International Psychogeriatrics (2012), 24:5, 753–765 © International Psychogeriatric Association 2012
doi:10.1017/S1041610211002675

Perceptions of family and staff on the role of the environment in long-term care homes for people with dementia

Linda J. Garcia,[1,2] Michèle Hébert,[3] Jean Kozak,[4] Isabelle Sénécal,[5] Susan E. Slaughter,[6] Faranak Aminzadeh,[2,7] William Dalziel,[7,8] Jocelyn Charles[9,10] and Misha Eliasziw[11]

[1] *Interdisciplinary School of Health Sciences, University of Ottawa, Ottawa, Canada*
[2] *Élisabeth Bruyère Research Institute, Ottawa, Canada*
[3] *Occupational Therapy Program, School of Rehabilitation, Faculty of Health Sciences, University of Ottawa, Ottawa, Canada*
[4] *Department of Family and Community Medicine, Centre for Healthy Aging, Providence Health Care, Vancouver, Canada*
[5] *Social Sciences and Humanities Research Council of Canada, Ottawa, Canada*
[6] *Faculty of Nursing, University of Alberta, Edmonton, Canada*
[7] *Regional Geriatric Program of Eastern Ontario, Ottawa, Canada*
[8] *Department of Medicine, University of Ottawa, Ottawa, Canada*
[9] *Veterans Centre, Sunnybrook Health Sciences Centre, Toronto, Canada*
[10] *Department of Family & Community Medicine, University of Toronto, Toronto, Canada*
[11] *Department of Public Health and Community Medicine, School of Medicine, Tufts University, Boston, Massachusetts, USA*

ABSTRACT

Background: Disruptive behaviors are frequent and often the first predictor of institutionalization. The goal of this multi-center study was to explore the perceptions of family and staff members on the potential contribution of environmental factors that influence disruptive behaviors and quality of life of residents with dementia living in long-term care homes.

Methods: Data were collected using 15 nominal focus groups with 45 family and 59 staff members from eight care units. Groups discussed and created lists of factors that could either reduce disruptive behaviors and facilitate quality of life or encourage disruptive behaviors and impede the quality of life of residents. Then each participant individually selected the nine most important facilitators and obstacles. Themes were identified from the lists of data and operational categories and definitions were developed for independent coding by four researchers.

Results: Participants from both family and staff nominal focus groups highlighted facility, staffing, and resident factors to consider when creating optimal environments. Human environments were perceived to be more important than physical environments and flexibility was judged to be essential. Noise was identified as one of the most important factors influencing behavior and quality of life of residents.

Conclusion: Specialized physical design features can be useful for maintaining quality of life and reducing disruptive behaviors, but they are not sufficient. Although they can ease some of the anxieties and set the stage for social interactions, individuals who make up the human environment are just as important in promoting well-being among residents.

Key words: dementia, long-term care, Alzheimer's disease (AD)

Introduction

The rapid aging of populations around the world contributes to the incidence of illnesses related to age, such as dementia. With an estimated 29 million elderly people currently affected (WHO, 2011) and a projected 81 million cases to be diagnosed by 2040 (Ferri *et al.*, 2005), or possibly more (WHO, 2011), dementia has become a worldwide concern. In Canada alone, over one million cases will be diagnosed by 2040 and close to half a million elderly people with dementia will live in long-term care facilities if no cure is found beforehand (Alzheimer Society of Canada, 2009).

Over the course of this health condition, 90% of people with dementia will experience one

Correspondence should be addressed to: Linda J. Garcia, Professor, Interdisciplinary School of Health Sciences Faculty of Health Sciences, University of Ottawa, K1N 6X1, Ottawa, Ontario, Canada. Phone: +1-613-562-5254; Fax: +1-613-562-5632. Email: linda.garcia@uottawa.ca. Received 10 Aug 2011; revision requested 19 Sep 2011; revised version received 22 Nov 2011; accepted 22 Nov 2011.

or more behavioral problems (Kverno *et al.*, 2008) often hindering the quality of life of both the individuals themselves and their caregivers (Chang *et al.*, 2009), as their demand for care can increase the burden placed on caregivers (Gaugler *et al.*, 2010). The overall prevalence of behavioral problems among people with dementia varies greatly by population (e.g. community vs. institution), operational definition, and method of measuring the behaviors (Kverno *et al.*, 2008), but the most frequently reported behavioral problems associated with dementia remain wandering, uncooperative behavior, aggression, hallucinations, sleep disorders, incontinence, and screaming (Pavlakovic, 2001). These behavioral disturbances have been found to be the strongest predictors of placement in nursing homes among people with dementia (Gaugler, 2010), followed by, among others, the severity of dementia (Andrén and Elmståhl, 2008) and the perceived level of caregiver burden associated with functional impairment (Etters *et al.*, 2008; Luppa *et al.*, 2010). While informal caregivers may obtain a certain degree of relief in dealing with the behavioral sequela of dementia through placement, once in the long-term facility, disruptive behaviors continue to impact the life of residents. The trying experience of caring for a "vocally disruptive" resident can lead staff members to distance themselves from the resident, creating a cycle in which the resident becomes increasingly isolated and disruptive (Hallberg *et al.*, 1990; McMinn and Draper, 2005).

In order to deal with these issues, an increasing number of long-term care homes have designed safe and supportive environments for individuals with dementia. Within the last decade, many solutions have been found through modification of the physical environment to better manage disruptive behaviors. Zeisel *et al.* (2003) have demonstrated that privacy and personalization in bedrooms as well as residential environments were associated with reduced aggressive and agitated behavior. Reimer *et al.* (2004) reported that special care units employing less traditional hospital designs were associated with greater environmental awareness by residents, less decline in activities of daily living (ADL), and less negative affect. Marquardt and Schmeig (2009) showed that wandering behaviors are associated with the size and shape of the facility, the presence of alcoves, and the number of times a resident had to change direction in hallways, as they affected orientation. In fact, modified designs such as barrier-free rooms and homelike environments are now characteristic of specialized dementia units and consideration is increasingly given to designs that foster social interaction such as not placing chairs at dead-ends of corridors (Duffin, 2008). Slaughter *et al.* (2006), using the Therapeutic Environment Screening Survey – 2+ (TESS 2+), were able to distinguish an environment designed for dementia from a regular unit with differences noted in orientation/cueing, privacy, quietness, and physical attractiveness. In specialized dementia units, community organizations, church groups, and families are welcome and staff members are encouraged to cook to create a homely environment. Such environments, which provide an open and homelike atmosphere, are now part of best practices to help manage disruptive behaviors while minimizing the use of medication or restraints (Fleming and Purandare, 2010).

