing behavioral symptoms. We tested a nonpharmacologic intervention to manage behaviors that involved instructing families in effective communication techniques, simplifying tasks and the home environment and using assistive devices. This paper describes the assistive devices provided to families assigned to intervention, extent of use of issued devices, their perceived helpfulness, and cost. **Design and Methods** Following each treatment session, occupational therapists (OT) documented time spent training in the use of strategies to manage problem behaviors. For families receiving assistive devices, OTs asked caregivers after 4 months whether they continued to use the device (yes/no), and extent to which it helped manage the targeted problems (not at all, somewhat, very helpful). We also tracked the costs associated with ordering, delivering and installing devices. **Results** Of 272 caregiver-patient dyads enrolled in the original trial, 136 were randomized to the intervention group, of whom 63 received one or more assistive devices. Of 13 intervention sessions, an average of 4 (31%) involved discussing or training caregivers in using assistive devices. A total of 197 devices (3 per dyad) were issued of which 87.6% were reported in use at 4 months. Caregivers reported that overall, devices were somewhat to very helpful. Devices ranged in cost from US$4.80 to US$282.93 with an average cost per dyad of US$152.52(SD=US$102.70) which included the device, its ordering, delivery and installation.

Keywords: Alzheimer's disease, environmental modification, behavioral symptoms

Over 5 million individuals live with dementia in the United States and 35 million have the disease worldwide[1,2]. Most individuals with dementia live at home and are cared for by family members. A common concern among family caregivers is managing behavioral symptoms such as wandering, shadowing, repetitive vocalizations or disengagement and apathy. These behaviors occur throughout the disease process but tend to be most prevalent at the moderate stage. As there is no cure for this progressive, degenerative disease and prevalence rates are expected to escalate, identifying optimal strategies for managing behavioral symptoms and promoting the life quality of individuals with dementia and their family caregivers is a public health priority both within the USA and worldwide.

Efforts to manage problem behaviors have typically involved pharmacologic treatments, especially off label use of atypical antipsychotic drugs[3,4]. However, pharma-

cotherapies yield modest benefit and pose considerable risk[5,6]. Additionally, many common behaviors that are troublesome to families (refusal of care, repetitive vocalizations, argumentation) do not respond to pharmacological treatments. For these reasons, recent consensus reports recommend nonpharmacologic approaches as the initial treatment modality[7,8].

A neglected nonpharmacologic approach to caring for people with dementia is the use of low-cost technologies such as grab bars, lighting, or monitors to enhance safety and ease burden of care. Dr. Lawton and colleagues' Competence-environmental Press Model provides a useful framework for understanding the potential role of assistive technologies in relationship to personal needs, abilities and social and environmental resources[9]. Applied to dementia, the model suggests that behavioral symptoms may reflect a mismatch between the person's capabilities (cognitive and functional) and environmental demands. As Dr. Fozard has discussed, technology can lower sensory barriers to independent functioning[10]. Thus, using technologies to decrease sensorial, physical and cognitive demands and align environmental stressors to fit patient abilities may reduce behavioral symptoms and enhance quality of life.

In a randomized controlled trial, we tested an intervention, Advancing Caregiver Training (ACT), to help family caregivers learn to manage behavioral symptoms by modifying the physical environment, simplifying everyday tasks and caregiver communications, and using assistive devices. These strategies were designed to decrease inappropriate interactions in the physical and social environment and enable patients to effectively engage within their environment, thereby increasing positive emotional, behavioral and functional states, and alleviating caregiver burden. As there is minimal knowledge concerning the range of common assistive devices that may help caregivers manage behavioral symptoms, this paper describes the assistive devices provided to those who received the ACT intervention[11]. We also evaluated extent of use by caregivers, caregivers' perceptions of their helpfulness, and costs of devices.

Methods

Sample

Recruitment and participant characteristics have been described elsewhere.[11,12] Briefly, participants were recruited between 2003 and 2007 from media announcements and mailings by social agencies. Eligible caregivers: lived with individuals who had a physician diagnosis of dementia or a Mini-mental State Examination (MMSE) score<24[13]; were≥21 years; English speaking; planning to live in area for 6 months; not actively seeking nursing home placement; managing behaviors; and reporting upset (>5 on 10 point scale). Patients were excluded with schizophrenia or bi-polar disorder, dementia secondary to probable head trauma, or an MMSE=0 and bed-bound. The last criterion excluded those non-responsive to their environment who could not benefit from ACT. Written informed caregiver consent, proxy patient consent, and patient assent were obtained at baseline using institutional approved forms. Following baseline assessment, caregivers were randomized to ACT or a usual-care control group who did not receive intervention contact. Of the 272 who enrolled, 136 were assigned to ACT, of whom 63 (46.3%) were provided one or more assistive devices as a strategy for helping to manage problem behaviors. Assistive devices were provided based on the occupational therapist's assessments of need and caregivers agreement to its use. This subgroup is the focus of this paper.

