# <u>Staff perceptions of successful management of severe behavioral problems in dementia special care units</u>

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#### **Abstract:**

Factors that promote successful management of persons with severe behavioral problems in special care units (SCUs) for dementia were evaluated. Using qualitative data from staff interviews conducted in 36 nursing home SCUs, the study examined the relationships among demographic and behavioral characteristics of 70 residents, management techniques of the staff, and family participation in the management of persons with severe behavioral problems. Problem behaviors were often managed successfully in SCUs, although unpredictable aggression was particularly difficult to control and was a common reason for discharge. Use of multiple non-pharmacological techniques was associated with a greater likelihood of successful management, and physical restraints were used as a last resort. SCU staff members also reported that large, physically aggressive men and residents with real or suspected psychiatric comorbidity were especially difficult to manage. Finally, family involvement and support were critical to resident success and often buffered against resident discharge.

**Keywords:** aggression | Alzheimer's disease | family | nursing home | SCU

#### **Article:**

#### Introduction

Behavioral problems exhibited by persons with Alzheimer's disease (AD) and related dementias present challenges to family and formal caregivers. Wandering, sleep disorders, paranoia, physical aggression and other behavioral disturbances are common in dementia. Such behaviors increase family and staff stress and create barriers to the provision of care. One response to the challenge of dementia care has been the formation of specialized residential programs, often termed special care units (SCUs).

As of 1996, nearly 22 percent of licensed nursing facilities in the United States had dementia SCUs with a total capacity of about 100,000, which is more than twice the 1990/91 availability of SCUs (Leon, 1994; Leon, Cheng, & Alvarez, 1997). SCUs are marketed as environments that

provide specialized services to minimize behavioral problems associated with Alzheimer's disease. Wandering paths, sensory-focused activities and dementia-trained staff are among the features that may be found in SCUs that are purported to decrease problem behaviors and provide a safe and comfortable environment for persons with dementia (Leon & Ory, 1999; Swanson, Mass, & Buckwalter, 1993).

Although the term SCU is used generically, there are currently no federal regulatory standards that uniquely identify special care units as 'special' in the United States. SCUs may be a part of a nursing home, part of an assisted living facility, or a free-standing facility. The most commonly shared features of SCUs are that the units are physically distinct from other parts of a long-term care facility with controlled entry and exit. Additionally, most residents in SCUs have dementia. Other features that may also distinguish SCUs from traditional care for elderly people include modified physical environments and specialized dementia-sensitive programming, although such special features are not ubiquitous (Leon et al., 1997). In fact, Gold and colleagues (1991) identified eight distinct types of SCUs in only 55 nursing homes. These SCUs ranged from *ideal* (for example, specialized staff, extensive staff interaction, and a therapeutic and caring environment) to *execrable* (for example, no specialized staff, low patient/staff interaction, apathetic attitude towards patients, and generally unclean).

SCUs are not homogeneous, and there is some controversy as to the overall effectiveness of SCUs in promoting quality of life and reducing problem behaviors (Grant, Kane, & Stark, 1995; Leon et al., 1997; Leon & Ory, 1999; Ohta & Ohta, 1988). Nevertheless, SCUs represent an increasingly accepted care option for elderly persons with dementia in the United States, and they provide opportunities to study techniques and approaches to the management of behavioral problems in dementia by virtue of their focus on dementia care.

Using data from staff interviews conducted in 36 nursing home SCUs, we identified distinguishing themes between 'successful' and 'unsuccessful' residents using a structured interview guide with SCU staff. The themes answer the following research questions: What are the relationships among demographic and behavioral characteristics of the residents and perceived success of the residents? What role(s) do management techniques play in resident outcomes? How important is family participation in the management of persons with severe behavioral problems in promoting success and preventing discharge from SCUs? By answering these questions, we offer recommendations for long-term care professionals and families regarding approaches that promote successful case management of institutionalized persons with dementia who are severely behaviorally disruptive.

#### Methods

Sample and data collection

Two researchers visited 53 SCUs in 49 state licensed nursing facilities in Maine, Mississippi, Kansas and South Dakota as part of a study of the effectiveness of dementia special care units (Phillips et al., 1997). This investigation is part of a larger study of the 'Collaborative Studies of Special Care Units for Alzheimer's Dementia' sponsored by the National Institute on Aging (grant no. AG11268).

During each visit to an SCU, a research assistant conducted an interview about SCU 'successes and failures' with a staff member who worked on the SCU. The respondent was required to be someone who worked on the unit who was familiar enough with the residents and day-to-day operations of the unit such that s/he could answer specific questions regarding behavioral problems and management strategies used with behaviorally challenging residents. The interview was conducted using a structured interview guide. The data were gathered from one SCU in each nursing home in the parent study that was open for at least six months and reported at least one resident whose behavioral problems presented significant challenges to the care staff. Additionally, staff members from facilities with multiple special care units were only interviewed once; one facility had four SCUs and one facility had two SCUs. Based on the inclusion criteria, 36 of 53 SCUs met these criteria and participated. No sites refused to participate in the interview.

