

# Quality of life indicators in long term care: Opinions of elderly residents and their families

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## Key words

■ Quality of life ■ Aged ■ Long term care

## Mot clés

■ Qualité de vie ■ Personnes âgées ■ Soins de longue durée

## Abstract

**Background.** *There are very few studies that have integrated the opinions of nursing home residents and their families into the process of developing valid outcome measures for the quality of life in long-term care facilities.* **Purpose.** *The objective of this study was to identify the interpersonal and environmental characteristics for the best substitute living environment, as perceived by recently (< 6 months) and not as recently (> 6 months of residency) admitted residents and their families.* **Methods.** *A qualitative research approach was used with 27 elderly residents and families from five nursing homes.* **Results.** *Of the 11 quality of life indicators identified by the participants, the three most important ones were being treated with respect, sympathetic involvement in relationships, and perceived competency through technical (nursing) acts and attitudes.* **Practice Implications.** *As nursing home residents age, substitute homes have to adapt if they are to continue offering opportunities for self-actualization and a continuing sense of identity. Opinions of elderly residents and their families are very helpful for occupational therapists particularly when designing programs in long-term care facilities.*

## Résumé

**Description.** *Peu d'études ont intégré les opinions des résidents des établissements de soins prolongés et de leur famille au processus visant à élaborer des mesures des résultats valides de la qualité de vie dans les établissements de soins de longue durée.* **But.** *L'objectif de cette étude était de déterminer les caractéristiques interpersonnelles et environnementales des milieux de vie substitués les plus sains, telles que perçues par des résidents récemment admis (< 6 mois de résidence) et admis moins récemment (> 6 mois de résidence) et leur famille.* **Méthodologie.** *Une méthode de recherche qualitative a été utilisée auprès de 27 personnes âgées provenant de cinq établissements de soins de longue durée et leur famille.* **Résultats.** *Parmi les onze indicateurs de la qualité de vie ciblés par les participants au sondage, les trois indicateurs les plus importants étaient les suivants : être traité avec respect, avoir un sentiment de complicité dans les relations avec les différents intervenants et avoir le sentiment que le personnel effectue les actes techniques (soins infirmiers) avec compétence et démontre des attitudes exemplaires.* **Conséquences pour la pratique.** *Avec le vieillissement des résidents des centres d'hébergement, les milieux de vie substitués doivent s'adapter afin de continuer à procurer aux résidents des possibilités de réalisation de soi ainsi qu'un sentiment d'identité. Les opinions des résidents âgés et de leur famille sont très utiles pour les ergothérapeutes, en particulier lorsqu'ils conçoivent des programmes pour les établissements de soins prolongés.*

Over the last few decades, nursing home residents have been growing increasingly older and frailer, in keeping with the ageing trends that characterize the general population. Moreover, as they age, the number of areas in which they are dependant increases and the size of their social network decreases. Dementia afflicts more than 50% of residents 65 years of age and over who reside in nursing homes (Société canadienne d'hypothèque et de logement, 1999). Their substitute home has the task to accommodate to their different needs within a community life built around

different cultures. Seniors interact with many different health professionals daily, who transform the home into a workplace. Many residents die within the second year of stay (Ministère de la santé et des services sociaux, 2003). As many aspects of their lives change around them, maintaining their identity becomes more challenging, as does their personal growth. How can seniors maintain their autonomy and self-actualize while ageing in a substitute home? The most cherished desires of residents are very likely to preserve the best quality of life and to feel at home. Very few studies have con-



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sidered the opinion of residents and families in matters of daily living and preserving one's identity and in developing a valid outcome measurement that is applicable to the quality of life in nursing home settings.

Environmental reference models are increasingly adapted to the elderly living conditions and to parameters pertaining to nursing homes (Eckert & Murray, 1984; Heikkinen, 1995; Lemke & Moos, 1986). The present study used Bronfenbrenner's environmental reference model (1986) to take an in-depth look at two of the three fundamental concepts: (a) the interpersonal environment (or human environment), as defined as all the personal characteristics and interpersonal relationships; and (b) the physical environment, including physical layout, rules, code of ethics, programs and activities of daily living (ADL) routine. Personal factors (the third concept) are often collected as descriptive variables.