Family concerns in relation to the lives of their loved ones in nursing homes are more often documented in relation to support for ADL, well-being, and medical care (Ducharme and Geldmacher, 2011). Despite the rich data on environmental designs of specialized care units for people with dementia in long-term care homes, family and staff perceptions of the environment's impact on disruptive behaviors and quality of life of residents remain more difficult to find. These perceptions are important to consider since behavior disturbances are frequent and often the first predictor of instutionalization. Families expect those behaviors will be better managed in specialized units. The goal of this multi-center study was to explore the perceptions of family and staff members on the potential contribution of environmental factors that influence disruptive behaviors and quality of life of residents with advanced dementia living in long-term care homes.

Methods

Using a qualitative research approach, data were collected through nominal focus groups with family and staff members in eight residential care units within six long-term care homes accommodating people with dementia in three Canadian cities.

Participants

In each of the eight participating units, two groups were formed: one included only family members while the other included only staff members. There were no restrictions for participation with regards to sex, age, education, or socio-economic status. Family members were included if they had visited a resident of one of the eight participating units at least once a week for the past four months or more. Since the mean length of stay of the residents in the homes was 3.5 years, families would have had ample experience with the units as they would have visited the resident since admission. Staff members performing any role were eligible to participate if they had been involved in the care of residents for at least six months. This included nursing and personal care staff as well as housekeeping staff. Family participants were kept separate from staff participants, as well as participants from different units, but the procedure was the same in all groups. In order to optimize transferability of the findings to other centers, participants were sampled from different cities (Calgary, Toronto, and Ottawa), from different relationships with residents (families and staff), from different language groups (French and English), from different staffing categories (registered nurses, housekeeping, attendants), from different sizes of centers (from nine to 48 beds), and from different care models (mixed units housing both residents with and without dementia vs. specialized dementia units). Ethical approval was obtained from all relevant university and city health research ethics boards. Written consent was obtained from all participants.

Units

Most units were small-scale homelike units that included design features to encourage person-centered care, normalization of daily life, and better quality of life for residents (Verbeek *et al.*, 2009). Such features included, but were not limited to, barrier-free rooms and corridors, homelike common areas, private bedrooms, and safe, self-contained outdoor areas or gardens. Three of the eight units were more traditional and did not include some of these features. For instance, they had barrier-free corridors but there were two residents to a room, whereas in newer designs, residents with dementia had private rooms. Some residences also had large multi-purpose rooms while others had smaller alcoves, living areas, and kitchens.

Eight units of care were thus included in the study:

- Unit 1 (Ottawa, Facility 1): specialized, primarily English, 48 beds in four sub units
- Unit 2 (Ottawa, Facility 1): traditional, primarily English, 42 beds in two sub units
- Unit 3 (Ottawa, Facility 2): specialized, primarily French, 40 beds in two sub units
- Unit 4 (Ottawa, Facility 2): traditional, primarily English, 40 beds in two sub units
- Unit 5 (Ottawa, Facility 3): traditional, primarily English, 31 beds in one sub unit
- Unit 6 (Toronto, Facility 1): specialized, primarily English, nine beds in one sub unit
- Unit 7 (Calgary, Facility 1): specialized, primarily English, 27 beds in four sub units
- Unit 8 (Calgary, Facility 2): specialized, primarily English, 36 beds in four sub units

Staffing ratios varied greatly from unit to unit. Day ratios were on average five residents per staff member and ranged from three to eight residents, the mean for evenings was six residents (ranging from two to nine residents), and for nights the resident/staff ratios ranged from five to 16 residents per staff member with a mean of 12. There was one registered nurse on the day shift in the units, with the exception of one unit that had one registered nurse working half-time and another that had two.

Procedure

With the consent of the executive officers, each facility was sent an initial contact letter that was distributed to families and staff members informing them briefly about the study and inviting them to an information session hosted at the facility. The investigators presented the study and addressed issues and concerns. Family and staff members unable to attend the presentation sessions were sent an explanation letter with a contact number for the study coordinators. Participants were invited to take the consent form and the information letter with them at the end of the presentation, and to return the consent form with signatures for inclusion in the study. Participants were also given the choice of providing their consent at the time of the presentation. Only family members and staff who met the inclusion criteria were invited to the project presentation. Hence, all attendees who were willing to participate in the study were included.

Following those presentations, nominal focus groups were organized. During group sessions, the discussions focused on participants' perceptions of the effect of the physical and social environments on residents' behavior and quality of life, including interpersonal interactions and care delivery. For each unit, family and staff members were invited to take part in separate discussion groups of six to ten participants lasting from one to 2.5 hours. The primary author facilitated all discussion groups using a nominal group technique (Brunelle and Tousignant, 1988). Each participant was asked to write on paper their perceptions about important environmental factors. They were asked to:

- Identify the elements from the physical and social environment that *hinder* behavior and the quality of life of residents.
- Identify the elements from the physical and social environment that *improve* behavior and the quality of life of residents.

To help stimulate their thoughts, family members were asked to think about their current observations and, if helpful, compare the current unit to others where their family member might have once lived. Staff members were asked to share their observations and compare their current unit, if appropriate, to others where they might have once worked. In order to maximize the chances that participants would speak freely, no administrators or supervisor–subordinate pairs were involved in the groups of staff members.