The respondents were predominately nursing staff (n = 19), about half of whom also indicated that they were the charge nurse or coordinator of the SCU. The remaining surveys were conducted with activity coordinators or social workers (n = 4) and unit coordinators not otherwise specified (NOS) (n = 9). The unit coordinators (NOS) were most likely nurses or social workers, but their specific degree affiliation was not obtained. All persons interviewed were required to have direct experience with the SCU residents in order to provide sufficient detail about the behavior challenges and management strategies used with the residents. The SCU staff member was asked the following:

I am interested in having you discuss residents with severe behavioral problems.

Think about some of the most disruptive residents on the unit in the last 18 months. Can you identify one of those residents whom you see as a **real success** for your unit – that is, a resident with serious behavioral problems who was helped through successful management of your unit? This should be someone about whose care you feel proud or satisfied.

Similarly, the SCU staff member was asked to identify

a resident on the unit during the last 18 months whose behavioral problems were **so** severe that your staff wasn't able to deal with them.

Thirty-seven successful and 34 unsuccessful residents were identified; one interviewee reported two successes, and two said they never had any failures. Each interview was structured to gather data on resident demographics (sex, age, marital status and primary diagnosis), degree of dementia (an open-ended format that allowed the nursing home staff to define the level of cognitive impairment), and whether or not the resident had been discharged and to where (if applicable). Additionally, open-ended questions elicited information about behavioral problems, medical and psychiatric comorbidity, management techniques and family involvement.

Written informed consent for audiotaping the interviews was obtained before the interview, and the staff member was provided with a copy of the consent form. All but two of the interviews

were taped; notes were taken during the other two interviews. A person unaffiliated with the project transcribed the interviews. Of 71 interviews completed, 70 were used for this analysis. One case was excluded because the interview was incomplete. A modest honorarium was provided to facilities to reimburse for lost staff time.

# Data analyses

A description of the SCUs, informants and residents was calculated using frequencies to provide a context to the study. Because of the small number of cases and the lack of a theoretical framework for quantitative analysis of SCU successes and failures, the analysis was conducted in several phases. First, two investigators read the transcribed interviews and identified factors associated with success and failure, independently. Second, the investigators re-read the transcribed interviews focusing on several questions from the interview guide used to synthesize the experiences of the successful and unsuccessful cases: What was different about these residents that led to such discrepant outcomes? Are there certain types of problem behaviors that the unit is not equipped to handle? If you had a chance to modify the care given, would you do anything differently? Did either of the experiences result in fundamental changes in the way the unit runs or in the policies of the unit? Third, the factors that previously emerged were reduced to the following themes: specific behavioral problem(s), types of behavioral management techniques, use of medication and restraints, medical and psychiatric comorbidity, and family interaction. After each step in the analysis, the readers met to discuss their findings and discrepancies, and to reach consensus regarding the distinguishing themes. This type of methodology is consistent with a content analysis of qualitative data.

We also counted the frequency of behavioral problems, medical and psychiatric comorbidity and management techniques mentioned in the interviews. Comparisons by resident success status were calculated using Fisher's exact test. This type of statistical approach is appropriate when comparing a count (or frequency) across two independent groups (successful vs. unsuccessful cases). Behavioral problems were clustered based on the Caretaker Obstreperous-Behavior Rating Assessment (COBRA) scale (Drachman, Swearer, O'Donnell, Mitchell, & Maloon, 1992). The COBRA was designed for caretaker assessment of the types and severity of difficult behaviors in persons with dementia, and it includes four behavior clusters: aggressive/assaultive, mechanical/motor, ideational/personality and vegetative. In addition to these four categories, we differentiated between physical and verbal aggression and included clusters for mood, resistive behaviors, sexually inappropriate behaviors, socially inappropriate behaviors and behaviors suggestive of medication side-effects.

Management techniques were categorized as follows: specific activities, caregiving/interpersonal approaches, removing the resident from a potentially volatile situation, force, medication management, physical restraints and other techniques. Detailed tables of the behavioral problems and management strategies are provided.

