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The rewards...

...of investing in quality

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Reimagining care

Rona J. Karasik and **Judy Berry** explain how investing heavily in upfront costs is paying dividends for a US care home – by offering better support for people with dementia before problems develop

Elsie loved Coco the miniature horse, so the animal specialist brought him to her bedside

Where do you go when no one else will take you? Imagine a woman with dementia who has been asked to leave not one or two but 12 care facilities – with each facility declaring that it was not able to cope with her 'behaviours'. Imagine her daughter, at a loss for what to do next.

Back then, in the 1990s, there were no good answers for me (Judy) and my mother, who was in precisely this painful predicament, but that is no longer the case in Central Minnesota in the United States. Now, there is Lakeview Ranch – a pair of small, rural specialist dementia care homes that focus on caring for people with dementia-related behavioural 'challenges'. In total, thirty people live in the two houses: 14 in Darwin House and 16 at Dassel House. I established Lakeview Ranch in 1999 and, although it was too late to help my mother, my experience of supporting her was my main motivation for developing a new model of care.

My approach has been to adopt the 'best of' various existing models of dementia care, while incorporating ideas from families and professional caregivers. Before starting Lakeview Ranch, I spent three years learning about emerging models around the country and visiting facilities that were focusing on person-centred care approaches. I sought out advice from experts in the field as well as feedback from front-line care staff regarding what was working well and what was not.

In 2006 I approached Rona to help me demonstrate the value and challenges of the Lakeview Ranch (LR) model. Rona helped me by placing my learning into the context of the current literature and research in the field. Then we collaborated on several community-based research projects: I identified the research questions I wanted answers to and we figured out how to answer them through scientific study and conducting the research. In this article, we want to share with you the key elements of the LR model.

The Lakeview Ranch model

An underlying premise of the LR model is that challenging behaviours stem from unmet needs that a person with dementia is trying to communicate. Identifying and meeting these needs can lead to a reduction in the challenging behaviours. The LR model takes this person-centred approach (see Kitwood 1997) and enhances it with specific strategies for how these needs can be met. Key elements of the LR model include:

- a staffing ratio high enough to allow staff to fully implement the LR care strategies
- extensive staff support and training to reduce turnover
- ongoing staff mentoring in the model's care philosophy
- extensive and ongoing medication reviews
- more direct nursing support for pro-active management of co-occurring medical issues and medication side-effects
- a nature-based setting which includes animal therapy
- a strong focus on residents' emotional and spiritual needs.

The team at Lakeview Ranch has made the very deliberate decision to invest funding up front in therapies and strategies designed to reduce the occurrence of behavioural issues in the first place – rather than directing resources primarily toward addressing behaviours only after they occur.

Staff to resident ratio

High staffing ratios have been shown to be critical in working with people with significant behavioural needs (Kayser-Jones & Schell 1997; Reid & Chappell 2003), but what constitutes an effective staff ratio? In researching the LR model, I (Judy) found a disparity between what facility administrators and their front-line

staff reported was adequate, with staff indicating they needed more help. Following extensive trial and error of the various staff configurations, we settled on a 1:3 staff to resident ratio as workable for supporting people with dementia with high levels of needs.

While the mix of staff varies and employees do have specific responsibilities (for example, direct care, activities, animal therapy, housekeeping, kitchen), they are also all universal workers to the extent that in the LR model there is nothing that is 'not my job'. Rather, all staff are expected to be available immediately to support residents with emotional and safety needs as they arise.

Without question, maintaining such a high staff to resident ratio – particularly with highly skilled staff – is costly. Understaffing, however, has associated costs as well, including limiting a facility's ability to effectively implement their care model. In addition to the obvious challenges that understaffing brings (that is, not enough people to meet residents' basic activities of daily living, much less their emotional and spiritual needs), understaffing can also undermine the implementation of new ideas and best practices for dementia care.

Staff retention

Continuity in care staff is also important. Caring for people with dementia, however, is stressful and can lead to high staff turnover rates (Coogle, Parham & Young 2007; Lyman 1993). Rates of staff turnover in nursing homes are notoriously high, with some documenting annual turnover rates for certified nursing assistants (CNAs) and nursing assistants to be as high as 80 to 100 per cent (Castle & Engberg 2006; Riggs & Rantz 2001) and even up to 400 per cent in some areas (Cohen-Mansfield 1997). In order to address issues of staff burnout and retention, the LR model limits most staff to a 32-hour (full-time) working week and encourages staff to monitor their individual stress levels and take breaks when necessary. The average annual turnover rate for Lakeview Ranch calculated for the ten-year period of 2002–11 was 48.01 per cent.

Staff support and training

The LR model also focuses significant resources on extensive, ongoing staff training and support. The team at Lakeview Ranch give special attention to educating staff about what happens to the person within as dementia progresses. In contrast to the media perception of 'the long goodbye', where the person with dementia slowly fades away (a perception that can give caregivers unconscious permission to ignore a person's emotional needs), the LR model focuses on the 'I'm still here' principle presented in various ways by Feil (1993) and Taylor (2007) among others. Caregivers are encouraged to see each person they support as a unique individual with their own wishes and needs, regardless of how those needs may currently be expressed.