The observations noted on paper by the participants were then shared with the group and discussed. This constituted the focus group portion of the procedure. Each element or factor proposed by participants was then reformulated in neutral terms on flip chart paper so that it could be perceived as either negative or positive by group members. For instance, "noise levels" could be perceived as positive (e.g. low noise levels) or negative (e.g. high noise levels). Once all elements were written on flip chart paper, the group facilitator, along with the participants, cleaned the list to eliminate any redundant information. From the resulting list, which often included between 30 and 60 elements, participants were asked to individually select and rank the nine most important elements that (1) hindered behavior and quality of life of residents, and (2) improved behavior and quality of life of residents (according to the technique described in Brunelle and Tousignant (1988): when a group generates more than 22 elements on their list, participants are asked to vote on the nine most important). This constituted the nominal portion of the procedure. Because participants were identifying elements privately and individually, they were not pressured by others to choose the same important factors. The result was a list of the nine most important environmental factors that facilitated or hindered residents' quality of life for each center as perceived by each group of staff or family members. The combined (focus and nominal group) technique allows participants to first reflect openly as a group on issues related to the target question while subsequently requesting that they individually select and rank those elements they consider most important. The technique offers the advantage of capitalizing on group dynamics while, at the same time, benefiting from the influence of each participant through the ranking and selection process.

All top nine statements as decided by members of each group were then collated into one large list across groups. Each statement was then coded independently by two researchers (Researchers 1 and 2), grouped in categories, and operational definitions were then created for each category by these same researchers (Figure 1). Based on the category definitions, the statements were then coded by two additional researchers (Researchers 3 and 4) who were not involved in the original coding

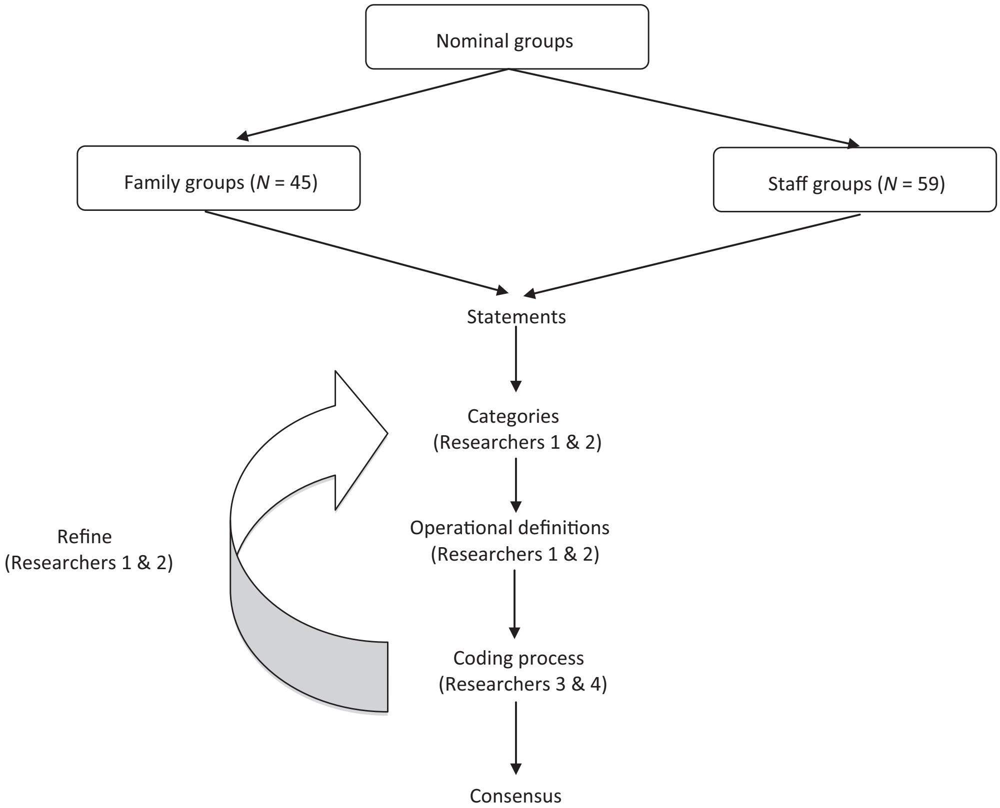

Figure 1. Coding of focus group statements.

and descriptions. The feedback from this last coding led to modifications of the code categories and operational definitions. Once these were modified by Researchers 1 and 2, Researchers 3 and 4 then re-coded each statement using the new categories. An example might be the following: "Staff knowing the residents' triggers, past interests, getting to know before, war history, beliefs." This statement offered by one of the groups was coded as "individualized care." When agreement was not reached among the four researchers, a meeting was called where researchers shared their viewpoints. After a brief discussion, consensus was sought.

The code categories served as a common language across groups. Hence, following the categorization, it was possible to convert each prioritized list of statements from each group into a list of code categories. For instance, in the example above, it was possible to use the code category "individualized care" rather than the lengthier statement "Staff knowing the residents' triggers, past interests, getting to know before, war history, beliefs" and tabulate the number of times "individualized care" was mentioned by the groups. It also became possible to determine the ranking given across groups for both facilitators and obstacles. For instance, for the code category "ratio of staff to resident/staffing levels," one staff group might select it as a first priority, another as a second priority, and three groups might select it as a third priority.

In order to arrive at a weighting that would identify the top nine code categories identified overall by staff and families, the following system was developed: code categories which appeared in the first position of priority were given nine points (the top number of priority categories); those in second position were given eight points; those in third place received seven points, and so on. In other words, the higher the number, the higher the priority. In the example given above, the weighting for the code category "ratio of staff to resident/staffing levels" could be calculated as follows:

- One staff group placed it in first position as a potential obstacle = 9 points
- One staff group placed it in second position as a potential obstacle = 8 points
- Three staff groups placed it in third position as a potential obstacle (3 groups × 7 points) = 21 points
- The total points for that code category as perceived by staff groups overall would receive, therefore, a total of 38 points

Tables 2 and 3 summarize these weightings for all code categories for the top nine rankings.

