



**Evidence on Interventions to Improve Quality
of Care for Residents with Dementia in
Nursing and Assisted Living Facilities**

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Abstract

Background: People with dementia in nursing homes and assisted living facilities are vulnerable to negative health and quality of life outcomes, which could be averted through the provision of appropriate care. Assuring high quality care for these residents should be informed by a thorough understanding of the research on interventions that have the potential to improve service provision.

Methods: The authors screened 325 peer-reviewed articles published between 1994–2003 for inclusion in this review. Of these, 101 met the inclusion criteria of focusing on long-term care residents with dementia, having a sample size of 10 or more residents, using an experimental or quasi-experimental design with a control group, and reporting statistical significance of findings. The review focused on interventions related to two broad categories: 1) activities of daily living (ADLs) and 2) psychosocial and behavioral characteristics.

Results: The review uncovered many quasi-experimental studies assessing interventions to alleviate psychiatric and behavioral symptoms, particularly those related to agitation and aggression. However, while several studies suggest various environmental design modifications, limited evidence was found to support the effectiveness of interventions to minimize limitations in activities of daily living.

Conclusions: This review clearly indicates a need for further research on interventions to improve care for people with dementia in nursing and assisted living facilities. Future research should include a focus on people with dementia as a unique subgroup within facilities and should evaluate interventions to improve eating, drinking and sleeping patterns, among other care areas. It is essential to outline an aggressive research agenda to expand our knowledge of effective treatments for persons with dementia and improve the care of a very vulnerable population.

Introduction

Given the continuing, documented problems with nursing and assisted living facility care (Wunderlich and Kohler, 2001), quality is a key concern for people with dementia who live in these homes. This group represents at least half of all nursing and assisted living facility residents (Morris et al., 1994; Sloane et al., 2001). Residents with dementia experience a unique constellation of symptoms, which include memory loss, disorientation, reduced ability to perform activities of daily living such as eating, bathing, and dressing, as well as psychiatric and behavioral symptoms such as agitation, depression, psychosis, and social withdrawal (Qizilbash et al., 2002). Further, many residents with dementia may be physically capable of performing a range of daily activities, but require supervision and assistance when doing so.

Generally, care for residents with dementia in long-term care facilities falls into two broad categories: 1) aspects of activities of daily living (ADLs), and 2) psychiatric and behavioral symptoms. These two areas may be further divided into subcategories -- physiological needs (i.e. eating, drinking, toileting and sleep), hygiene (i.e. bathing, dressing and grooming), ambulation, and psychiatric and behavioral symptoms. Each of these subcategories is a fundamentally important aspect of care for residents with dementia in nursing and assisted living facilities, contributing directly to resident quality of life.

Providing and assuring quality care for these residents should be informed by a thorough understanding of the research on interventions that have potential to improve service provision to people with dementia. This paper provides a comprehensive review of the evidence on service interventions that focus on the institutionalized population with dementia because studies that do not focus on this population fail to take into account the unique symptoms that persons with dementia have. This review will be useful to consumers, providers, and regulators seeking to improve the quality of care for residents with dementia in institutional settings. Further, the review proposes principles to guide future research in this area.

Methods

The authors reviewed articles in the peer-reviewed literature from 1994 – 2003. To identify potentially useful items, the authors conducted a comprehensive search of Medline, CINAHL and PsychInfo, using various combinations of relevant search terms, such as dementia, quality, long-term care, nursing homes, assisted living facilities, and manual searches of all relevant articles' reference sections; these methods resulted in the collection of 325 articles.

These articles were reviewed and appear in this literature review only if they focus on long-term care facility residents with dementia, report on use of experimental or quasi-experimental methods, and report the statistical significance of findings. Trials are not included in the review if they have poorly defined interventions, fewer than 10 participants or no control condition. Literature reviews, and consensus statements, which reported systematic methods of analyzing extant studies, were included in this review if they were no more than five years old to ensure that valuable information published

before 1994 could be included. This selection process resulted in the inclusion of 101 studies and review articles. Review of articles on assessment instruments and comparisons of the efficacy of different medications in the management of dementia symptoms are outside the scope of this review. The literature on special care units as an intervention is not in this review because the definition of such units varies considerably and results have been inconclusive (Maslow and Ory, 2001).

Results

The articles included in this review address care for residents' physiological needs, hygiene, ambulation, and psychiatric and behavioral symptoms.