## Results

Description of the SCUs

The interviews were conducted in SCUs in four states: Maine (n = 10), Mississippi (n = 1), Kansas (n = 14) and South Dakota (n = 11) (see Table 1). About half (55.6 percent) of the SCUs were located in for-profit facilities, with a mean size of 110 beds. The SCUs had been open for an average of three years and averaged 36 beds. More than half of the informants were nursing staff, some of whom also directed the overall operations of the unit. The remaining respondents were predominately unit coordinators who were likely nursing or social work staff, although these data were not obtained. Four of the informants did not mention their staff position in the facility. The interviews were compared by staff type, but no differences in the quality of responses were identified. Thus, all data were analyzed collectively.

Table 1. Characteristics of facilities, SCUs and informants

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Facility characteristics (n = 36)						
Location of nursing home (%)						
Maine	28					
Mississippi	3					
Kansas	45					
South Dakota	36					
Ownership (%)						
For profit	55					
Not for profit	42					
Government-owned	3					
Certification (%)						
Medicaid only	31					
Medicare and Medicaid	69					
Licensed nursing home beds $(\bar{x}, sd)$ /range	110.1 (47.3)					
	53–235					
Pay Rate $(\bar{x}, sd)$						
Private pay single occupancy	\$95.52 (\$34.31)					
Private pay double occupancy	\$84.70 (\$21.48)					
Per diem Medicaid rate	\$72.21 (\$15.47)					
SCU characteristics						
SCU bed size $(\bar{x}, sd)$	20.7 (9.0)					
Age of SCU in months $(\bar{x}, sd)$	42 (29.3)					
Informant characteristics (%)	• •					
Nursing staff	51					
Activities or social work	10					
Unit coordinators, not otherwise specified	27					
Missing	11					

#### Description of the residents

Table 2 provides the profile of the 70 residents. The mean age was 79. Most were widowed, female and had a primary diagnosis of Alzheimer's disease. Non-Alzheimer's diagnoses included multi-infarct dementia (14.3 percent of subjects), non-specific dementia (one resident) and schizophrenia (one resident). On average, unsuccessful residents were reported to have had a greater length of stay on the SCU than had the successful residents. However, the unsuccessful residents were more than five times as likely to subsequently have been discharged from the SCU.

Table 2. Characteristics of the sample of SCU residents by management success <sup>a</sup>

	_	Resido	ent type	_
	Total sample	Successful	Unsuccessful	-
	(n = 70)	(n = 37)	(n = 33)	p
Age, $(\bar{x}, sd/range)$	79.4 (8.1)	79.0 (7.4)	79.9 (9.8)	ns
	63–97	64–97	63–94	
Married (n, %)	29 (42.0)	14 (20.3)	15 (21.7)	ns
Female (n, %)	41 (58.6)	23 (32.9)	18 (25.7)	ns
Alzheimer's diagnosis (n, %)	58 (82.9)	32 (45.7)	26 (37.1)	ns
Other diagnosis (n, %)	12 (17.1)			ns
Length of stay on unit in months $(\bar{x}, sd/range)$		13.0 (11.0)	16.2 (15.6)	ns
	0.3-60	2–48	0.3-60	
Discharged from unit, # (%)	14 (20.0)	2 (2.9)	12 (17.1)	0.002
Behavior problems				
Aggressive behaviors (e.g. hitting)	48 (68.6)	25 (67.6)	23 (69.7)	ns
Verbal abuse/disruption	20 (28.6)	10 (27.0)	10 (30.3)	ns
Mood (e.g. depression)	20 (28.6)	11 (29.7)	9 (27.2)	ns
Disordered ideas (e.g. reclusive)	11 (15.7)	8 (27.6)	3 (9.1)	ns
Psychotic symptoms (e.g. delusions)	8 (11.4)	4 (10.8)	4 (12.1)	ns
Resisted behaviors (e.g. refused care)	21 (30.0)	8 (21.6)	13 (39.4)	ns
Mechanical abnormalities (e.g. wandering)	32 (45.7)	24 (64.9)	8 (24.3)	0.001
Behaviors suggestive of medication side-effects	2 (2.8)	2 (5.4)	0	ns
(e.g. 'pill-rolling')				
Vegetative disorders (e.g. decreased eating)	19 (27.2)	14 (37.8)	5 (15.2)	0.06
Sexually inappropriate (e.g. public masturbation)	4 (5.7)	2 (5.4)	2 (6.1)	ns
Socially inappropriate (e.g. public urination)	4 (5.7)	3 (8.1)	1 (3.0)	ns
Other comorbid conditions	•	•	` ′	
'Big Man' syndrome	5 (7.1)	1 (2.7)	4 (12.1)	ns
Medical comorbidity indicated	19 (27.1)	9 (24.3)	10 (30.3)	ns
Suspected psychiatric comorbidity	8 (11.4)	1 (2.7)	7 (21.2)	0.02

<sup>&</sup>lt;sup>a</sup> Differences were compared between the 'successful' and 'unsuccessful' cases for all resident characteristics using Fisher's exact test. P values are reported for those with statistical significance.