Results

The nominal focus groups included 45 family members and 59 staff members in 15 focus groups. Seven groups of families and eight groups of staff members with each group having six to eight participants took part in discussions that lasted from one to 2.5 hours. Resident participants were accommodated in homes that were quite representative of the population of individuals with dementia living in long-term care homes. The mean age of residents across all homes was 83 years with a range from 68 to 96 years. In Ottawa, 68% of residents were women, compared with 75% of the residents in Calgary. The home in Toronto was not typical as it was designed primarily for veterans and accommodated only nine male residents. Due to the severity of their dementia, many residents could not be tested using standardized dementia scales. For half of the residents, severity scores were available from the charts and might have been noted at time of entry into the home. In three units, the mean of residents' scores on the Global Deterioration Scale (GDS; Reisberg *et al.*, 1982) was 5.5. In the remaining five units, the mean of residents' scores on the Mini-Mental State Examination (MMSE; Folstein *et al.*, 1975) was 14.5/30 indicating moderate to severe dementia. Using the Functional Assessment Staging Test (FAST; Reisberg, 1988) as a measure of functioning, the median score was 7a indicating that residents generally experienced difficulties with dressing, proper hygiene, using the toilet, had urinary and fecal incontinence, and had language often reduced to short phrases. Families and staff who participated in the nominal focus groups therefore had, as a frame of reference, individuals with moderate to advanced dementia with significant functional limitations.

Data collection started with the four Calgary groups followed by the two Toronto groups. By the time the investigators had reached the Ottawa groups, data saturation was becoming evident. Some items were added by the Ottawa groups but the elements that were selected in the top nine were basically the same.

While both family and staff groups listed anywhere from 30 to 60 items each, the nine most important statements selected by each group were coded and regrouped into 19 categories relating to the facilities themselves, five categories relating to the residents and their families, and 11 categories relating to the staff (including volunteers). Table 1 lists these categories and their operational definitions.

According to both staff members and families (Table 2) the most important environmental obstacles that increased disruptive behavior and

Table 1. Categories from nominal focus group data operational definitions

CATEGORIES	DEFINITIONS
Staff	Individuals who *work* in the unit (either paid or unpaid).
S1: Staff approach	Refers to the way in which the staff interacts with both the residents (e.g. uses facial expressions, therapeutic touch, non-threatening) *and* with the families (e.g. giving updates to family re: resident). Although this may be a result of training or may lead to individualized approaches, the focus group item does not explicitly refer to training or individualized approach. Hence, the item is a reference to a global staff approach.
S2: Staff consistency/continuity	Refers to the staff turnover, which can affect the level of familiarity staff have with the residents and in turn, familiarity of the resident with the staff. Does not refer to the number of staff available.
S3: Staff flexibility	Refers to the staff performing tasks that are different than those normally completed in accordance with their job description/time schedule. Does not refer to the flexibility in the residents' schedule.
S4: Staff training	Refers to the fact that the staff have received information or training (formal or informal) in the area of dementia whether this is regulated by the facility or not.
S5: Ratio of staff to resident/staffing levels	Refers to the number of staff in relation to the number of residents. Insufficient staffing levels may affect stress levels, availability to residents, teamwork, or staff approach. However, this category refers explicitly to staffing levels.
S6: Staff/volunteer language	Refers to the language used by the staff/volunteer when speaking to the resident. Usually implies that the resident and caregiver staff/volunteer are using different languages. There is a mismatch between the staff/volunteer and the resident in terms of linguistic/cultural background. Does not refer to same-language communication partners who use a therapeutic approach to intervention (see S1).
S7: Staff teamwork	Refers to the staff working together towards a common goal.
S8: Volunteers	Refers to the presence of volunteers interacting directly with the residents.
S9: Individualized care	Refers to the fact that the staff know the individual residents well in terms of behavior, needs, and personal history and can thus provide care which focuses on each resident separately. Care is tailored in the context that each resident is an individual human being.
S10: Medication/drugs	Refers to the degree of drug/medication dispensed to residents. Could be over-utilization or under-utilization of medication.
S11 Presence of specialized staff	Refers to the presence of a multi-disciplinary team as staff (includes social worker, activity coordinator, physicians, etc.).
Residents	Individuals living in the unit and their family members (beneficiaries).
R1: Number of residents	Refers to the number of residents in the facility. Groups may have felt that the shear number of residents was too high (perhaps regardless of staff–resident ratio) or may have felt that the numbers were just right.
R2: Resident–resident interaction	Refers to the opportunity, method, and proximity with which residents interact among each other, whether it be positive or negative.
R3: Mixed needs	Refers to the inclusion of residents with different needs on a same unit. This can mean grouping together residents with and without dementia.
R4: Family involvement	Refers to the level of involvement and expectations of family members on the unit (e.g. entourage, visits from grandchildren, etc.).
R5: Communication/hearing levels of residents	Refers to the residents' levels of communication skills, which might impact their interaction with others.
Facilities Aspects	Aspects of the facility, such as activities, environments, rules, which aid or hinder the residents' behavior. These relate to the physical, social, and organizational environments.
F1: Music	Refers to the presence of music on the unit. The music may be there to (over)stimulate or soothe the resident.
F2: Generalized activities and stimulation	Refers to presence within the facility of different types of activities that appear meaningful to the residents. Activities are used to stimulate in a therapeutic manner (e.g. "cooking groups," animal visits, presence of Snoezelen rooms, etc.).
F3: Barrier in the environment	Refers to the perceived absence or presence of a physical barrier in the environment, which may impede or facilitate the circulation of residents. These can include movable/stationary objects, access to the outside world, uneven pavement, glass barriers, heavy doors, long hallways, dead ends, circular corridors, etc.

Table 1. Continued.