Intervention

ACT, described in detail elsewhere[11,12], involved a 16-week active phase of up to 8 occupational therapy (OT) sessions and 2 nursing sessions (one at home and one per telephone), and a maintenance phase (16-24 weeks) of 3 brief OT telephone contacts. OTs met with caregivers to identify targeted

problem behaviors, and observe the home environment and caregiver-patient interactions (for instance, communication style) using standardized checklists. In subsequent sessions, OTs used problem solving to help caregivers identify antecedents and consequences or potential modifiable triggers (for instance, clutter, communication style) of the target behavior. OTs brainstormed with caregivers to identify acceptable management strategies including the possible role of assistive devices. A typed 'action plan' was provided stating targeted problem behavior, treatment goal, potential triggers, and management strategies (adapting physical environment, potentially helpful assistive devices, simplifying communication and tasks, engaging patients in activity). Caregivers were instructed in stress reduction and self-care techniques.

Based on the OTs' assessment of need and caregiver willingness, assistive devices were provided free of charge to families and were paid for through grant funds. The ordering, delivery and installation, if necessary, of devices was coordinated by the Housing Department of the local area agency on aging (Philadelphia Corporation for Aging), who assured accuracy and quality. To identify potential devices, OTs discussed options with families and showed catalogues and samples. An average of US$150 per dyad was initially budgeted per family, although as much as US$500 was allowed if necessary. For ease of tracking and reporting, we categorized devices into 3 domains and 11 categories: instrumental activities of daily living (IADLs) included devices for mobility (wheelchair), seating (for instance, padding, pillows), medication taking (medication dispensers), transfers (for instance, bed transfer handles), and leisure activities (for instance, videos, crafts, exercise equipment); Activities of Daily Living (ADLs) devices included those for eating (for instance, mug with lid), bathroom and toileting (for instance, grab bars, tub mat, tub rail), and grooming (for instance, sock donner); safety included medical alert identification bracelets, and monitors (for instance, motion detectors); and other devices (for instance, lost item finders).

Measures

Descriptive data included caregiver sociodemographic characteristics (age, gender, race, education, relationship to patient, living arrangement, and years caregiving), and patient characteristics (age, gender, race, number of problem behaviors, and MMSE). For those receiving one or more assistive devices, caregivers were asked at 4 months by the OTs whether they used the device (yes/no) and the extent to which they found it helpful (1=not helpful, 2=somewhat helpful, 3=very helpful). We also recorded the cost of each device including its shipping and delivery charges. For all dyads assigned to intervention, OTs also indicated the number of sessions in which assistive devices were either discussed or for which training occurred in their use to manage a targeted behavior.

Results

Background characteristics

Caregivers were primarily female (79.4%), white (69.8%), on average giving care for 3.7 years (SD=2.8) and were on average 66.4 years old (SD=12.8) (*Table 1*). Dementia patients were primarily female (54.0%), white (69.8%) and older (Mean=82.2 years, SD=9.1) with an average MMSE of 11.0 (SD=8.1) and range of 0.0 to 27.0. On average, caregivers reported the occurrence of 9.3 (SD=3.8) problem behaviors in the month prior to study entry.

Within the intervention group, we compared those who received devices (n=63) to those who did not (n=73) on background characteristics. The only characteristic exhibiting a statistically significant difference was the MMSE score (z=-2.77, p=0.006) of patients. Those with lower scores were more likely to receive devices than those with higher MMSE scores.(M=11.0 vs. M=14.6, respectively).