Many quantitative studies have pre-determined a range of quality of life indicators such as measures of verbal communication interaction (Sommer, 1970), well-being (Goldfard, 1977), participation level in social activities or engagement in the community (Chavis & Wandersman, 1990; Feingold & Werby, 1990; Heller, Byerts & Drehmer, 1984; Lawton, 1980; Normoyle & Foley, 1988) and integration in the community (Maltais, 1999). The risk of pre-determining indicators is to overlook key factors relating to quality of life that residents might never have a chance to express, except through participation in qualitative studies.

## Literature Review

In 1982, Bowker researched the subject of humanizing nursing homes in the United States. He analyzed over 300 hours of in-depth interviews and participant observations collected from residents, caregivers and care managers. He identified three categories of quality of life indicators: social relationships, environmental structure, and administrative politics and programs. However, the main focus of his data concerned the opinions of caregivers and care managers. Later, the Quebec Government set out health guidelines in the report entitled "Vers un nouvel équilibre des âges" [Toward a new balance of ages] (Gouvernement du Québec, 1991). A working group of experts identified five general quality of life indicators for nursing home residents: identity, control, intimacy, security and comfort. Also, two studies identified quality of life indicators using qualitative methods with in-depth interviews of nursing home residents. Loiseleur et al. (1997) identified the following quality criteria in short-term geriatric units: staff competence and interpersonal qualities such as kindness, respect, dedication and patience. A recent study in China explored quality of life indicators in nursing homes from the residents' point of view. Interviews with 10 residents and participant observations lead to seven groups of quality of life indicators: environment, professional competence,

quality assurance, basic human rights, direct care attitude, social interaction, and needs satisfaction (Yang & Shyu, 2001).

These qualitative studies do not provide a sufficient number of specific indicators with which to make modifications to the environment and provide a sense of control, continuous identity, privacy, security and comfort (Jonsen, Siegler, & Winslade, 1986). Furthermore, the studies are often based on experts' opinions (Gouvernement du Québec, 1991) which frequently differ from those of residents. In some studies (Yang & Shyu, 2001), the methodological decisions have not been completed with sufficient scientific rigour in terms of the criteria for qualitative research. Also, none of the studies included family caregivers and residents suffering from dementia, or compared the opinions of recently admitted residents with those of long-term residents, using an environmental reference model as a guide for the whole research process. Finally, the current literature deals with the evaluation of quality of care indicators in nursing homes (Berg et al., 2002; Saliba & Schnelle, 2002).

The main objective of this study was to identify interpersonal and environmental characteristics that describe the best substitute living environment as perceived by recently and less recently admitted residents (less than or more than 6 months of stay, respectively) and their families. Specifically, the objectives were to:

- a) Identify and organize a hierarchy of characteristics for the best substitute living environment.
- b) Identify divergent opinions between residents and families.
- c) Compare the lists of characteristics identified by recently and less recently admitted residents.

## Methods

This study used a qualitative approach with semi-structured interviews, use of verbatim transcripts and content analysis. The inclusion criteria were the following: over age 65, ability to communicate (according to caregiver's knowledge of the resident) and ability to recognize at least a few people from their environment. After identifying the eligible participants, the nurse in charge of the units randomly selected 30 residents and 15 family caregivers based on the date of admission. Lofland and Lofland (1984) suggested that with a questionnaire of about 10 questions, the sample size should be 20 to 35 participants (i.e. when no more new data could be extracted from the verbatim transcript of the interviews). Data saturation was obtained with a final sample size of 27 participants.

