

Quality of Life in Dementia: Do Professional Caregivers Focus on the Significant Domains?

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The domains of quality of life that are considered important by people with dementia and professional caregivers are not in agreement. This explorative study addresses the question, "To what degree do professional caregivers, in their daily working routine, focus on the quality-of-life domains that people with dementia consider essential?" Study participants were nursing assistants who work in 24-hour nursing home care and professionals who offer daytime activities. Three hundred and seventy-four caregivers working on 29 units and 3 day care facilities of 13 nursing homes and in 12 meeting centers filled out a

questionnaire. The caregivers reported to focus at least to some degree on most domains considered important by people with dementia. However, relatively little attention was paid to "financial situation" and "being useful/giving meaning to life." Professionals who offer daytime activities focused more than 24-hour care staff on "attachment," "enjoyment of activities," "sense of aesthetics," and "being useful/giving meaning to life."

Keywords: quality of life; dementia; professional caregivers

Evaluating quality of life in people with dementia has become increasingly important, for example, in assessing the effectiveness of interventions or making treatment decisions.¹ The dementia-specific quality-of-life approaches on which these assessments are frequently based²⁻⁴ usually include a variety of domains that may be affected by the dementia.⁵ For instance, Brod et al.² found the following domains to be of importance: physical functioning, daily activities,

discretionary activities, mobility, social interaction, interaction capacity, bodily well-being, sense of well-being, sense of aesthetics, and overall quality of life. Logsdon et al.³ selected the following other domains: physical health, energy, mood, living situation, memory, family, marriage, friends, self, ability to do chores, ability to do things for fun, money, and life as a whole. Furthermore, Rabins et al.⁴ included social interaction, awareness of self, enjoyment of activities, feelings and mood, and response to surroundings (see reference 5 for an extensive overview of quality-of-life approaches).

This variation may result from the different sources of information that were used by the researchers. Brod et al.² used 3 separate focus groups of people with dementia, their caregivers, and care professionals to develop their conceptual framework. The domains included by Logsdon et al.³ were primarily based on a review of the literature on quality of life in older and chronically ill adults. Their resulting measurement instrument (the QOL-AD) was reviewed by people with dementia, their caregivers, and clinical experts. Rabins

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et al.⁴ also involved caregivers and clinical experts at a later stage but did not consult persons with dementia. The publications on these approaches do not clarify which domains of quality of life were considered important by the different focus groups, whether they agreed on the relevant domains of quality of life, and what the final selection of domains was based on.²⁻⁴ Depending on the extent to which the groups disagreed, one can question whether the choices that were made do them justice, and whether it makes sense to search for the common denominator (which renders differences between parties invisible) (see also references 6 and 7).

The differences in the selected domains of the dementia-specific approaches were addressed in an earlier article by the working group Quality of Life in Dementia.⁸ It reported on an explorative study into what extent the domains that people with dementia consider important for their own quality of life, coincide with what professional caregivers think that people with dementia consider important, and how both relate to the models and measurement instruments for quality of life in dementia as described in the literature.

First, an overview was obtained of the domains of quality of life included in current conceptual approaches and measurement instruments for quality of life in dementia. Second, in order to gain a general impression of what people with dementia and their caregivers consider important for quality of life in dementia, focus groups were conducted with persons with dementia and professional caregivers separately. Their answers were categorized into domains by a multidisciplinary group of 10 experts in the field of psychogeriatrics, on the basis of the above-described overview of quality-of-life domains. For aspects that could not be categorized into the existing domains, new domains were introduced. The domains that were mentioned by people with dementia were affect, self-esteem, attachment, social relations, enjoyment of activities, sense of aesthetics, physical and mental health, financial situation, security and privacy, self-determination and freedom, being useful/giving meaning to life, and spirituality (Table 1). Most of the quality-of-life domains that were considered important by the persons with dementia were also mentioned in the literature, and by the professional caregivers. A few domains, however, were not included in the existing dementia-specific quality-of-life approaches and instruments, that is, "security and privacy" and "self-determination and freedom." Domains that were mentioned by people with dementia but were not brought

up by the professional caregivers are "sense of aesthetics," "financial situation," and "being useful/giving meaning to life." Moreover, although not investigated in the study described above, research in nursing homes has shown that various stakeholders involved in nursing home care attach different levels of importance to a given set of quality-of-life domains.⁹