The LR staff training approach includes 16 hours of orientation, followed by 6-10 days of individual mentoring of new staff as they interact with residents. Training and subsequent mentoring focuses on various areas:

- debunking myths about what the progression of dementia symptoms are doing to the 'person within' (for example, how increasing disability may affect a person's ability to perform activities of daily living and communicate needs, but that it does not make the person themself fade away)
- the importance of getting to know each person and their individual emotional, spiritual and physical needs in order to identify underlying feelings behind changes in behaviour
- how to validate residents' feelings
- how to approach each resident slowly with dignity and respect for their individual choices
- how to be flexible in prioritising care tasks.

Maintaining a person-centered focus requires ongoing mentorship so LR 'culture mentors' are assigned to each shift. Mentors are staff with a minimum of one year of experience at Lakeview Ranch. Each culture mentor completes additional training in how to teach and support others in techniques such as validation of feelings, attention to emotional needs first, resident choice, flexibility in what really matters or does not, and how to redirect staff when they fall back into task-oriented behaviour. Additional ongoing training is provided by full-time staff nurses who teach about pro-active medical support such as how to spot early signs of medical issues such as pain, pneumonia, and urinary tract infections. Monthly staff meetings and expert speaker events are also a part of the LR training and staff support process.

Medication reviews

Behaviour-related medications, often used to 'assist' staff in coping with challenging behaviours, can also be the cause of certain behaviours and cognitive losses themselves, as well as other unwanted side-effects (Aupperle 2006; Harrison & Therrien 2007, Power 2010). The LR model seeks to minimise the amount of medicinal behavioural intervention necessary through frequent medication reviews and close individual supervision by staff RNs. The LR model employs dementia care specialists whose job is not only to get to know each resident personally, but also to work closely with the residents' psychiatrists, medical doctors, and family members to obtain the best possible outcomes.

Each new resident is given a 'buddy' (1:1 staff person) from the time they arrive and for 6-10 days as needed to start building a trust relationship, reduce patient fear and anxiety that is often present during transition, and to learn about the patient's individual needs. After this individual observation, staff nurses collaborate with physicians and psychiatrists on a programme of reviewing any psychotropic or mood altering drugs given to the resident. ➤

Residents and staff enjoy fishing in the lake

➤ Following this initial intake, LR nurses spend 40 hours per week overseeing 15-17 residents, monitoring both their medical and psychiatric needs, keeping a close eye on medication effects and focusing on reducing and eliminating any psychotropic drugs that may be in use. Side-effects of any medications used are monitored daily and all medications are then evaluated monthly for efficacy and adjusted accordingly. Staff nurses familiar with each individual resident's medical and psychiatric history accompany residents on all medical appointments.

Nature-based setting

While several programme models have adopted nature-based settings (Bossen, 2010; Hinman & Heyl 2002; Sampsell 2003), the LR model expands and combines the concept of a pastoral setting with horticulture programmes. Large outdoor areas with gardens give people the opportunity to walk outdoors freely when they choose, eliminating wandering as a 'behavioural concern'.

The LR model also includes an extensive animal therapy programme. Animal assisted therapy has been found effective in managing dementia care challenges including agitation (Williams & Jenkins, 2008), social interaction (Richeson 2003), and nutritional intake (Edwards & Beck 2002). Since its inception, Lakeview Ranch has been home to a variety of domestic, farm, and exotic animals as a way to draw residents out and to provide an alternative vehicle to enhance the emotional connection, communication, and satisfaction of residents, even those in the later stages who are no longer able to communicate verbally.

Resident Elsie Marie Wegner passed away three hours after the picture on p28 was taken. The LR animal specialist knew how much Elsie loved Coco, a miniature horse, and brought her to Elsie's bedside for a last goodbye. Although she had not been responding much before this interaction, Elsie surprised everyone by opening her eyes ever so slightly. She smiled, then reached up to stroke Coco's muzzle. This was just another substantiation of the fact that "We *are* all whole human beings, with feelings, emotions and needs right until we take our last breath."

Focus on residents' needs

Attending to each individual resident's needs is a central tenet of the LR model. Several studies (Gaugler *et al* 2004; Gaugler *et al* 2005) argue for the importance of meeting unmet physical needs. However, similar attention must also be given to residents' social and

Morning exercise

emotional needs which can include depression, loneliness, grief, frustration or fright. Care providers, however, may mistake a person's inability to communicate their needs with a lack of needs (Egan *et al* 2007; Kovach *et al* 2006; Perry & Bottorff 2005).

The LR staff are trained to look for and interpret residents' thoughts and feelings. This requires staff to know each resident's family history and daily context so they may better read residents' non-verbal communication. Early changes in a resident's behaviour or mood can then be addressed pro-actively. For example, staff might sit down with a resident who appears to be becoming agitated and say, "I can see you are feeling frustrated". Similarly, staff may stop to hold the hand of someone who seems frightened and reassuringly listen to their fears. This approach requires significant time as well as staff flexibility because for people with dementia things change daily, sometimes hour to hour, based on the progression of their disease, the time of day, and how well their needs are being met.