Assistive devices

Documentation of the OT sessions was available for 128 of 136 assigned to interven-

Table 1. Sample characteristics of intervention participants receiving equipment (n=63); SD=Standard Deviation

Characteristic		%	Mean (SD)	Range
Caregiver				
Age			66.4 (12.8)	33.0
Gender	Male	20.6		
	Female	79.4		
Race	White	69.0		
	African-American	27.0		
	Other	3.2		
Relation to patient	Spouse	49.2		
	Non-spouse	50.8		
Education	< High school	6.3		
	= High school	25.4		
	> High school	68.3		
Years caregiving			3.7 (2.8)	59.0
Dementia patient				
Age			82.2 (9.1)	59.0
Gender	Male	46.0		
	Female	54.0		
Race	White	69.0		
	African-American	27.0		
	Other	3.2		
Number of disruptive behaviors			9.3 (3.8)	2.0
Mini-Mental Status Examination			11.0 (8.1)	0.0

tion. We found that OTs spent an average of 4 of 13 sessions discussing use of assistive devices to help manage a targeted behavior, about 31% of all sessions. This is in comparison to 9.3 sessions spent on communication strategies, 5.7 sessions spent on using activities, 5.4 sessions on task simplification strategies, and 3.4 sessions on modifying the physical environment.

For the 63 individuals receiving assistive devices, a total of 197 devices were provided, an average of 3 devices per dyad. The average cost of devices was US$45.60 (SD=US$43.88) and was as low as US$4.80 and high as US$282.93. The average cost per dyad including ordering, delivering and installing was US$152.52 (SD=US$102.7). Of devices issued, 87.6% were reported by caregivers as in use at 4 months. Caregivers also reported that devices overall were somewhat to very helpful (Mean=2.56; SD=0.68) at 4 months.

The greatest number of assistive devices which were ordered were for activity engagement (for instance, videos, puzzles, crafts), and bathroom and toileting challenges (for instance, grab bars, raised toilet seats, tub benches), with the least number of devices issued for ambulation (for instance, wheel chair, walker) and transferring (for instance, bed bar) (*Table 2*). This reflected the primary behavioral concerns expressed by this sample which included resistance to bathing, agitation, and disengagement. While the most expensive device was for automatic medication dispensers, only 2 were issued. Within each device category, 50% or more were reported in use with the exception of safety, for which only 33.3% of the 6 devices issued were reported being used. Similarly, all devices were perceived as somewhat to very helpful, with bathroom, seating and mobility devices reported as being very helpful.

Discussion

We show in this descriptive study that low-cost common technologies can be a helpful part of a caregiver skills training program to manage complex, troublesome behaviors. Although communication appeared to be the most important category of strategies provided to caregivers for behavioral management as evidenced by the number of treatment sessions in which communication training occurred, instruction in use of assistive devices occurred in 31% of treatment sessions, and resulted in 63 (46%) of 136 dyads receiving 1 or more devices. The assistive devices provided were of relatively low cost and commonly available. They were mostly issued to help patients bathe and toilet such as grab bars, raised toilet seats or tub benches as well

*Table 2. Costs, % used and helpfulness (rated scored 1-3) by equipment categories; SD=Standard Deviation; *= no SD because of only 1 item*

Category	# Item issues	Costs, US$		% used	Helpfulness (SD)
		Mean (SD)	Range		
ADLs					
Eating / dining	8	19.95 (12.55)	5.91-41.90	100	2.5 (0.9)
Bathroom / toileting	59	38.24 (20.40)	8.49-98.52	92.2	2.8 (0.5)
Grooming	4	15.08 (3.99)	9.31-17.95	100	2.5 (0.6)
IADLs & mobility					
Medication	2	137.98 (7.04)	133.00-142.95	100	2.5 (0.7)
Mobility	2	134.00 (21.21)	119.00-149.00	50	3.0*
Seating	11	98.13 (83.34)	35.66-237.93	91	2.8 (0.6)
Transfer assists	4	120.25 (66.41)	48.00-209.00	75	2.3 (0.6)
Leisure	66	31.18 (22.96)	5.95-99.95	89	2.3 (0.7)
Safety					
Safety	6	19.48 (10.54)	7.95-35.00	33	2.3 (1.1)
Monitoring	18	73.21 (62.60)	14.95-282.93	94	2.6 (0.7)
Other	17	58.11 (45.52)	4.80-129.95	67	2.6 (0.5)

as to facilitate participation in discretionary, pleasant activities to reduce agitation and disengagement. Bathing and toileting devices are designed to enhance functionality and reduce caregiver physical burden and concerns for safety. For example, providing a tub bench and handheld shower may enhance safety of the person with dementia and make it easier to get in and out of the tub, thus reducing possible fear and resistance. Enabling the person to have control over water pressure and its placement by using a handheld shower may also reduce fear of bathing.