The semi-structured questionnaire was written according to the suggestions of Patton (1990), and Kaufman (1994) concerning the sequence of an interview with an older person. The first part, which served as an introduction, contained questions on life experiences and daily activities. The

TABLE 1  
Socio-demographic description of participants

|                             | Age            | Gender |      | Educational level    | Length of stay          |                         | Cognitive status <sup>†</sup><br>MMT/30 | Parental link   |
|-----------------------------|----------------|--------|------|----------------------|-------------------------|-------------------------|---|---|
|                             |                | Female | Male |                      | More Than<br>Six Months | Less Than<br>Six Months |   |   |
| <b>Residents<br/>(n=19)</b> | 82,5*<br>(8,5) | 14     | 5    | 7, 6 years*<br>(3,5) | (n=11)                  | (n=8)                   | 25,0*<br>(4,9)                          |   |
| <b>Families<br/>(n=8)</b>   | 66 **          | 6      | 2    | 11 years**           | (n=6)                   | (n=2)                   |   | 3 daughters<br>2 spouses<br>1 friend<br>1 sister<br>1 brother |

**Diagnoses of main residents:** Dementia : 5, Frailty : 4, Multiple sclerosis : 3, Stroke : 3, Macular degeneration : 3, Blindness : 2, Femoral amputation: 1, Paget's Disease: 1, Obesity : 1, Parkinson's Disease : 1

\*: mean and standard deviation

\*\* : median

†: Mini Mental State Examination (Folstein & Folstein, 1975).

second part included general and specific core questions. Some of the key questions were repeated but worded differently and presented to the interviewee at different times during the interview to ensure as complete an answer as possible. The majority of the questions were open-ended except for the last ones involving socio-demographic data. The project was approved by the Ethics Committee of the Université Laval.

An initial draft of the questionnaire was used with two residents and one family caregiver. As a result of this pilot testing, the wording of a few questions was altered, the selection criteria of the analysis units were further refined, contextual factors influencing the validity of the information collected during the interviews were identified, and, finally, procedures of analysis were given additional focus for the two analysts (the principal investigator and a research assistant specialized in qualitative analysis).

The main investigator conducted the interviews and took notes regarding the contextual factors of the interviews

in a diary. This diary has been useful for analyzing and validating procedures. The data were first analyzed by reading each verbatim transcript and by listening to the tapes. Once a few interviews were complete, the vertical analysis procedures began. They included four steps as proposed by Gubrium and Sankar (1994): preparation of material (units identification), codification, themes identification and validation. NUDIST software was used to facilitate the data management (Qualitative Solutions and Research Pty Ltd, 1996).

Lincoln and Guba's work (1985) guided the strategies chosen to ensure rigour. The strategies included credibility, transferability, reliability and confirmability. Different data collection procedures assured that these criteria were complied with and presented to three different groups of people (residents, families and care managers) which served to enhance the accuracy of the results. Triangulation of the analysis procedures was performed with a specialized research assistant. Triangulation of the validity of the results was completed by presenting the results to an additional two residents.

TABLE 2:  
Residents' and family caregivers' opinions on human environment

|                          | Opinion of/about   |   |  |  |
|--------------------------|--|---|--|--|
|                          | Peers  | Family caregivers   | Care managers and Caregivers   | Health professionals   |
| <b>Residents</b>         | Taking care of others, feeling of being part of a group, sharing good times, maintaining respectful relationships, admiring others, gossiping. | Being supported physically and emotionally, keeping a sense of continuity by their parental role. | Feeling loving care, reciprocity in relationships, devotion, respect and compassion.                         | Presence, transparency, open-minded, confidence toward the residents, affective security from the community counselor. |
| <b>Family Caregivers</b> | Needs the presence of cognitively intact residents, needs to volunteer.  | Needs to decrease emotional stress and guiltiness.  | Feeling of availability, competence, good willingness, loving care, complicity in relationships and respect. | Presence, open-minded.   |

TABLE 3

Residents' and family caregivers' opinions about physical and institutional environment

|                          | Opinion of/ about   |  |  |   |
|--------------------------|---|--|--|---|
|                          | Organizational structures and external links  | Material and human resources   | Programs and activities  | Architectural environment   |
| <b>Residents</b>         | Need of feeling emotional security by seeing the care managers, need of feeling the "outdoor life". | Need to never feel the financial restrictions but the availability of the caregivers and health professionals. | Having occasions of self-actualization.                          | Having access to adaptive ADL facilities.   |
| <b>Family Caregivers</b> | (no concern)  | Need to never feel the financial restrictions but the availability of the caregivers and health professionals. | Having access to welcoming activities and spirituality services. | Having access to extra rooms and spacious private rooms including facilities, Need of a cleaned and friendly environment. |

## Results

The interviewees included 19 residents and 8 family caregivers. The mean age of the residents was 82.5 and most of the participants were women. Eleven residents had a length of stay greater than 6 months and 5 of the residents suffered from dementia (see Table 1).