CATEGORIES	DEFINITIONS
F4: Safe/supervised environment	Refers to issues surrounding safety and supervision. Can refer to environments where safety or supervision cannot be assured or, on the contrary, offers better safety and supervision (may include unique situations, i.e. separation of sexes)
F5: Space size	Refers to the range of area/space where residents circulate (e.g. large, small, all on 1-level).
F6: Changing physical environment	Refers to changes in the residents' environments. For instance, residents might experience the necessity to change rooms, change roommates, change units or facilities, go outside instead of staying inside, etc. The change itself is the issue at hand.
F7: Working staff areas within environment	Refers to areas in which the staff executes its work all the while being in the center of the residents' environment. This may lead to confusion on the residents' part and may create unnecessary reasons to deny them access to yet one more area.
F8: Physical environment for socializing	Refers to a space reserved for residents to be able to socialize.
F9: Environment for special needs	Refers to a *space* reserved for residents who need to be cared for separately from the other residents. For example, during medical flare-ups (e.g. urinary tract infections), behavioral disturbances, or palliative care.
F10: Environment with visual stimulation	Environment is designed to facilitate integration but is not meant to be necessarily interactive. Environment is there to observe (e.g. rose bushes, children playing outside, decorations, and color contrasts, etc.).
F11: Temperature	Refers to the temperature of the rooms or of the facility (e.g. too hot, too cold). Can include moments when the temperature changes too quickly.
F12: Maintenance	Refers to the amount of maintenance given to the facility (e.g. frequency with which things are repaired, cleanliness, odor).
F13: Noise levels	Refers to the amount of noise to which the resident is exposed. Includes noise created from residents.
F14: Rules	Refers to rules and regulations that are put forth by the government or facility administration (e.g. residents must have two baths per week, assigned seating, flexibility of schedule, choice of residence by family/resident, screening staff, etc.) and are out of the control of the frontline staff.
F15: Food	Refers to the types and variety of foods residents receive.
F16: Lighting	Refers to the amount of light to which residents are exposed (e.g. too bright, not enough sunshine). Refers to both artificial and natural light.
F17: Restraints	Refers to the use of restraints to control behavior.
F18: Privacy	Refers to allowing the integrity of an individual's personal belongings, personal care, and personal space, in either a physical or social context. For instance, can include opportunities to have a private space as well as have the opportunity to be left alone or having personal clothing locked up.
F19: Home-like environment	Refers only to the physical environment, which evokes a sense of belonging in the resident. Attempts are made by the facility to make it look like a home. These changes are not made specifically for stimulation (e.g. décor).

hindered quality of life were the low ratio of staff to residents, the level of noise, the lack of consistency in the staffing, and the presence of rigid organizational rules/regulations. Six of the groups ranked noise as one of the top two factors increasing the likelihood of disruptive behavior. Many groups simply identified "noise" as a generic sound while others specified that the most irritating noise came from the television, music, or resident verbalizations.

Other than noise, having sufficient personnel to manage large numbers of residents was by far the most important for managing disruptive behavior. Both families and staff mentioned how low staff numbers and high turnover rates negatively affected the homes' abilities to manage this challenging group of residents. All groups stressed the importance of reducing staff turnover. Residents became accustomed to the staff which, when changed, resulted in behavioral triggers. Rigid government and facility rules and regulations were also perceived as contributing to the creation of conflict between staff and residents. Examples included requiring two baths per week, assigning seating plans in the dining room, and inability to access outside gardens.

Among the environmental facilitators that improved quality of life (Table 3) and diminished behavioral disruptions, both staff and families identified the approach adopted by staff, the homelike environment, and the ability to attend to the residents' individual needs. Both families and staff stressed the importance of taking the time to interact with residents. They noted that the best results were obtained when staff used comforting language, reassurance, faced the resident when speaking, knew when to withdraw, and interacted with residents in a respectful, gentle, positive manner. Both staff and families also noted that this approach could be achieved through training and staff consistency, thereby offering continuity in the staff-to-resident interactions. Through a deeper understanding of the residents' backgrounds, the participants felt that staff could better avoid the triggers that led to disruptive behavior. The groups emphasized the impact of homelike environments in allowing residents to truly experience life in a relaxed setting. Participants made reference to safe fireplaces, the presence of familiar objects, places to visit, the presence of a central activity center, presence of a washer and dryer, and an outside design that was visually integrated into the neighborhood. Eight groups identified a homelike environment among their top three environmental facilitators. Families and staff also placed great emphasis on accommodating residents by offering generalized, meaningful activities and stimulation. The majority of groups identified this factor as an important facilitator, although only one of these groups voted it among the top three facilitators.

Closer analysis of the results suggested that some environmental factors appeared more important for either the staff or the family groups. Staff groups, for instance, felt that it was important not to mix cognitively impaired with cognitively intact individuals. That is, staff participants believed that the needs of people with dementia required special attention and could conflict with the needs of people without dementia. It was felt that mixing the needs of residents from both cognitively impaired and cognitively intact groups on the same unit would increase the likelihood of behavioral issues. Families spoke about the negative effect of forced social groups within units, residents being bothered by other residents, and the proximity of other residents in common areas. There was a sense that being in such proximity increased the possibilities of violations of personal space, which could lead to undesirable behaviors. Four of the eight staff groups identified this factor as the most important environmental factor. Although more important for staff, families also felt this was important with three of the seven family groups voting this as an environmental obstacle in the top nine most important obstacles.

Staff also identified physical environmental barriers as very important in eliciting undesirable behaviors, although no group voted this factor among the top three obstacles. These included

Table 2. Code categories in top nine ranks: obstacles

	STAFF GROUPS		FAMILY GROUPS		GROUPS – OVERALL	
RANK	CODE CATEGORY	WEIGHT	CODE CATEGORY	WEIGHT	CODE CATEGORY	WEIGHT
1	Noise levels	57	Ratio/staffing levels	63	Ratio/staffing levels	101
2	Rules	40	Noise levels	34	Noise levels	91
3	Ratio/staffing levels	38	Staff consistency/continuity	27	Staff consistency/continuity	61
4	Mixed needs	36	Medication/drugs Resident to resident interaction	23	Rules	60
5	Staff consistency/continuity	34	Rules	20	Mixed needs	44
6	Barrier in the environment	32	Privacy	18	Barrier in the environment	38
7	Number of residents	19	Number of residents	17	Number of residents	36
8	Staff approach Temperature	16	Individualized care Staff/volunteer language	12	Resident to resident interaction	30
9	Environment for special needs	15	Communication/hearing of residents	11	Medication/drugs	23

having homes with such design features as dead-end corridors, visible exits with no access, or movable objects in residents' paths.