Physiological Needs

The physiological interventions in the literature address the difficulties that residents with dementia have in eating and drinking, using the toilet, and sleeping. Only four studies and three literature reviews address eating specifically for persons with dementia and only one of these addresses drinking. When certified nurse assistants (CNAs) allow residents to control more of the eating process, they consume a higher proportion of their food; however, CNAs' empathy with residents did not affect food consumption (Amella, 1999). In a randomized, controlled trial, when CNAs used verbal prompts to remind people how to eat and positive reinforcement, residents were more likely to complete eating and drinking tasks (Coyne and Hoskins, 1997). In another randomized, controlled trial, residents receiving nutritional supplements for one year experienced fewer infections and days in bed (Gregorio et al., 2003). A fourth study found that when residents ate while listening to music, they consumed more food and were less irritable and anxious (Ragneskog et al., 1996). According to one review, dining in small rooms adjacent to living quarters reduces aggression and promotes better eating because residents have less time for problems to occur in transit between living and eating areas (Day et al., 2000). According to another review, consistency of caregivers, and increased nutritional value of foods improved eating (Burgener and Twigg, 2002). Two literature reviews on tube feeding challenge the notion that this is a viable option for people with dementia because there is no evidence of efficacy related to the problems tube feeding is supposed to address, such as avoiding malnutrition, and this form of feeding results in significant risks to residents such as aspiration of food into the lungs and local infections (Finucane et al., 1999).

Although there is much in the literature about incontinence and nursing home residents, only two literature reviews specifically address continence issues for residents with dementia. One review found that making toilets visibly accessible to residents increases the frequency of their use (Day et al., 2000). According to another review, prompted voiding, behavior modification, and scheduled toileting should be used to reduce urinary incontinence (Doody et al., 2001).

The evidence about sleep interventions primarily involves using bright light therapy to improve residents' circadian rhythms and increase the time they spend sleeping at night. Most of the nine studies and four reviews focus on introduction of bright light

daily for several hours during the day. Two reviews, one of which was a quantitative meta-analysis, found that exposure of residents to bright light regulates circadian rhythms and improves sleep (Day et al., 2000; Luijpen et al., 2003). Two other reviews found that there was not sufficient evidence of good quality to support use of bright light therapy (Kim et al., 2003; Forbes et al., 2004). Five studies' results indicate that bright light exposure during the day results in more sleep at night. One of these studies examined the effects of bright light on those with vascular dementia and Alzheimer's disease and found that bright light was effective for the former group, but not the latter (Mishima et al., 1998). Another study of residents with Alzheimer's disease did find that bright light improved sleep (Yamadera et al., 2000). A study of exposure to bright light in residents' living areas promoted improved sleep (Van Someren et al., 1997), as did one where residents were exposed to bright light during breakfast and medication administration (Fetveit et al., 2003). A fifth study, which was a randomized, controlled trial, showed improvement in nocturnal sleep for those exposed to bright light for two hours in the morning (Lyketsos et al., 1999). However, a sixth study of bright light therapy under varying conditions found no significant change in sleeping patterns (Ancoli-Israel et al., 2002), as did a seventh study that combined administration of vitamin B12 and bright light therapy (Ito et al., 2001).

Two studies administered melatonin to residents with dementia. One found that residents' sleep improved at night (Asayama et al., 2003). The other found no increase in nighttime sleep but less daytime sleep (Cohen-Mansfield et al., 2000).

The research literature suggests that environmental modifications, such as making the environment easy for residents to understand and, perhaps, increasing light intensity within facilities' common areas, may help address the basic physiological needs of residents. Regarding eating and drinking, letting residents take the lead at meals could lead to increased food and fluid intake. Also, residents may use toilets more effectively when they are reminded to do so and when the toilet is visible or clearly marked.

Activities of Daily Living: Hygiene and Personal Care

Two studies addressed general performance of ADLs and seven articles specifically address bathing and dressing. One study found no significant effects on ADL performance in a trial of three sets of individually-tailored interventions, which involved 1) behavioral and communication techniques to improve ADL functioning, 2) psychosocial techniques, and 3) a combination of the first two sets of techniques (Beck et al., 2002). In contrast, a randomized, controlled trial found that when residents received group training involving verbal prompting, demonstration of ADLs, and positive reinforcement for all ADLs, residents improved their ADL functioning (Tappen, 1994).