Table 2 presents the residents' and the families' opinions on the human environment. Individuals provided their opinions on the people who were part of their daily lives such as their peers, families, caregivers, care managers and other health professionals. They were asked questions such as "What are the qualities of the best caregiver?" The residents expressed many concerns about their peers while the families expressed concerns about the caregivers. According to the residents, the human environment should give them an opportunity to share enjoyable moments, take care of others,

feel like part of a group, feel respect within a relationship, admire others, and even to gossip. Families stressed the availability of the caregivers, good will, helpfulness, loving care, sympathetic involvement, reciprocity in relationships, competence, and respect. In one example taken from the verbatim transcript, it is clear that some residents would like to see a nurturing role enacted toward or around them. The following quotation was provided by a resident with moderate dementia: "Giving care to someone, it's a kind of love, and we received as much as we give. I know that, because that's what I did all my life" (Resident No. 10). Families also emphasized the need to feel that caregivers are available: "A good caregiver is the one who pays attention to the resident's needs, listens, gives exclusive time to the resident and leaves personal problems at home" (Family No. 1).

Residents and families identified other characteristics concerning the physical and institutional environment

TABLE 4:

Hierarchy of the main characteristics of the best substitute home as perceived by residents and family caregivers

| Interpersonal characteristics   | Environmental characteristics   |
|---|---|
| 1) Feeling respect of the residents' identity (needs, interests, habits, capacities) from the caregivers. |   |
| 2) Feeling complicity in relationships between caregivers, residents and families.                        |   |
| 3) Appreciating the caregivers' competence within attitudes and daily technical acts.                     |   |
| 4)  | Having easy access to a private room with facilities and extra spaces to use, besides the room. |
| 5) Feeling compassion and affective support.  |   |
| 6) Maintaining a role in the community.   |   |
| 7) Sharing good times, laughing, playing, teasing with peers, families and caregivers.                    |   |
| 8) Preserving the sense of control.   |   |
| 9)  | No feeling of financial restrictions.   |
| 10)   | Staff stability.  |
| 11)   | Having access to hobbies, leisure and spirituality resources.                                   |

including the organizational structure, material and human resources, programs and activities, physical layout and external links (see Table 3). Residents spent most of the time talking about the resources; families spoke about the physical layout of the nursing home. For example, residents said that the new financial restrictions should not be visible: "In the last few years, the needs have increased and the financial resources have decreased. The nursing home is no longer adapted to the elderly who were either very ill or impaired. It is difficult for the staff and for us too, you know" (Resident No. 13). Family caregivers said large extra spaces, private rooms and programs are important: "It is important for my mother to know that she has access to a lot of activities, including the chapel. Usually, she goes every Sunday morning, it's important for her" (Family No. 7).

Finally, Table 4 presents the interpersonal and environmental characteristics on a scale from most to least important, combining the opinions of residents and family caregivers. The relative importance of the characteristics was determined in two ways: by counting verbatim comments related to each characteristic and by the ranking given to each characteristic by the participant. Interpersonal characteristics are the most detailed and included: feelings of respect, involvement, reciprocity in relationships, and competency through technical (nursing) acts and attitudes.

The objectives of the study also included comparing the residents' and family caregivers' opinions mainly by identifying differences. Families prioritized the non-human environment while residents spoke more frequently about relationships. "If there is not enough space in her room, she can not move easily with her wheelchair. The private room is very important, she spends her entire day in the room" (Family No. 3). "What I like the most is when she (another resident) comes to visit me. She asks me questions about my health and my problems" (Resident No. 17).