While families and staff groups generally seemed to stress the same items, it also became apparent during the data analysis that families also differed qualitatively on some items. For instance, some family groups highlighted the role of medication and its side effects in creating disruptive behaviors as well as the sheer number of residents in the homes as some of the most important obstacles. In terms of facilitators, three of the family groups voted training as the top factor facilitating the management of behavior. In addition, more than half of the family groups also rated the need for privacy among the top five facilitators. One last qualitative difference between families and staff is the great importance staff placed on the inclusion of music as a facilitating factor and the great importance families placed on both the staff's and the residents' communication skills.

Table 3. Code categories in top nine ranks: facilitators

	STAFF GROUPS		FAMILY GROUPS		GROUPS – OVERALL	
RANK	CODE CATEGORY	WEIGHT	CODE CATEGORY	WEIGHT	CODE CATEGORY	WEIGHT
1	Staff approach	69	Ratio/ staffing levels	33	Staff approach	98
2	Homelike environment	59	Individualized care	30	Homelike environment	87
3	Individualized care	39	Staff approach	29	Individualized care	69
4	Music	28	Homelike environment	28	Rules	48
5	Staff Consistency/ continuity	27	Rules Privacy	27	Ratio/ staffing levels	47
6	Generalized activities and stimulation	23	Staff training	26	Staff Consistency/ continuity	44
7	Staff flexibility	22	Mixed needs	20	Staff training Privacy	40
8	Rules	21	Staff Consistency/ continuity	17	Staff flexibility Generalized activities and stimulation Music	36
9	Safe supervised environment	17	Generalized activities and stimulation	16	Family involvement	26

Discussion

Both families and staff agreed that there are facility, staffing, and resident factors to consider when creating optimal environments for individuals with moderate to advanced dementia when behavioral disturbances are a concern. Social environments were perceived to be more important than the physical environments, and flexibility in these environments was perceived to be essential. The results of this study suggest that individuals with moderate to advanced dementia manifesting disruptive behaviors would best be suited in a home that offers a homelike environment with minimal barriers, a certain degree of privacy to residents, and, above all, a minimal level of noise. The administration and staff should make every effort to adapt the environment to the residents' individual characteristics, thereby reducing the chances of eliciting disruptive behaviors and this escalating to unmanageable levels. According to the participants in this study, funding would need to take into account appropriate staff/resident ratios, flexibility in the application of government and administrative rules and regulations, consistent assignment of staff to residents, staff training, and an approach that is appropriate for this population (e.g. using facial expressions, therapeutic touch, non-threatening language). To facilitate this work, the ideal home would not only have a high staff-to-resident ratio but also a manageable number of residents overall. Lastly, those residents who do not have cognitive challenges would not be living in the same units as residents with dementia. A

Table 4. Mnemonic for remembering the most important environmental factors (C.A.R.E.F.U.L.)

ELEMENT	APPROACH
C: Consistency	As much as possible, provide a consistent staff assignment for residents. Despite residents' cognitive impairment, the familiarity of the human environment seems to give individuals with dementia a better sense of well-being.
A: Approach	Train staff members to use therapeutic approaches such as following the lead of resident-initiated conversation and actions, smiling, showing respect, giving gentle care, facing the residents when speaking to them, not surprising the residents, knowing when to back off and when to use touch, etc.
R: Ratio of staff to residents	Non-pharmacological behavioral management techniques are only possible when staff/resident ratios are appropriate. Staff members who have to care for an overwhelming number of residents are unable to use the techniques necessary to alleviate residents' anxieties.
E: Environmental design	Many of the participating homes were designed with the specific purpose of offering a homelike environment with few physical barriers. Creative environments that feel like home set the stage for positive social interactions.
F: Flexibility	Allow flexibility in residents' schedules and allow staff to interact freely with residents, regardless of their professional roles.
U: Understanding	Staff members should get to know the residents' unique life histories as well as they can. This helps in identifying behavioral triggers and activities that are tailored to the residents' likes and dislikes and their unique psychosocial needs.
L: Level of noise	Individuals with dementia do not like abrupt environmental changes and noise can be a very disruptive stimulus in this regard. It is important to keep noise levels down to tolerable levels.

mnemonic – C.A.R.E.F.U.L. – was developed to help summarize the key elements that emerged from this study (Table 4).

The study adds to the already large body of literature on the role of the environment and its influence on behavior and quality of life of individuals with dementia in long-term care homes. Our results support a review of the literature on non-pharmacological interventions in dementia (Cohen-Mansfield, 2001), and more recently, a study on the relationship between environment and neuropsychiatric behaviors (Zuidema *et al.*, 2010). Beyond caring for the physical needs of the residents, the literature suggests that social contact and meaningful activities are important foci for intervention in dementia care environments. This is not possible without sufficient staff numbers or without the assistance of volunteers. Cohen-Mansfield (2001) found evidence to support the use of modeling to engage residents in the use of environmental stimuli. When engagement in these activities was affected by noise levels, indicating that residents are indeed influenced by their environments, residents interacted more with objects such as stuffed animals, squeeze balls, magazines, or folding towels when modeling of the activity occurred. Human interaction is important to help residents make sense of their environment. Physical environments are indeed only part of the story (Schwarz *et al.*, 2004). In short, choosing a residence that is beautiful but understaffed may be less desirable than one that is less visually pleasing but has more individuals present contributing to care.

Staff and family participants in this study were not restricted *a priori* in what they chose to identify as environmental factors affecting behavior and quality of life. They came from large, small, traditional, innovative, French, and English units. They came from homes in different cities and had different roles within the homes. Yet, despite this heterogeneous sampling, after approximately four to six groups, we saw the same concepts emerge. Having mentioned many physical environmental factors during the nominal focus group discussions, when asked to select the most important elements, the choices of staff and family participants reflected factors mostly related to the social environments. It is intuitive to think that small, homelike environments would positively affect behavior and quality of life, but a review by Verbeek *et al.* (2009) found no overwhelming support for designing small living facilities. When compared to facilities with ward-like designs, they were unable to find convincing evidence to support the design of small-scale facilities to improve quality of life in residents. The majority of the participants in our study were associated with centers that included special design features but some were involved with homes that had more traditional designs such as those with multi-purpose rooms. Yet the discussion in all groups was focused on staff approach rather than the existence of small, cozy alcolves or wing-back chairs. Fleming and Purandare (2010), in reviewing the literature on long-term care for people with dementia, also found no support for size of residences but did find support for other physical features such as few physical barriers.