# Factors that distinguish successful from unsuccessful residents

Five factors emerged in the qualitative analysis that clearly distinguished between the successfully and unsuccessfully managed residents: behavior prevalence and severity, management techniques, use of psychotropic medication and physical restraint, comorbidity, and family interaction. These findings were also supported in our quantitative analyses.

## *Behavior prevalence and severity*

Physical aggression was the most prominent behavior mentioned for both successful and unsuccessful cases (see Table 2). Behaviors included hitting, biting, throwing furniture, destroying the environment, slamming doors, choking others and self-mutilation. The qualitative analysis revealed that the factor distinguishing the successful from the unsuccessful cases was not physical aggression per se, but greater unpredictability and severity of the violent acts among the cases deemed 'failures'. One staff member described the physically aggressive behaviors of an unsuccessful case as follows:

His misbehaviors are so terrible. He has it in him to kill somebody; it's scary. I don't think he'd mean to, he just doesn't understand. He gets mad enough. I've caught him choking another resident in our dining room area, where the little quiet ladies sit, he was choking one of those little ladies. It's happened a number of times. . . .

Conversely, residents whose aggression was triggered by time of day, bathing, noise and so on were typically managed successfully. Staff identified 'triggers' and modified the environment or the care delivered to preempt a behavioral outburst.

Motor agitation was described as a common behavior among successful residents (and much less so for unsuccessful residents). Reported motor behaviors included wandering, pacing, exit-seeking and climbing over bed-rails. A nurse described the approach to one of the residents whom she deemed 'successful':

When she came into the unit . . . we realized that she was at [her old job] in her reality. The second day she was here, at quarter of five, she decided she was going home and gathered her things in her pocketbook. The agitation that [she] experienced was really much greater than normal sundowning. . . . Her reality was that her husband was home waiting for her and she needed to leave.

Resistive behaviors (for example, refusing care), verbal abuse (for example, yelling, cursing), mood disturbance (for example, anger, depression) and vegetative disorders (for example, excessive sleeping, not eating) were also mentioned with some frequency across successful and unsuccessful cases. There was no indication that successful management rested on these types of behaviors.

Finally, disordered ideas (for example, reclusiveness, territoriality, hoarding and rummaging), psychotic symptoms (primarily paranoia), and sexually (for example, public masturbation) and socially inappropriate behaviors (for example, public urination, disrobing and spitting) were rare among both unsuccessfully and successfully managed residents.

Although side effects from medications are not typically categorized as 'behavior problems', staff regarded them as such:

At that time [of admission], she had dyskinesia, pill rolling, a stumbling gait, decreased appetite, and drooling – all the adverse effects of (a specific psychotropic medication). . . . We dropped her to a very minimal amount [of medication], and she started to increase in her appetite and became very personable.

Overall, the severity and unpredictability of physical aggression and the ability to successfully manage motor agitation distinguished the unsuccessful from the successful cases.

#### Management techniques

A variety of approaches were attempted in managing both successful and unsuccessful residents, including activities, interpersonal approaches, reducing stimuli, punishment/force, medical

management, physical restraints and other techniques (see Table 3). Despite the breadth of approaches used, we found that more activities and interpersonal approaches were used with the successful cases (on the whole) and that the successful cases responded more favorably to behavioral interventions. In other words, staff did not necessarily use one approach with greater frequency among residents deemed successful, but used a greater variety of techniques with each resident.

Table 3. Behavioral and environmental management techniques used for severe behavioral

