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Abstract

Finding a place that can provide satisfactory and appropriate care for persons with significant dementia related behavioral issues (e.g., wandering, aggression, combativeness) is an on-going challenge for families. The current study examined the impact of an innovative model of care on family members' levels of stress and satisfaction. The model focuses on meeting residents' emotional and spiritual needs, as well as their physical needs in order to reduce challenging behavioral issues and thus the need for behavior-related medications and hospitalizations. Respondents (n=89) indicated that prior to the current care model, their family members with dementia lived in a variety of settings, including: assisted living (46%), nursing homes (43%), independent senior living (11%), and geriatric psychiatric units (9%). Dementia-related behaviors included anger (40%), hallucinations (33%), combativeness (32%), and paranoia (30%). While research suggests that outplacement does not necessarily relieve family stress (McLean, 2007; Watari, et al., 2006), family caregiver stress and burden has been associated with a number of variables including the quality of care families perceive their loved one is receiving (Robison, 2007; Tornatore & Grant, 2004). In this study, respondents overwhelmingly indicated high levels of satisfaction with their family member's current care and relatively low to moderate levels of stress. Cost was the only factor that brought a more mixed level of satisfaction. In addition to examining factors related to levels of stress and satisfaction, the current study provides a qualitative analysis of family members' recommendations for coping with challenging behaviors, finding appropriate care, and managing levels of stress.

Introduction

- It is well established that caring for persons with dementia is stressful and can result in significant burden and high burnout rates for caregivers and many family caregivers find they must turn to outside placement for their loved one with dementia.
- The social and emotional burdens of care, however, have been shown to continue for family members following outplacement, with levels of on-going stress and burden for family caregivers being associated with a number of variables, including the quality of care they perceive their loved one as getting in their care setting.
- This is particularly true for families of persons with dementia-related behaviors, who face the added challenge of finding an appropriate care site willing to take on their loved one and their behaviors
- In the current study, the experiences of family members of persons with Dementia Related Behavioral Issues who were placed in the current model of care were examined with regard to stress, burden, and level of satisfaction with the model of care.

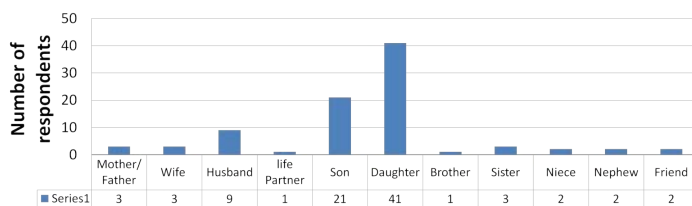
Methods

- In the current phase of this study, family members of current and past residents of Lakeview Ranch were surveyed regarding their experiences with the LR model of dementia care (as well as other models/approaches they may also have encountered).
- All families of persons who had ever resided at Lakeview Ranch (N=122) were sent a hard copy of the survey, along with a cover letter describing the study and a self-addressed stamped envelope to return the survey to the researcher.
- Respondents also had the choice of logging onto a website identified in the cover letter and responding electronically if they preferred.
- In order to preserve the privacy of the potential respondents, the agency used their mailing list to send out the surveys, but all responses were sent directly to the researcher. Thus, the researcher did not have access to individual names and the agency did not have access to individual responses.
- 89 out of the 122 surveys sent were returned either by mail or electronically for a 72% response rate. Because not all respondents answered all questions, missing data is evident for some of the response categories.
- Data were analyzed using both quantitative (descriptive statistics) and qualitative methods (open coding) methods.