It was our experience that administrators of residential units for persons with dementia often refer to these dwellings as homes. Aminzadeh *et al.* (2010) explored the notion of home with individuals with dementia as they were contemplating being relocated to collective dwellings. They found that leaving their "home" meant leaving a repository of memories, a place where life was familiar and consistent, where they could express their personal interests, their achievements, their status, where they could connect with others and socialize, where they felt competent and could engage in meaningful activities. It was a place where they could be free and have choices. While some of these features can be achieved in long-term care environments, the perceptions of family and staff confirmed the importance of these elements in creating a sense of home. People who live in your home do not constantly change. They usually know you well and do not wear uniforms. Noise levels are kept to a reasonable level and there are no rules for when you must eat or take a bath.

The current results also highlight the importance of systemic changes to help improve quality of life in these homes. Much of the literature to date has placed a great deal of emphasis on the local changes that can be made in the homes themselves. Some of the items highlighted in the current results and supported by others suggest more systemic changes and interventions. The emphasis on social environments and individualized care begs for innovative funding formulas that place equal emphasis on the resources needed to manage behaviors as to those needed for more physical demands such as transfers and mobility. While it is challenging for governments to find more money for publicly funded facilities, emerging initiatives geared towards the redesign of funding allocations are to be encouraged. Similarly there is a call for more research on the regulations pertaining to these homes and the ways they can be revised to allow staff and administration more flexibility in adapting the care to the ever-increasing population with dementia. Last but not least, there is a strong message from the current results to support studies on the precursory role of physical environmental design that will support social design. The results of the current study suggest that it may be pointless simply to physically redesign our long-term care homes for people with moderate to advanced dementia without attending to the social design of these homes.

Strengths and limitations of the study

One strength of the current study is the purposive sampling of units, which included participation from three different cities, Anglophone and Francophone units, traditional and specialized dementia units, and participants in various roles. While it might be considered a study limitation that all categories of staff, including nursing, personal care staff, and housekeeping, participated in the staff nominal focus groups, we were careful not to include individuals with administrative responsibility over other members in the group. Despite this, some participants may have felt that some members had more power and may have felt they needed to be silent during the discussions. Contrary to more traditional focus groups, the procedure adopted in the current nominal focus groups allowed for each participant to rank confidentially, without undue influence, what they considered to be the most important elements improving and hindering behavior and quality of life. Every individual therefore influenced which factors were included in the top nine. The wide range of participants involved in this study increases the transferability of our findings to other long-term care units (Creswell, 1998).

Despite attaining data saturation (Strauss and Corbin, 1990) after approximately six groups, we continued to investigate using an additional nine groups. The additional nine groups added variation in the participants, as it was in these groups that we recruited Francophones as well as families and staff from more traditionally designed homes. A notable strength of this study is the consistency of the results between families and staff about the most important environmental factors. Another strength of the study is the triangulation of investigators (Denzin, 1989). The first four investigators participated in the coding and recoding the nominal focus group data. This contributed to the rigor of the study. The coherence of the results, combined with the results in the literature, offer clear direction for future research targeting interventions to improve resident outcomes.

While the current study brings certain added strengths, it is not without limitations. It is not possible from the current results to identify which of the top rated environmental factors would be the most effective in reducing the behavioral manifestations of dementia experienced in these homes. The study did not permit a pre- and post-design and control of each of the environmental factors. The data are the results of perceptions rather than objective outcomes. This being said, the design and results do allow us to identify avenues of future research.

For instance, this study calls for an attention to the noise that residents are exposed to in nursing home settings. We were unable to find a single scientific article focusing specifically on the effect of noise on the behaviors of individuals with dementia in long-term care. A recent web-based seminar by the Alzheimer Knowledge Exchange (2011) stressed the importance of different types of noise and offers some suggestions for reducing the level to help foster better care. There remains, however, a dire need for scientific evidence that the impact is real and that reducing noise will lead to less disruptive behavior.

Conclusion

The results of the study indicate that specialized physical design features can be useful for maintaining quality of life and reducing disruptive behaviors, but they are not sufficient. Although they can ease some of the anxieties and set the stage for social interactions, our evidence suggests that individuals who make up the human environment of the residents (i.e. staff members and visitors) are just as important in promoting the psychosocial well-being of residents. Staff members play a key role in shaping the environment in which residents live. In designing environments for individuals with advanced dementia, we must have a facilitating physical environment, trained staff, and flexible organizational rules that will allow the staff to put into practice what they have learned through training.

We encourage policy-makers to devise new funding schedules that will take into account the psychosocial care so desperately needed by the population of individuals with advanced dementia. We recommend using the mnemonic C.A.R.E.F.U.L. to remember the factors needed to create a social environment within long-term care facilities. As their numbers will increase despite the system shift towards care at home, attention to the C.A.R.E.F.U.L. design elements will enable individuals with dementia to experience the best quality of life possible while reducing the care load on both formal and informal caregivers.

Conflict of interest

None.

Description of authors' roles

L. Garcia, M. Hébert, and J. Kozak were the principal investigators and designed the study following consultations with S. Slaughter, F. Aminzadeh, W. Dalziel, J. Charles, and M. Eliasziw. All three principal investigators guided the phases of the project. I. Sénécal coordinated the entire project and was directly involved in ethics applications and focus groups data collection and analysis. All authors attended group meetings to guide the project, provided feedback on the written product, and read and approved the final paper.

Acknowledgments

The authors thank the funders of this study: the Alzheimer Society of Canada, the Alzheimer Society of Ottawa and Renfrew County, the Canadian Institutes of Health Research, and the University of Ottawa. We also thank the staff and families of the eight residential care units for their thoughtful insights.

References

Alzheimer Knowledge Exchange (2011). *Dementia-Friendly Design Considerations: Noise*. Toronto: Alzheimer Knowledge Exchange. Available at: http://www.akeresourcecentre.org/files/Design/Noise%20K2P%20Physical%20Design%20V6.pdf.