problems amongst successful and unsuccessful residents a,b

	Total sample	Successful	Unsuccessful	
	(n = 70)	(n = 37)	(n = 33)	p
Specific activities	n (%)	n (%)	n (%)	-
Sensory activities (e.g. ball toss, play cards)	15 (21.4)	10 (27.0)	5 (15.2)	ns
Take for walks	7 (10.0)	5 (13.5)	2 (6.1)	ns
Phone friend or relative/use tape of voice	5 (7.1)	4 (10.8)	1 (3.0)	ns
Offer sweets	3 (4.3)	2 (5.4)	1 (3.0)	ns
Use dolls or stuffed animals	2 (2.9)	2 (5.4)	0	ns
Bring children on to unit	1 (1.4)	1 (1.4)	0	ns
Caregiving/interpersonal approaches				
Redirection	16 (22.9)	10 (27.0)	6 (18.2)	ns
One-on-one	13 (18.6)	7 (18.9)	6 (18.2)	ns
Validation	8 (11.4)	7 (18.9)	1 (3.0)	0.06
Use calm voice	8 (11.4)	3 (8.1)	5 (15.2)	ns
Flexibility	8 (11.4)	5 (13.5)	3 (9.1)	ns
Consistent care	5 (7.1)	4 (10.8)	1 (3.0)	ns
Use specific staff for caregiving	5 (7.1)	4 (10.8)	1 (3.0)	ns
Diversion	5 (7.1)	3 (8.1)	2 (6.1)	ns
Close monitoring	3 (4.3)	1 (2.7)	2 (6.1)	ns
Remove resident/reduce stimulation	, ,	, ,	•	
Feed resident in his/her room	3 (4.3)	1 (2.7)	2 (6.1)	ns
Isolate resident	7 (10.0)	4 (10.8)	3 (9.1)	ns
Give resident his/her own space	3 (4.3)	3 (8.1)	0	ns
Decrease noise level	4 (5.7)	3 (8.1)	1 (3.0)	ns
Stop activities on the unit	1 (1.4)	0	1 (3.0)	ns
Punish/force resident				
Force	1 (1.4)	0	1 (3.0)	ns
Reprimand	1 (1.4)	1 (2.7)	0	ns
Other techniques				
SCU environment (in general)	5 (7.1)	5 (13.5)	0	0.06
Educate staff	2 (2.9)	2 (5.4)	0	ns
Educate family	1 (1.4)	1 (2.7)	0	ns
Rule out medical problems	2 (2.9)	0	2 (6.1)	ns

<sup>&</sup>lt;sup>a</sup> Differences were compared between the 'successful' and 'unsuccessful' cases for all resident characteristics using Fisher's exact test. P values are reported for those with statistical significance.

In one successful case, the resident had worked as a businesswoman for 32 years, and she was accustomed to handling things and being in control. The nursing staff reported how they used person-centered activities to manage her problem behaviors:

<sup>&</sup>lt;sup>b</sup> Other techniques were used with limited frequency including persistence, reorientation, using behavior modification charting, making eye contact, positive reinforcement, learning more about the resident's history, approaching resident from the front, talking with and using resident's name, and affection.

She was very confused about her business; she'd think she was still working and had all these things to take care of. So when she'd talk about her shipments that were supposed to come in, we'd validate her and reassure her that we'd taken care of the shipments for the day. We'd give her forms to fill out and she'd scribble on them a bit. . . . It didn't matter as long as she had a clipboard and something to write on. Sometimes we'd even help her make a phone call to check on something.

A variety of interpersonal approaches were mentioned in the interviews. Redirection, one-on-one care, validation, using a calm voice and flexibility were reported with regularity, especially among the residents described as successful. One staff member described management of a successful resident who was combative, angry and not participating in activities: 'We tried to bring about redirection by giving simple explanations. . . using a soft, very gentle voice'. Additionally, flexibility was often emphasized as a necessary element of successful behavioral management: 'We learned not to force her into doing things, but to let her decide when she was ready. For example, just because everybody else ate at 7:00 didn't mean that she had to get up and eat then'.

Less frequently mentioned interpersonal approaches included humor, persistence, reorientation, charting behaviors, eye contact, using additional staff during caregiving, providing attention, approaching from the front, talking with the resident, using the resident's name, affection, individualized care and not allowing the resident to leave the unit.

Removing the resident from a potentially volatile situation or otherwise decreasing stimuli were less commonly used than specific activities or interpersonal approaches. In four cases, the noise level was minimized on the unit, therefore promoting resident success in three cases and failure in one case. Additionally, activities were completely stopped on one unit in an attempt to manage problem behaviors of a resident whose management was ultimately deemed a failure. One nursing staff member explained the importance of the environment in the case management of a resident whose behaviors markedly decreased after moving to the SCU:

We placed her on the secure unit here; she had been in a regular unit in another home. We allowed her to wander in the yard and the halls of the locked unit. It is a confined, controlled environment with less stimulation and less traffic . . .

However, environmental manipulation or the security and serenity of the SCU were mentioned with less frequency than staff-initiated approaches and may be considered immutable by some caregiving staff.

Use of psychotropic medication and physical restraint

Medication information was available for 65 of the 70 cases. Successful residents were more likely to be on no medication or to have their medications adjusted (successful n = 24 vs. unsuccessful n = 14). However, we did not gather specific medication histories on the residents and therefore may not have an accurate representation of the details of their medication management.

Physical restraint information was available for 52 of the residents. Restraints were more commonly used among the unsuccessful residents and included waist restraints, posey vests and geri chairs (successful n = 6 vs. unsuccessful n = 13). However, it was clear from the interviews that physical restraints were considered a last resort, used only when behavior management failed:

We really try not to use them. We tried geri chairs, but he would go back and forth in the chair, and now we've got holes in our walls. . . . One time we tried a soft, fuzzy vest restraint in the bed; we thought that would be better than the geri chair because at least he'd be in bed. No way – it didn't work. The geri chair and (an antipsychotic medication) are the only things that have worked when he is out of control. When he gets really bad, I just wish we had a padded room we could lock him in and let him go.