Our previous research has shown that involving individuals with dementia in meaningful activities reduces behavioral symptoms and enhances quality of life[14]. In this study, we issued a range of leisure-type objects including large numbered remote controls to enhance ease of use, videos of nature, animals or babies which were found to be soothing and absorbing, enlarged puzzles, bead sorting kits or other craft kits which appeared to provide individuals with dementia a sense of purpose and reconnect them positively with their environment.

Noteworthy is that patients with lower cognitive status scores were issued equipment more often than those with higher cognitive status scores. This suggests that assistive devices can have a positive role in helping families at the moderate and severe stages of the disease and thus this approach should be considered regardless of cognitive impairment level. This is in keeping with Lawton and colleagues' competence-environmental press framework which suggests that any level of competency can be supported through appropriate environmental adjustments[9]. The devices provided did not require new learning. Rather, they served primarily to aid caregivers in helping patients carry out specific tasks or to minimize a targeted problem behavior such as resistance to care or agitation.

The rate of device use overall was relatively high (87.6%). We believe this in large part reflects the client-centered approach of the ACT intervention. OTs worked with caregivers to identify the most problematic behaviors they identified and wished to target; also, the strategies for managing problem behaviors were jointly derived and mutually agreed

upon. Assistive devices were provided only upon caregiver approval and after considerable discussions with the OT as to their potential utility. Furthermore, OTs trained caregivers and patients in safe and appropriate usage of all devices issued and were able to make adjustments as needed to caregiver communication style or environmental setups to assure success in device use.

We report elsewhere the main outcomes for the ACT trial in which we showed a reduction in both the problem behaviors caregivers targeted as most troublesome, and caregiver's associated upset[12]. However, one study limitation is that we can not determine the treatment effect on behavioral and caregiver outcomes for any one device that was issued for this subgroup. Nevertheless, we do show that caregivers who received assistive devices perceived them as beneficial, with most devices reported as being somewhat to very helpful. Another study limitation is that we do not know if device use continued beyond the 4-month study period.

This descriptive study adds further evidence that low-cost and seemingly small changes to the patient's environment can improve daily life. As studies continue to show that pharmacotherapies are ineffective in managing problem behaviors and may cause harm, nonpharmacologic approaches such as assistive device use are promising in helping families manage the burden of the disease. Of importance, device use did not result in any adverse events; rather, it appeared to facilitate the patient's continued engagement in IADLs, ADLs and discretionary activities.

As grant monies supported the purchase for assistive devices, caregivers did not have to absorb any financial burden. While the average cost for devices was under US$50.00, an average of US$152 per dyad was spent. This could present as a financial challenge to families as dementia care overall is a significant economic drain for caregivers. It is unclear how financial considerations would influence the decision of families to use assistive devices. Research examining caregiver willingness-to-pay scenarios would be important to pursue[15]. However, from a societal and health policy perspective, as we show, the average device cost was quite low. If assistive device use can help prevent caregiver burnout and enhance patient quality of life, it may represent a cost effective approach to helping families keep their relative with dementia at home. Thus, payment mechanisms for offsetting the costs associated with purchasing devices and training in their use would be an important health policy consideration.

Although new technologies to support daily functioning of older people and specifically, people with dementia are needed[16,17,18,19, 20], we show in this study that even small, low-cost common assistive devices can be helpful to families. We contend that assistive devices should be considered part of skill-building programs for family caregivers. Device use alone may not in itself sufficiently address problem behaviors. However, in combination with other nonpharmacologic strategies such as communication and environmental modifications, assistive devices may contribute to a potentially powerful multi-pronged approach to reduce excessive environmental demands that compromise the well-being of individuals with dementia and their family caregivers.