Evaluating the model

We have conducted two studies to evaluate the model's effectiveness (see Karasik *et al* 2012, Karasik & Berry, 2011, 2010 and Karasik *et al* 2009). The first compared residents' recorded psychiatric medication and hospitalisation use both prior to and following admission to Lakeview Ranch. For this study, data for Lakeview Ranch's first eight years (1999-2007) was compiled, including information from family interviews, pre- and post-admission screenings and assessments. Medication usage was gathered by using past and current medical records. A pre- and post-admission comparison was made of the overall individual use of behaviour-related drugs, for example Seroquil (quetiapine), Haldol (haloperidol), Resperidol (risperadone), Depakote (divalproex sodium).

Of the 122 current and former LR residents, 60 residents (49.2 per cent) had an average of 2.13 psychiatric hospitalisations in the year prior to arriving at LR but only 0.07 hospitalisations after arriving at LR. Of those 60, 56 (93.3 per cent) had no additional psychiatric hospitalisations after arriving at LR. None of the residents had more than one psychiatric hospitalisation after arriving at LR.

Comparisons of medical records from before and after admission to Lakeview Ranch showed that of the 122 current and former residents studied, 44 (36.1 per cent) experienced a decrease in the use of behaviour-related medications after moving to LR.

Family satisfaction with care

The second study involved surveying residents' families regarding their perceptions of their family member's care. In particular, respondents were asked about (1) their experiences with previous care for their family member, (2) their reasons for selecting Lakeview Ranch and (3) their current satisfaction with their family member's care.

The majority of respondents were extremely satisfied with the various aspects of their loved one's care at Lakeview Ranch, particularly in regard to the level of emotional care provided (88.4 per cent), attention to the needs of the person with dementia (86.4 per cent), staff willingness to work with families (n=76, 87.4 per cent); and the level of staff training and knowledge (n=69, 82.1 per cent). 88.4 per cent of respondents were extremely satisfied with the overall quality of the care provided. The only area where respondents were more mixed in their satisfaction rankings was in regard to the cost of the care provided.

Challenges

The Lakeview Ranch model highlights what is possible when care for persons with significant dementia-related behavioural concerns is reimagined. Fewer psychiatric hospitalisations, fewer psychotropic drugs, satisfied families, and most of all – care that focuses on the person rather than the symptoms of dementia. There is, however, more reimagining still to be done.

Developing and implementing Lakeview Ranch requires ongoing attention to a number of challenges. The rural location, for example, while ideal for providing a wide range of animals for therapy, has the potential to limit the pool of potential employees. Finding a certified animal therapist, in fact, has posed a challenge because so few such therapists are local to the area. The rural location also

initially posed another challenge, in that several neighbours expressed concern regarding zoning and the forthcoming presence of "those people" (meaning persons with dementia). While the NIMBY (not in my backyard) problem is not a new one, it is surprising how many people are still so unaware of the realities of dementia and the challenges one can face in the name of being a good neighbour.

Misperceptions about dementia lead to another set of challenges as well – in this case from caregivers – both family and professional. The myth of the 'long goodbye' and the notion that a person who is no longer able to communicate by traditional means is 'no longer there' can be difficult to overcome. Indeed, it is an ongoing challenge to get caregivers (regardless of training) to invest as much effort in someone who does not seem able to communicate as in someone retaining at least some traditional modes of communication. A great deal of time and training must go into reminding everyone that a person with dementia is 'still there'. This requires being able to show caregivers that a person with dementia is still the same, whole person they have always been. They have only lost their ability to communicate.

While Lakeview Ranch has been able to address many of the challenges above, probably the most difficult challenge to overcome relates to cost. Under the current US health care system, reducing challenging behaviours essentially reduces the level of reimbursement care providers receive for care (for example, from Medicare, Medicaid) because reimbursement levels are based on case mix and level of care need. Thus, success in reducing challenging behaviours consequently also reduces the amount of money available to continue doing so. The actual cost of care, however, has not gone down, but rather has been shifted toward measures of prevention such as increased staff ratio, training and ongoing support. Thus, care providers face a catch-22 where success at improving quality of care leads to less money to provide such care. Care providers are then faced with the following options: (a) reduce costs by giving up the very elements that are effective but costly (b) raise rates and accept only private pay residents who can afford the care or (c) go out of business for lack of sustainability.

Can there be yet another option? Perhaps a better solution is to focus on the policies that govern reimbursement so that providers who improve care are not penalised because their residents also improve. Such thinking, while logical, will require a significant paradigm shift in how care is reimbursed. It is hoped that as more examples of success emerge, policy-makers will see the value in aligning reimbursements with these newer, person-first positive approaches to dementia care. In the meantime I (Judy) established the non-profit Dementia Care Foundation to raise funds to make the care at Lakeview Ranch available to those who needed it, regardless of their financial status. A caring start, imagine that.

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