In general, physical restraints were rarely used, and when they were used, the restraints were implicated as unsuccessful management strategies.

The 'big man' syndrome

One of the themes that emerged during the qualitative analysis was the importance of physical strength and size of the resident. In four unsuccessful cases, the staff specifically described the resident's size, stamina and strength as major contributors to the inability to manage the behavioral problems:

He was an extremely big man, about six foot three and 210 to 220 (pounds). He towered over most of the other residents, and most of the staff members were afraid of him. There was no interaction between him and the staff; they wanted to leave him alone, because they were so afraid of getting hurt.

All four 'big men' were discharged. Two were transferred to state mental hospitals, one went to another nursing home and the fourth was discharged to another part of the same facility.

One of the successful cases was also described as a 'very active man and . . . very strong. In contrast to the four unsuccessful cases, he was not combative unless provoked'. Disease progression, multiple medication changes, staff meetings and use of staff that he liked led to his successful retention: 'We're all very proud of the fact that we managed to keep him here'.

## Medical and psychiatric comorbidity

Many successful and unsuccessful residents were described as having significant medical comorbidity Arthritis, pain, seizure disorders and hearing loss were some of the comorbid conditions identified by the staff in describing successful and unsuccessful residents. One unsuccessful resident exhibited sleep disruption, eloping behaviors and physical aggression towards staff and residents: 'We also found out that he had bad arthritis, so we put him on ibuprofen to decrease his pain. That calmed him down some'. In another instance, a resident was described as 'feisty with staff' until he received a hearing aid. No single medical comorbidity differentiated the two groups, although it was clear from the interviews that identifying and

treating comorbid conditions was important in successfully managing the behavior of dementia residents.

Suspected psychiatric comorbidity was reported in five of the unsuccessful cases and only one of the successful ones. A chronic history of alcohol abuse, a diagnosis of schizophrenia and a history of spouse abuse were confirmed for three of the unsuccessful residents. The other unsuccessful residents with suspected psychiatric comorbidity were described as having frequent mood swings and manic behavior change. In all five unsuccessful cases, the staff questioned whether the resident had a primary psychiatric disorder rather than (or in addition to) dementia. They reported an inability to anticipate behavioral problems, describing the individuals as 'sneaky, controlling' and 'psychotic'. This unpredictability created difficulty in devising a behavioral management plan, and was therefore regarded as unsuccessful. Three of the five cases were men, all of whom were discharged. The two women were living on the SCU at the time of the interview.

One of the nurses described some of the challenges in managing a resident with chronic alcohol abuse:

He had no standards. He lived only for times when he was in and out of hospitals. By the time he got here, I think his brain was fried, to tell you the truth. His support system was non-existent, except for adult protective (services).

Profound depressive symptoms and anger characterized one successful resident who had a suspected psychiatric comorbidity. Management strategies included medication modification, humor, environmental alteration (a longer, more comfortable bed for this large man), respecting his space and allowing him to 'come and go' to activities as he pleased.

#### Family interaction

Among the most striking themes identified by the respondents was that of family interaction with the resident and SCU staff. Family roles in the study SCUs included problem solving with staff, ongoing monitoring of case management, and interaction and socialization with the resident. Three family interaction styles emerged from review of the qualitative reports: active, supportive and unsupportive.

1. Active. Fourteen successful and nine unsuccessful cases had family members who were highly involved in the decision-making and care of the resident. These families visited frequently, worked with staff and provided information on family and friends, food likes and dislikes, past hobbies/games and the employment history of the resident. Many staff interviewees commented that the background information helped identify behavioral intervention strategies for difficult residents. Furthermore, the interviewees reported that these family members were actively involved in supporting the staff's ideas and recommendations:

Always, at any point in time, there was support from the family. . . . They gave us a lot of background information on this particular resident, and that's so very important. . . . He (husband) is there daily and is very supportive. It's nice to see that he can see her through

the dementia . . . (He) holds her hand or brushes her cheek, and he's just totally devoted in spite of the dementia. A lot of families are frightened by it, but I think because these men have support in place and they know the care is given, they have the energy to give. We feel good about that, too.

2. Supportive. Nineteen successful and nine unsuccessful residents had family members who were supportive of the staff's recommendations and management of the behavioral problem, but were not actively involved in decision-making and care. Such family members came to the SCU only occasionally or were interactive via phone. There were several factors that emerged regarding families' supportive yet inactive role in care: (1) distance prevented regular interaction and visitation; (2) it was emotionally difficult for family members to deal with the behavior problems, so they gave 'free rein' (but remained supportive) to staff members; and (3) lack of knowledge or education about AD:

The family can't cope with her behavior very well. . . . She [the resident] recognizes the staff more than her daughter. . . . Her daughter has been very supportive and appreciative, but hasn't played any role in her mother's care. It's a problem we have with most of the families; they can't cope with it. . . . But we have their support, which means a lot to us.