Four studies report on interventions designed to reduce resident agitation and aggression during bathing and indicate that frequency of these behaviors is reduced when residents listen to their favorite music (Clark et al., 1998), or when residents have their baths in an environment with nature sounds and large, bright pictures, and are offered sweet food (Whall, 1997). A third study indicates that having a clinical nurse specialist observe worker and resident interaction and help CNAs solve problems leads to an

improved bathing experience (Hoeffler et al., 1997). A fourth study suggests that when nurse aides receive a short training session, designed to teach behavioral approaches, such as reassurance and distraction, resident agitation and aggression during bathing declines (Mickus et al., 2002).

Two studies and one review specifically consider dressing. One study, which trained CNAs to tailor their care to the capabilities of the individual resident, resulted in improvements in residents' dressing independence (Beck et al., 1997). In this study, dressing took one minute longer on average than during the baseline period. The second study used research therapists to assist residents in gaining independence in dressing through use of verbal prompts, and physical assists, resulting in increased independent dressing behaviors (Rogers et al., 1999). The literature review asserts that presenting clothing in sequential order enhances residents' independence in dressing (Day et al., 2000).

Overall, studies suggest that a pleasant environment promotes completion of bathing while minimizing resident aggression and agitation. Also, individually tailored interventions that focus on residents' capabilities may promote independence in dressing. Further, resident skills training improves their ADL functioning in general.

Ambulation

Several studies' interventions relate to maintaining a resident's ability to walk, avoiding falls, or wandering or pacing that some persons with dementia do. One study found that people in walking groups could walk significantly longer compared to their baseline performance than those in the control group who were not in a walking program (Tappen et al., 2000). However, another study found that a walking program produced no effect on ambulation (Cott et al., 2002). According to one review, reduction in falls occurs through use of low chairs, railings, and non-skid bath mats and chairs (Day et al., 2000).

Two studies and one literature review provide the most information on interventions related to wandering. The interventions that address this topic include staff rewarding non-wandering behavior and various environmental strategies (Allen-Burge et al., 1999). These strategies include providing a secure place to wander, which reduces the consequences of doing so (Allen-Burge et al., 1999), and using strategies that obscure doorways and door knobs to reduce exiting behavior (Day et al., 2000). One study found that when corridors had nature and homelike scenes, residents spent more time in these spots and showed more signs of pleasure than when corridors did not have these scenes. However, no significant differences in pacing behavior occurred (Cohen-Mansfield and Werner, 1998). Another study tested the effects of a staff training program, which educated CNAs about wandering and strategies to manage it, and found that while staff knowledge about dementia and wandering increased, the percentage of residents subject to restraints increased after the program and no significant changes in resident behavior occurred (Cohen-Mansfield et al., 1997).

The conclusion one can draw from the literature related to ambulation is that behavioral and environmental strategies may help prevent falls. These types of strategies also can be used creatively to deal with such potentially harmful activities as pacing, wandering, and exiting.

Psychosocial and Behavioral Symptoms

Most of the research on interventions has investigated strategies for minimizing the psychiatric and behavioral symptoms of dementia. These symptoms include agitation, aggression, withdrawal from social activities, depression, and psychosis. In addition, a limited number of researchers have tested interventions designed to improve communication between persons with dementia in residential care and their paid caregivers.

The body of work on agitation and aggression encompasses 20 individual intervention studies and 11 reviews of the behavioral health literature. In large part, the studies show reductions in resident agitation or aggression using a variety of interventions including morning bright light (Ancoli-Israel et al., 2003; Thorpe et al., 2002); twice daily application of lemon balm oil to residents' hands and faces (Ballard et al., 2002a); aromatherapy using lavender oil (Holmes et al., 2002), administration of melatonin (Cohen-Mansfield et al., 2000); admission to special care units with the environment altered to reduce sound, increase visual stimulation, and facilitate safe wandering (Belleli et al., 1998) listening to "white noise" (Burgio et al., 1996); use of a therapy dog (Churchill et al., 1999); one-to-one interaction between residents and research staff and residents viewing a videotape of family members talking to them" (Cohen-Mansfield and Werner, 1997); music therapy (Cohen-Mansfield and Werner, 1997; Gerdner, 2000; Goddaer and Abraham, 1994; Gerdner, 2000) staff training (Hagen and Sayers, 1995); increased nurse staffing in a special care unit (Holmes et al., 2000); a walking program (Holmberg, 1997); multi-sensory stimulation program (Holtkamp et al., 1997); hand massage (Kim and Buschman, 1997; Snyder et al., 1995); and individually-tailored interventions (Opie et al., 2002).