The final results concern the comparisons between the opinions of recently and less recently admitted residents (<6 months and >6 months of stay respectively). Newly admitted residents said that it is important to feel helpful for the community, as one resident said: "I feel ashamed to be useless" (Resident No. 6). One of them also mentioned the importance of meeting a more recently admitted resident as a way of helping him: "I would like to be introduced to the very new ones to help them" (Resident No. 16). In comparison, a less recently admitted resident said: "See what time it is now, I am still undressed, I do not like to rush in the morning, and take care of myself" (Resident No. 12).

## Discussion

Occupational therapists are aware of the importance of quality of life indicators. This qualitative study identified the relationships and physical environment characteristics that are most important to residents and family caregivers respectively. It

highlights the fact that elderly people like everyone else, need to feel they are still alive, growing and part of community life. The 11 characteristics for the best substitute living environment as identified by the 27 participants could be considered the most useful quality of life indicators for outcome measures. Although families do not live in nursing homes, they talked about what they observed during their visits. They are concerned about relationships, but the environment seems more important to them than to the residents. New residents continue to attempt to adapt to community life in care facilities and need to feel a sense of continuity. Once they are admitted to a nursing home, any change may cause a weakening of their identity. Residents of long term care facilities need to feel that they still have the same identity which will facilitate their growth.

These results are very similar to those obtained in previous studies, but they provide more tangible details about the indicators frequently used for the quality of life concept in long term care. For one, according to Frijters et al. (2001), the more the residents are committed to the community, the better their quality of life is. Green and Cooper (2000) indicated that residents' quality of life is greatly influenced by the role each one plays in non-traditional activities.

The results have a strong internal validity because of the control of the scientific criteria of credibility, transferability, dependability and confirmability. The information collected is exhaustive, because data saturation was obtained with the five nursing homes, validation was done with additional participants, and useful notes were taken after each interview. The study was guided by a reference model for the data collection and analyses. Finally, until now, no study has considered the opinion of the residents with dementia as valid information. Mozley et al. (1999) also confirmed that a high proportion of elderly people can answer questions about their quality of life, even in the presence of significant cognitive deficits. However, another type of validation could have been performed by using a validation method based on two extreme cases: one case with a very well-adapted resident and another one with a resident with adaptation difficulties. Not only would this type of validation have enhanced the quality of the research, but it would also have made it possible to further explore the process of adapting to a substitute environment.

The concept of quality of life has been studied by Voyer and Boyer (2001). They compared different types of quality of life assessments in order to clarify the concept. This included the type of measure, type of evaluation and time factor. According to these authors, quality of life is defined by the general feeling of well-being, the satisfaction of needs, a favourable objective evaluation on the life conditions from another person, and no mental disease symptoms. With respect to this definition, our results focused only on the subjective and affective evaluation of quality of life. For this reason, our consideration of the quality of life concept may



represent a limitation of the study. However, these authors confirm the influence of time on the perception of the concept, since evaluation criteria for quality of life appear to change once a resident has begun adapting to his or her environment.

Finally, when Conyne and Clark (1981) studied the quality of life concept in relation to the environment, they strongly emphasized the sense of community component. This component reflects the values, beliefs, politics and attitudes governing the community life (Chavis & Wandersman, 1990; Zaff & Devlin, 1998). Timko and Moss (1991) and Pretty (1990) call it the ecological climate, which is sometimes used to temper the perceptions that residents have on their environment. This recent concept seems to stand in very close relation to quality of life, and it should be promoted within the daily life in long term care. Occupational therapists have an important role when promoting characteristics of the optimal ecological climate in nursing homes.

The results of the current study demonstrate the importance of humanization in nursing homes. Since the residents spend some of the most important years of their lives in nursing homes, managers and clinicians should orient their services towards respecting the residents' opinions. Nursing home residents still report lower quality of life than do elderly individuals living in personal dwellings and specialized housing (Crist, 2000). There is a need to develop a sense of community specifically suited to a substitute living environment that encompasses caregivers and families, and respects each person in their engagement of life. Since the results give a better description of the elderly residents needs, occupational therapists can be more aware of what is valuable to their clients who they work with in long-term care. The results can also guide further evaluative research as the eleven characteristics have shown to be valid quality of life indicators.

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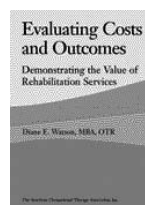


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