Another staff member discussed the long-term role of family involvement and how family interaction may change over the course of institutionalization of the resident.

His wife was absolutely exhausted. She had tried very hard to keep him home. For the first six months she was in here two or three times a day and was very tearful. . . . Now, a couple years down the road, she is making her own life.

3. Unsupportive (including absent). Unlike the active and supportive families, staff perceived the unsupportive families as providing no support for the SCU staff, and/or often failing to cooperate with the care staff and resident needs. Three sub-themes comprise the unsupportive families.

In one type of family interaction profile, staff perceived families to be initially supportive. However, because of changes in their own personal circumstances (for example, increasing ill-health or move to a more distant location) or unhappy relationship with the institutionalized family member, the family members progressively disengaged from ongoing interaction, care monitoring and involvement. They seemed to 'hand over the baton' of care to the SCU staff and to no longer concern themselves with the resident's ongoing welfare:

The family tried to be active in supporting him, but because he declined so quickly, they basically just threw up their hands. They were here, but did not provide much support for him because they were typically upset when they came in. The visits were not productive at all; often they made matters worse.

In some cases, families were actively involved but their interaction style was perceived as negative by the staff. According to the staff, the family disturbed the resident's adjustment to the SCU facility, contradicted the staff's care decisions and/or confronted staff in an adversarial or judgmental manner:

A friend of [resident's] daughter came to see her and decided that this was not the place for her. . . . After that, the daughter took up this crusade, and got the nursing home ombudsman to come and see her. They [ombudsman, daughter and friend of daughter] started coming to see her and, I felt, brainwashing her. They told her she shouldn't be here and that they would help her move back. It came down to a hearing at which a permanent guardian was going to be named. We settled out of court, but by then the whole thing had dragged on so long that her behavior had just deteriorated.

The other type of unsupportive scenario involves no identified family. This occurred in five cases, all of which were considered to be unsuccessful by the staff member, and all of which were ultimately discharged. Four of these were male.

Comparing the successful and unsuccessful residents of one facility, a nurse describes the impact of family on the management of behavioral problems:

We actually had more family history on him [the successful resident], even though his wife was not here a lot, plus he had hobbies and things that we could zero in on. On the other hand, the other resident was a bachelor and lived by himself; the family didn't know him well. . . . That might have had some bearing on our success.

In another case the staff member acknowledges the importance of family history and relationships in shaping the involvement after a resident has moved to an SCU: 'I remember the family was out of the picture and didn't want anything to do with him. We had to get the state's attorney involved in order to keep him under control'.

## **Discussion**

Many SCUs are specifically designed to manage problem behaviors through such environmental characteristics as secured exits and paths that promote safe wandering (Swanson et al., 1993). Furthermore, low-stimulus environments with activity opportunities are believed to minimize agitation while providing a diversion from potentially volatile situations. Although the environment in which care is delivered may be an important feature of successful behavior management, the process of care is probably more important for institutionalized persons with dementia. This was evident during the interviews with the staff, who predominately acknowledged the social rather than physical environment as the integral part of behavior management. The process of care becomes particularly evident in the case of residents whose behaviors are especially disruptive (Sloane & Mathew, 1991).

Physical aggression is the most difficult behavior to manage, yet SCU staff members in this study reported that they were equipped to manage *most* physically aggressive residents through behavioral and pharmacological interventions. This may be because of the observation that many aggressive behaviors are precipitated by some external event and are therefore predictable (Bridges-Parlet, Knopman, & Thompson, 1994). However, severe and unpredictable outbursts in nursing homes pose significant threats to the safety of other residents and care staff (Zimmer, Watson, & Treat, 1984). Additionally, staff report a breadth of activities and interpersonal

approaches to behavioral management. However, management of severe behavioral problems may be compounded by several factors: psychiatric comorbidity, the size and strength of the resident, and the family involvement.

In this study, psychiatric comorbidity was a significant problem for care staff in SCUs and was associated with resident discharge. Long-term care nurses may not be trained in psychiatric nursing and therefore may be unprepared to assess and manage behaviors specific to persons with mental illness. In order to resolve this problem, long-term care facilities could offer continuing education for management of psychiatric comorbid conditions. Furthermore, it is important to conduct a thorough psychiatric assessment of residents prior to admission to determine whether it is appropriate to place the individual in dementia care settings or whether the individual should reside elsewhere.