The Lakeview Ranch Model of Care

- The Lakeview Ranch (LR) model focuses on the provision of specialized dementia care for persons with significant behavioral issues.
- Stems from a grass-roots approach of adopting "the best of" various existing models of dementia care for persons with behavioral issues, while incorporating ideas from family and professional caregivers.
- Goal is to address the specific individual needs of persons with dementia who exhibit behaviors that other care facilities are often unable to address or which are addressed via behavior-related medication use, psychiatric hospitalization, or discharge ("de-admittance") to another facility.
- Key elements of the LR care model include:
 - A high staff to resident ratio (1:3)
 - Extensive medication reviews
 - Individualized registered nurse coverage
 - A nature-based setting which includes animal therapy and a strong focus on residents' emotional and spiritual needs
 - Attention to support and training of staff in order to:
 - Decreasing the financial and emotional costs of staff turnover
 - Change staff perception of how dementia affects the resident
 - Switch from task oriented behavior to person centered behavior

Sample (N=89)



The majority of the respondents were sons/daughters of the care recipients (70.5%), while 14.7% of the respondents were the significant other of the care recipient (Husband, Wife, Life Partner).

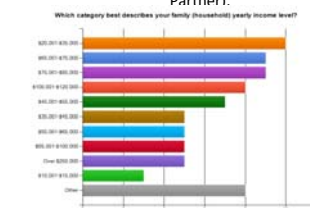
Gender: 30 males (33.7%) and 57 females (58.4%) with 7 people not identifying their gender.

Age: Ranged from 33-90 years of age with a mean age of 59.7 years.

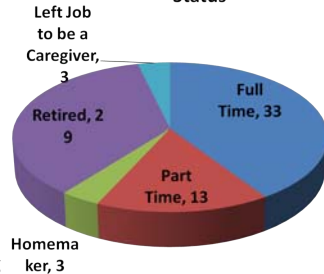
Dementia-Related Behaviors: Forty-four respondents indicated that their loved one was de-admitted from another care setting before coming to LVR. Reasons given for de-admission included a variety of "behaviors" including: agitation (n=13, 29.5%), aggression (n=13, 29.5%), wandering (n=10, 22.7%), hitting (n=10, 22.7%), shouting (n=2, 4.5%), and incontinence (n=2, 4.5%).

Settings Lived Prior to LVR

- The majority (77.3%, n=68) of persons with dementia spent some time in a specialized dementia care facility after they were diagnosed with dementia.
- A large portion (45.5%, n=40) of the respondents indicated that their loved one lived in an assisted living facility prior to LVR



Respondents Current Employment Status



Findings

Choosing LVR

There were many reasons respondents (n=88) gave for why they chose LVR including: Specialized knowledge of dementia (n=80, 93.0%), High staff to client ratio (n=79, 91.9%), Home Like Setting (n=78, 90.7%), Individualized attention (n=78, 90.7%), Not a Nursing Home Setting (n=63, 73.3%), Location (n=51, 59.3%).

Challenging Behaviors:

Respondents found the following behaviors most difficult behaviors to deal with:

- Sundowning 45.9% (n=39 out of 85 responses)
- Memory Loss 45.9% (n=39 out of 85 responses)
- "Wanting to go home" 28.2% (n=24)
- Wandering (16.5%, n=14)

Findings (continued)

Respondent Recommendations:

Coping with BPSD

- "Understand the progress of the disease, you will need increased levels of care and assistance."
- "Take a class that teaches you what to expect as the disease progresses. Many conflicts can be avoided if you know how to ask questions and answer the patient."
- "Join a support group"

Finding Appropriate Care

- "Give yourself plenty of time off by using any available respite care"
- "Get information and find people who have the experience to help you understand the challenges."
- "Seek supportive help from family and friends who love the loved one. Get all the information you can and ask people who have traveled this road with a loved one"
- "Seek help from Family, Physicians, specialized dementia caregivers. Remember to take care of yourself too."