Seven of the 11 literature reviews cover intervention research reaching back to the early 1980s and report that a variety of interventions, which are similar to those briefly described above, are capable of reducing resident agitation and aggression (Allen-Burge et al., 1999; Bartels et al., 2003; Doody et al., 2001; Herrman, 2001; Opie et al., 1999; Snowden et al., 2003; Spector et al., 2000a). Four reviews found insufficient evidence to support the use of validation therapy (Neal and Briggs, 2003), reminiscence therapy (Spector et al., 2000b), multi-sensory therapy (Chung et al., 2002), and aromatherapy (Thorgrimsen 2003) to improve behavioral symptoms of dementia. Critical to understanding the import of these four reviews is that all of them are "Cochrane" reviews, which generally accept only randomized, controlled trials. Given the difficulties in setting up this kind of trial in long-term care facilities, it is important to assess and use the evidence of those trials that incorporate quasi-experimental designs.

Although the methods of reducing agitation and aggression are diverse, the studies have several underlying themes. When residents live in environments that reduce

disruptive stimulation such as excessive noise, and provide bright, entertaining areas for residents, agitation and aggression may be reduced. In addition, properly trained and supervised staff, who have training in handling the behaviors associated with dementia, have the potential to reduce residents' agitation and aggression.

Little research is available on interventions to promote staff communication with residents and resident socialization. One study tested a staff-training program designed to improve workers' communication with residents and found that staff improved their communication skills compared to control groups by talking more with residents, providing more one-step instructions, and providing more positive statements (Burgio et al., 2001). Another study found less resident resistance to care routines after nursing staff received clinical supervision designed to help them improve their relationships with residents (Edburg et al., 1996). One review article asserts that residents socialize more when they are involved in small group activities; a small group is defined as having eight or fewer participants (Allen-Burge et al., 1999). Reminiscence therapy, which involves helping persons with dementia remember past events in their lives, also can promote socialization (Allen-Burge et al., 1999).

Only six studies tested interventions to address depression or psychosis, with one focusing on psychosis. One researcher tested two interventions; one involved a care plan supervised by an interdisciplinary team, case managers providing individual therapy, and behavioral techniques and the second involved provision of resident care plans to the facility (Brodaty et al., 2003). Neither type of treatment reduced depression or psychosis. An intervention, which involved partnering nursing home residents without cognitive impairment with those with such impairments, backfired, in that both groups in the experimental condition experienced increases in depression (Cohen et al., 1999).

Unlike the two previously described interventions, four others had positive effects on resident depression. Two studies involved staff training and two studies tested physical activities. One study found that a staff training and supervision program involving consultation with a psychiatric nurse resulted in reduced depression scores among residents in the treatment group (Proctor et al., 1999). Another training program increased the percentage of residents who were screened and treated for depression (Evers et al., 2002). One study found that when residents increased their time in a platform rocking chair, their depression and use of pain medications decreased (Watson et al., 1998). Another study showed that time spent in a therapeutic biking class, where a specially designed wheel-chair for residents was attached to a bicycle, reduced residents' low and moderate levels of depression (Buettner and Fitzsimmons, 2002).

Three studies address the effects of withdrawal of medications used to control behavioral health symptoms. One research team realized a reduction in use of neuroleptics in facilities where a nurse visited weekly to consult on use of these drugs; control homes did not experience such a reduction (Ballard et al., 2002b). Withdrawal of neuroleptics from residents who had been stable on their medications for three months resulted in no differences in physically aggressive behavior between the treatment and control groups (Bridges-Parlet et al., 1997). In a randomized, controlled trial, when a pharmacist provided consultation services to a nursing home, use of medications decreased

in the treatment group in comparison to the control group, which experienced a significant increase in medication use (Schmidt et al., 1998).

Two decades worth of research on behavioral issues has led three groups to publish treatment guidelines (Howard et al., 2001; American Geriatrics Society and American Association for Geriatric Psychiatry, 2003; Doody et al., 2001). Several treatment principles flow from these guidelines and the research discussed above:

1. Careful assessment of potential causes of agitation, aggression, and depression is essential to determine whether some underlying cause such as adverse medication effects, infections, dehydration, pain, delirium, fecal impaction, or injury is causing the behavior. When assessment provides insight into a cause for behavioral issues, the identified cause should be addressed before moving on to other methods of treating behavioral symptoms.
2. Environmental or behavioral techniques, such as those reviewed above, should be used as a first line treatment of agitation, aggression, and depression, rather than beginning with pharmacological interventions. To determine which intervention might work best with a given resident, practitioners must collect information about the resident's life before entering the institution and should try a variety of interventions before moving on to pharmacological treatments.
3. If non-pharmacological options fail, then medications should be considered if residents have the potential to harm themselves or others or a resident's condition has not improved within 30 days. Medications should be administered under the care of a mental health professional. Medications should be used as a last resort and must be used judiciously to avoid severe side effects, such as over sedation and Parkinsonism. Treatments should begin with the lowest efficacious dose and increase slowly. Continued need for treatment should be reassessed every three months.