The resident's size and strength also emerged as a risk factor for lack of successful behavior management. As a result, it is worth considering how the SCU staff will manage large male residents who have a history of physical aggression.

The role of family in dementia care has received considerable attention in the caregiving literature. Family members experience both negative and positive consequences as a result of providing assistance to someone with dementia (Pearlin, Mullan, Semple, & Skaff, 1990; Seltzer & Greenberg, 1999; Skaff & Pearlin, 1992; Thompson, Futterman, Gallagher-Thompson, Rose, & Lovett, 1993). The bulk of the literature focuses on family characteristics and care before the resident's placement, or contrasts institutionalized with community-dwelling dementia-impaired seniors and so on (Cohen-Mansfield & Billig, 1986; Grant et al., 1995; Laurence, 1986; Leon & Ory, 1999; Newby, 1996; Richter, Roberto & Bottenberg, 1995; Sloane & Mathew, 1991). However, one study followed caregivers during the transition of institutionalization. They found that caregivers were relieved of some of the day-to-day pressures of caregiving such as having more time to engage in personal activities, yet the wellbeing of the caregivers was not necessarily improved overall after the older person was institutionalized (Zarit & Whitlatch, 1992). Aneshensel and colleagues (1995) describe caregiving as a multistage career whose impact continues after in-home care has ceased. They suggest that long-term care placement 'does not affect loss of intimate exchange with the patient' (1995, p. 235) and that placement relieves some but not all stressors related to caregiving.

This study highlights that SCU staff recognize the critically important role that family involvement plays in successful post-placement case management of SCU residents. Staff respondents reported that families often stayed involved through visits with the resident and communication with the staff, and that family support was critical to successful behavior management. Furthermore, a cluster of 'failed' cases had no family. This was especially true for male residents. While these data do not identify why behaviorally disruptive males seemed to be especially likely to have no support network, lack of family involvement has implications for the care of persons with Alzheimer's disease. Typically, the responsibility of care for those without family is shared by a court-appointed guardian, long-term care social workers, and the facility administration; however, the high discharge rates noted in this study suggest that there is no true substitute for family. One of the most striking contributions of this study, therefore, is to highlight the paucity of research on the role played by families in the ongoing care of

institutionalized seniors, especially given their apparently critical role in successful case management.

A limitation of this study is the use of staff-only reports to generate our typology of resident success. On the one hand, such an approach may be appropriate because formal care staff are primarily responsible for administering day-to-day care after placement. However, staff may distort reporting of behavior severity, behavior management techniques, restraint use and quality of family involvement to 'alleviate' blame for resident non-success. Therefore, future research may benefit from obtaining the perspectives of multiple sources, including staff, family and perhaps the resident, to better focus on resolving complex issues of behavior management. Another study limitation is the relatively small sample size, which included respondents with diverse training in nursing, social work and recreational therapy. Although this may be problematic, we did not find that the quality of interviews differed by staff type. We may have alleviated this problem by requiring all respondents to have direct contact with the SCUs and to have a thorough knowledge of the behavioral challenges and management strategies used with the resident(s) in question. Nonetheless, issues surrounding respondent bias are always a concern in qualitative interviews of relatively limited sample size. Thus, the findings from this study require replication before the recommendations can be considered generalizable to other SCUs.

In spite of these caveats, these data indicate that SCU staff recognize that behavior management of severely disruptive residents is difficult, but that appropriate interventions and comprehensive care can ensure success among persons with dementia. Management requires an evaluation of the behavior and underlying causes, such as external cues or medical comorbidity; creative and persistent behavioral interventions; and a thorough social history of the resident. Furthermore, a sense of 'helplessness' develops among staff when severe behaviors are unpredictable and severe, when the resident has a true or suspected psychiatric comorbidity, and/or when the size and stamina of the resident interferes with management. Such helplessness must be addressed head on, in order to maintain unit morale and to achieve optimal resident management. Of particular interest is the recognition by staff that families are a central element of the care of institutionalized persons with dementia and that active and supportive families seem to provide the best opportunity for resident success and buffer against discharge. Family involvement can be fostered by encouraging participation in care planning (by conference call or evening meetings, if necessary), activity planning, support groups and encouraging families to assist the SCU staff with caregiving (if desired). Families need to feel that they are supported for making recommendations and working with care staff.

This study highlights the perceptions of nursing home staff in managing severe behavioral problems of dementia residents. An integration of behavior approaches, medical management, a thorough psychosocial history and family involvement can greatly enhance the likelihood of success. However, when such strategies do not work and the resident is ultimately discharged, the nursing staff often regard the discharge as a personal and institutional defeat. A sound policy on behavior management and discharge criteria will likely reduce the number of perceived resident and staff failures.

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