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References

1. Alzheimer's Disease International. World Alzheimer report. Alzheimer's Disease International; 2009
2. Alzheimer's Association. 2009 Alzheimer's disease facts and figures. Alzheimer's Association; 2009
3. Sink KM, Holden KF, Yaffe K. Pharmacological treatment of neuropsychiatric symptoms of dementia: A review of the evidence. JAMA 2005;293(5):596-608
4. Schneider LS, Tariot PN, Dagerman KS, Davis SM, Hsiao JK, Ismail MS, Lebowitz BD, Lyketsos CG, Ryan JM, Stroup TS, Sultzer DL, Weintraub D, Lieberman JA. Effectiveness of atypical antipsychotic drugs in patients with Alzheimer's disease. New England Journal of Medicine 2006;355(15):1525-1538
5. Ballard C, Hanney ML, Theodoulou M, Douglas S, McShane R, Kossakowski K, Gill R, Juszczak E, Yu LM, Jacoby R. The dementia antipsychotic withdrawal trial (DART-AD): Long-term follow-up of a randomised placebo-controlled trial. Lancet Neurology 2009;8(2):151-157; doi:10.1016/S1474-4422(08)70295-3
6. Gauthier S, Loft H, Cummings J. Improvement in behavioural symptoms in patients with moderate to severe Alzheimer's disease by memantine: A pooled data analysis. International Journal of Geriatric Psychiatry 2008;23(5):537-545
7. Salzman C, Jeste DV, Meyer RE, Cohen-Mansfield J, Cummings J, Grossberg GT, Jarvik L, Kraemer HC, Lebowitz BD, Maslow K, Pollock BG, Raskind M, Schultz SK, Wang P, Zito JM, Zubenko GS. Elderly patients with dementia-related symptoms of severe agitation and aggression: Consensus statement on treatment options, clinical trials methodology, and policy. Journal of Clinical Psychiatry 2008;69(6):889-898
8. American Psychiatric Association Work Group on Alzheimer's disease and other dementias. American Psychiatric Association practice guideline for the treatment of patients with Alzheimer's disease and other dementias. 2nd edition. American Journal of Psychiatry 2007;164(Suppl.12):5-56
9. Lawton PM, Nahemow L. Ecology and the aging process. In: The psychology of adult development and aging. Washington: American Psychological Association; 1973; pp 619-675
10. Fozard JL. Technology's uses in lowering the sensory barriers to independent functioning in later life: Discussion of Professor Schieber's lecture. In: Charness NE, Schaie KW, editors, Impact of technology on successful aging. New York: Springer; 2003; pp 100-112
11. Gitlin LN, Winter L, Dennis MP, Hauck WW. A non-pharmacological intervention to manage behavioral and psychological symptoms of dementia and reduce caregiver distress: Design and methods of project ACT. Clinical Interventions in Aging 2007;2(4):695-703
12. Gitlin LN, Winter L, Dennis MP, Hodgson N, Hauck WW. Targeting and managing behavioral symptoms in individuals with dementia: A randomized trial of a nonpharmacologic intervention. Journal of the American Geriatrics Society; in press
13. Folstein MF, Folstein SE, McHugh PR. 'Mini-mental state': A practical method for grading the cognitive state of patients for the clinician. Journal of Psychiatric Research 1975;12(3):189-198
14. Gitlin LN, Winter L, Burke J, Chernett N, Dennis MP, Hauck WW. Tailored activities to manage neuropsychiatric behaviors in persons with dementia and reduce caregiver burden: A randomized pilot study. American Journal of Geriatric Psychiatry 2008;16(3):229-239
15. Jutkowitz E, Gitlin LN, Pizzi L. Evaluating Willingness to Pay Thresholds for Dementia Caregiving Interventions: Application to the Tailored Activity Program; submitted
16. Carrillo MC, Dishman E, Plowman T. Everyday technologies for Alzheimer's disease care: Research findings, directions, and challenges. Alzheimers Dementia 2009;5(6):479-488
17. Carswell W, McCullagh PJ, Augusto JC, Martin S, Mulvenna MD, Zheng H, Wang HY, Wallace JG, McSorley K, Taylor B, Jeffers WP. A review of the role of assistive technology for people with dementia in the hours of darkness. Technology and Health Care 2009;17(4):281-304
18. Sixsmith A. New technologies to support independent living and quality of life for people with dementia. Alzheimer's Care Quarterly 2006;7(3):194-202
19. Mollenkopf, H, Fozard, J.L. Technology and the good life: Challenges for current and future generations of aging people. Annual Review of Geriatrics and Gerontology 2003;23:250-267
20. Fozard JL. Gerontechnology: Optimizing relationships between aging people and changing technology. In: Coulson IC, Minichiello V, editors, Contemporary issues in gerontology: Promoting positive ageing. Sydney: Allen & Unwin; 2005; pp 241-268