Discussion

This literature review shows that much is known from the largely quasi-experimental literature about interventions that can help alleviate psychiatric and behavioral symptoms that can arise from dementia, primarily agitation and aggression. However, there is limited evidence on strategies for helping residents with dementia minimize limitations in various activities, such as eating, drinking, and sleeping. Available research indicates that pleasant, noxious-stimulus-free environments, which provide opportunities for residents to improve their functioning, can lead to better performance of daily activities. Possible environmental interventions involve modifications to make the institution as home-like as possible with access to secure wandering places, the outdoors and pleasant environments.

Further, the more nursing home staff know about residents and their preferences, and individually tailored approaches that can help reduce unpleasant behaviors, the greater the likelihood that staff will be able to craft methods for improving resident behaviors. This requires trained staff who receive supervision designed to improve their communication and interactions with residents.

Although the literature on interventions that can help improve the quality of residential care for those with dementia is voluminous, it has some limitations related to the scope and quality of the research. First, most of the research has been conducted in nursing facilities, not in assisted living facilities or board and care homes. However, the findings regarding treatment of persons with dementia in nursing facilities are likely to be applicable in other types of residential care where persons with similar severity of dementia reside. In addition, the majority of the intervention articles either are not precise about what type of dementia residents had, or about the severity of their dementia. Fortunately, the literature describing the interventions themselves is generally precise; those articles lacking clear descriptions of the interventions were not included in this review.

Another issue related to the scope of the research is that, by far, most articles address behavioral health interventions, primarily those designed to treat various forms of agitation and aggression. There was a paucity of studies addressing such fundamental issues as eating, drinking, pain management, and communication with residents who have dementia, because the larger nursing home literature on interventions in facilities generally does not analyze data on those with dementia separately from those without.

Few studies involve randomized, controlled trials of interventions, which is the “gold standard” of scientific research. Random selection of participants and their random assignment to treatment and control conditions is designed to test whether a treatment’s results are significantly better than no treatment.

Running randomized, controlled trials are quite difficult and may not be desirable in long-term care facilities for several reasons. Randomization of residents is not feasible if staff are part of the treatment because any training or intervention staff use will likely affect how they care for all residents. In addition, an intervention for one nursing home resident may affect another, who might be serving as a control. Therefore randomization may need to be conducted by facility rather than person. Even if randomized controlled trials are the optimal method, they may not be feasible. For example, finding a comparable control can be very difficult in some studies.

Notwithstanding these limitations, examination of a sufficient volume of randomized controlled trials and studies with quasi-experimental designs allows some conclusions to be drawn about the types of interventions that are likely improve quality of care for people with dementia living in residential care settings.

Despite what we do know about services for people with dementia in residential care settings, much remains to be learned. For example, we have available one intervention study on how to improve fluid intake and only a handful address food intake, despite the fact that malnutrition and dehydration are significant problems among nursing home residents. Although there is much literature on treating incontinence among nursing home residents, little of it is specific to the population with dementia. Pain management and depression are also major issues for nursing home residents for which there is little information available about effective interventions.

Based on the gaps in the literature we propose that four principles guide future research directed toward improving dementia care in long-term care facilities.

1. Any government or foundation-funded research on quality in nursing and assisted living facilities should analyze the population with dementia as a distinct group to determine if an intervention is effective for them.
2. Priorities for future research should include methods of helping residents improve their eating, drinking, and sleeping patterns. It is not hard to understand why a resident who is not getting his or her basic needs met might express their discomfort through behavioral symptoms.
3. Models of staffing and staff supervision and mentoring should be tested to determine how best to configure staffing for effective care for those with varying severity of dementia.
4. Studies should also be conducted to test how to implement research findings in the typical long-term care facility because few, if any, studies address this topic.

Researchers and funders should incorporate these principles in their work and recognize the need for well-designed intervention evaluation in long-term care facilities. These steps would expand our knowledge of effective treatments for persons with dementia and improve the care of a very vulnerable population.

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