Managing Stress

- "Don't ask them a lot of questions. Don't say, 'Don't you remember'. Just be with them and hold them."
- "To read as much as literature as possible regarding dementia. To realize that not two individuals progress at the same rate of decline. To ask questions of physicians, care facilities etc."

| | Caregiver Stress (How Stressful would you rate the following?) | | | | Response count (n) |
|---|--|------------------|----------------------|---------------------|--------------------|
| | Not at all Stressful | Mildly Stressful | Moderately Stressful | Extremely Stressful | |
| Your OVERALL experience of providing care to your loved one with dementia | 4.9 % (4) | 24.7 % (20) | 35.8 % (29) | 34.6 % (28) | 81 |
| Your OVERALL experience with Health Care Providers | 34.7 % (19) | 37.7 % (29) | 27.3 % (21) | 10.4 % (8) | 77 |
| Your OVERALL experience with Lake View Ranch | 84.7 % (72) | 12.9 % (11) | 2.4 % (2) | 0.0 % (0) | 85 |

Level of satisfaction with current care

The majority of respondents were extremely satisfied with the various aspects of their loved one's care at LVR – although respondents were more mixed in their satisfaction with the cost of care provided.

| | Not at all satisfied | | Somewhat satisfied | | Extremely satisfied | N/A | Respondents |
|---|----------------------|----------|--------------------|------------|---------------------|----------|-------------|
| Level of care provided | 0.0% (0) | 0.0% (0) | 2.3% (2) | 13.8% (12) | 82.8% (72) | 1.1% (1) | 87 |
| Level of emotional care provided | 0.0% (0) | 0.0% (0) | 2.3% (1) | 9.3% (4) | 88.4% (38) | 0.0% (0) | 43 |
| Level of spiritual care provided | 0.0% (0) | 1.1% (1) | 4.6% (4) | 12.6% (11) | 74.7% (65) | 6.9% (6) | 87 |
| Overall quality of the care provided | 0.0% (0) | 0.0% (0) | 1.2% (1) | 9.3% (8) | 88.4% (76) | 1.2% (1) | 86 |
| Cost of care provided | 0.0% (0) | 9.5% (8) | 20.2% (17) | 19.0% (16) | 44.0% (37) | 7.1% (6) | 84 |
| Attention to the needs of person with dementia | 0.0% (0) | 0.0% (0) | 3.4% (3) | 10.2% (9) | 86.4% (76) | 0.0% (0) | 88 |
| Attention to the needs of family members/care providers | 0.0% (0) | 1.1% (1) | 5.7% (5) | 15.9% (14) | 77.3% (68) | 0.0% (0) | 88 |
| Willingness to work with families | 0.0% (0) | 0.0% (0) | 3.4% (3) | 9.2% (8) | 87.4% (76) | 0.0% (0) | 87 |
| Level of staff training/knowledge | 0.0% (0) | 0.0% (0) | 2.4% (2) | 15.5% (13) | 82.1% (69) | 0.0% (0) | 84 |

Discussion

The Lakeview Ranch model combines many of the best practices in the current literature, including person-centered care focusing on meeting the emotional needs of residents, validating feelings, animal therapy, a high staff ratio, and a focus on flexibility with both staff and residents – an essential component of person-centered care (Cohen-Mansfield & Bester, 2006). The model also highlights the differences between a biomedical, disease-based model which focuses on treating abnormal behaviors as artifacts of a diseased brain, and a communications approach which adheres to the idea that all behaviors are a form of communication. The goal of a communications-based model of care, such as the one used at LVR, is to properly interpret and meet the underlying need(s) expressed by the residents through their behaviors (McLean, 2007), thus preventing or reducing the occurrence of challenging behaviors that other care models find costly or impossible to treat (and often lead to an increased use of behavior-related medications, hospitalizations, and/or de-admission from the facility.) Previous studies have indicated that the LVR model does reduce the number of behavior-related hospitalizations, medications, and need for de-admission (Berry, Eden, Habben, Liesch & Karasik, 2007; Berry, Karasik & Takamatsu, 2008a; Berry, Karasik, Takamatsu, 2008b). The current study finds that family members experienced significant challenges in providing care and finding appropriate outside care for their loved-ones with dementia-related behavior issues prior to coming to LVR. Overwhelmingly, respondents expressed satisfaction with the LVR approach, with the possible exception of cost of care (although it is unlikely that any model of care will meet with full satisfaction with regard to cost). Family recommendations include the need to learn as much as possible about dementia, communication techniques and strategies, and available options for care. Future study is planned to examine issues of staffing and the impact of the LVR model on reducing staff burnout and turnover.

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