Alzheimer Society of Canada (2009). *Rising Tide: The Impact of Dementia on Canadian Society*. Toronto: Alzheimer Society of Canada.

Aminzadeh, F., Dalziel, W. B., Molnar, F. and Garcia, L. J. (2010). Meanings, functions, and experiences of living at home for individuals with dementia at the critical point of relocation. *Journal of Gerontological Nursing*, 36, 28–35.

Andrén, S. and Elmståhl, S. (2008). Effective psychosocial intervention for family caregivers lengthens time elapsed before nursing home placement of individuals with dementia: a five-year follow-up study. *International Psychogeriatrics*, 20, 1177–1192.

Brunelle, J. and Tousignant, M. (1988). Les techniques de prélèvement de perceptions en activité physique. In J. Brunelle, D. Drouin, P. Godbout and M. Tousignant (eds.), *La Supervision de l'intervention en activité physique* (pp. 179–186). Montréal: Gaétan Morin.

Chang, E. *et al.* (2009). Challenges for professional care of advanced dementia. *International Journal of Nursing Practice*, 15, 41–47.

Cohen-Mansfield, J. (2001). Nonpharmacologic interventions for inappropriate behaviors in dementia. *American Journal of Psychiatry*, 9, 361–381.

Creswell, J. W. (1998). *Qualitative Inquiry and Research Design: Choosing among Five Traditions*. Thousand Oaks, CA: Sage.

Denzin, N. K. (1989). *The Research Act: A Theoretical Introduction to Sociological Methods*, 3rd edn. Englewood Cliffs, NJ: Prentice Hall.

Ducharme, J. K. and Geldmacher, D. S. (2011). Family quality of life in dementia: a qualitative approach to family-identified care priorities. *Quality of life research*, 20, 1–5.

Duffin, C. (2008). Designing care homes for people with dementia. *Nursing Older People*, 20, 22–24.

Etters, L., Goodall, D. and Harrison, B. E. (2008). Caregiver burden among dementia patient caregivers: a review of the literature. *Journal of the American Academy of Nurse Practitioners*, 20, 423–428.

Ferri, C. P. *et al.* (2005). Global prevalence of dementia: a Delphi consensus study. *Lancet*, 366, 2112–2117.

Fleming, R. and Purandare, N. (2010). Long-term care for people with dementia: environmental design guidelines. *International Psychogeriatrics*, 22, 1084–1096.

Folstein, M. F., Folstein, S. E. and McHugh, P. R. (1975). "Mini-mental state": a practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, 12, 189–198.

Gaugler, J. E. *et al.* (2010). The effects on incident and persistent behavioral problems on change in caregiver burden and nursing home admission of persons with dementia. *Medical Care*, 48, 875–883.

Hallberg, I. R., Norberg, A. and Eriksson, S. (1990). A comparison between the care of vocally disruptive patients and that of other residents on psychogeriatric wards. *Journal of Advanced Nursing*, 15, 410–416.

Kverno, K. S., Rabins, P. V., Blass, D. M., Hicks, K. L. and Black, B. S. (2008). Prevalence and treatment of neuropsychiatric symptoms in advanced dementia. *Journal of Gerontological Nursing*, 34, 8–15.

Luppa, M., Luck, T., Weyerer, S., König, H.-H., Brähler, E. and Riedel-Heller, S. G. (2010). Prediction of institutionalization in the elderly: a systematic review. *Age and Aging*, 39, 31–38.

Marquardt, G. and Schmeig, P. (2009). Dementia-friendly architecture: environments that facilitate wayfinding in nursing homes. *American Journal of Alzheimer's Disease and Other Dementias*, 24, 333–340.

McMinn, B. and Draper, B. (2005). Vocally disruptive behavior in dementia: development of an evidence based practice guideline. *Aging & Mental Health*, 9, 16–24.

Pavlakovic, R. (2001). Management of behavioral disorders in the facility care setting. *Stride*, May/July, 21–24.

Reimer, M. A., Slaughter, S., Donaldson, C., Currie, G. and Eliasziw, M. (2004). Special care facility compared to traditional environments for dementia care: a longitudinal study of quality of life. *Journal of the American Geriatrics Society*, 52, 1085–1092.

Reisberg, B. (1988). Functional assessment staging (FAST). *Psychopharmacolgy Bulletin*, 24, 653–659.

Reisberg, B., Ferris, S. H., de Leon, M. J. and Crook, T. (1982). Global Deterioration Scale (GDS). *American Journal of Psychiatry*, 139, 1136–1139.

Schwarz, B., Chaudhury, H. and Brent Tofle, R. (2004). Effect of design interventions on a dementia care setting. *American Journal of Alzheimer's Disease and Other Dementias*, 19, 172–176.

Slaughter, S., Calkins, M., Eliasziw, M. and Reimer, M. (2006). Measuring physical and social environments in nursing homes for people with middle to late-stage dementia. *Journal of the American Geriatrics Society*, 54, 1436–1441.

Strauss, A. and Corbin, J. (1990). *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*. London: Sage.

Verbeek, H., van Rossum, E., Zwakhalen, S. M., Kempen, G. I. and Hamers, J. P. (2009). Small, homelike care environments for older people with dementia: a literature review. *International Psychogeriatrics*, 21, 252–264.

WHO (2011). *The World Health Report: Executive Summary*. Geneva: World Health Organization. Available at: http://www.who.int/whr/1997/media_centre/executive_summary1/en/index14.html.

Zeisel, J., Silverstein, N. M., Hyde, J., Levkoff, S., Lawton, M. P. and Holmes, W. (2003). Environmental correlates to behavioral health outcomes in Alzheimer's special care units. *Gerontologist*, 43, 697–711.

Zuidema, S. U., de Jonghe, J. F. M., Verhey, F. R. J. and Koopmans, R. T. C. M. (2010). Environmental correlates of neuropsychiatric symptoms in nursing home patients with dementia. *International Journal of Geriatric Psychiatry*, 25, 14–22.