These differences can create a discrepancy between what the person with dementia considers important for his or her quality of life, and what professional caregivers focus on in actual practice. Thus, it is essential that professional caregivers are aware of these possible discrepancies. A caregiver who is aware of the limitations of her[†] own actions may be able to address new domains or involve and stimulate other caregivers to do so. If caregivers are able to jointly remove the discrepancies, the care they offer will be more in line with what the person with dementia considers important for his or her quality of life. Especially nursing assistants in 24-hour care and activity professionals are significant in this respect. They have the highest potential to contribute to quality of life, since they have the most intense and regular contact with people with dementia and may focus on different domains because they have different tasks in the care process.^{10,11}

The above resulted in the central question of this explorative study: To what degree do professional caregivers, especially those who have the most contact with people with dementia, that is, 24-hour care staff and activity professionals, in their daily working routine, focus on the quality-of-life domains that people with dementia consider important? A second question was: Do the 2 disciplines (24-hour care and activities) differ in the domains of quality of life they focus on in daily practice?

Methods

Design and procedure

In this explorative study, a questionnaire (Table 1) was distributed among all 24-hour care staff and activity professionals working at 29 psychogeriatric units and in 3 psychogeriatric day care centers of 13 nursing homes, and in 12 meeting centers for people with dementia and their informal caregivers in the Netherlands.

[†]As female professional caregivers are in the majority, caregivers are referred to in the feminine form to simplify reading. Of course, male caregivers are also included.

Table 1. Questionnaire on Quality of Life in Dementia That Was Administered Among the Professional Caregivers

In my work with people with dementia I focus on:	Circle the answer that applies to you					
	Not applicable	To a very limited degree	To a limited degree	To some degree	To a high degree	To a very high degree
1 Affect This means that people with dementia can express their feelings, positive as well as negative. Humour, cheerfulness, sorrow, feelings of loneliness.	0	1	2	3	4	5
2 Self-esteem/ self-image This means they feel appreciated, accepted, and respected. Being able to be themselves.	0	1	2	3	4	5
3 Attachment This means they feel involved in the things around them. Feel understood. Experience the environment as familiar.	0	1	2	3	4	5
4 Social relations This means they can have social relations with family, friends, and others; love; intimacy.	0	1	2	3	4	5
5 Enjoyment of activities This means they can do things they enjoy.	0	1	2	3	4	5
6 Sense of aesthetics in living environment This means that they can enjoy nature, (classical) music, or art, etc.	0	1	2	3	4	5
7 Physical and mental health This means that their physical disabilities bother them as little as possible; that they feel healthy and fit.	0	1	2	3	4	5
8 Financial situation This means they have no money worries.	0	1	2	3	4	5
9 Security and privacy This means they experience the (living) environment as safe, with sufficient privacy and care.	0	1	2	3	4	5
10 Self-determination and freedom This means they determine as much as possible what they do and when they do it.	0	1	2	3	4	5
11 Being useful/giving meaning to life This means they can be of use to others, see a purpose to life.	0	1	2	3	4	5
12 Spirituality This means they can experience their religion.	0	1	2	3	4	5

The Meeting Centers Support program offers information and support to people with dementia by means of a social club in community centers on 3 days a week. Simultaneously, their informal caregivers are offered 8 to 10 informative meetings and a biweekly, long-term discussion group. Both patients and caregivers can visit the weekly consulting hour and participate in social festivities and excursions. Support is supplied by a small professional staff (eg, a psychologist, an activity therapist, and a nursing assistant). Based on a cooperation protocol, they work together with the professional care and welfare services in the neighborhood that are involved with persons with dementia, for example, the general practitioner, the community worker, home care services, and the nurse or psychiatrist of the Regional Community Mental Health Care Organization.

Psychogeriatric day care in The Netherlands is usually offered on separate units in nursing homes that specialize in offering care to people with dementia. Treatment is offered by multidisciplinary teams in which the social, psychological, paramedical, and medical disciplines are represented. Treatment is comparable with the support offered to the persons with dementia in the Meeting Centers Support Program and varies from social activities to reality orientation training, reminiscence, validation, psychomotor therapy, and music therapy. If necessary, medical care, physiotherapy, or occupational therapy are offered.¹²

Of the 13 nursing homes, 6 were situated in the urbanized western part of the country and 7 in the more rural eastern part. The 12 meeting centers were situated in the western, central, northern, and eastern areas of the country.

Participation in the study was voluntary. Members of the working group Quality of Life in dementia of the Leo Cahn Foundation requested the cooperation of the professional caregivers at the nursing homes and meeting centers where they work and distributed the questionnaires personally to the units, day care centers, and meeting centers. In order to establish a satisfactory response rate, respondents were repeatedly reminded of the questionnaire in staff meetings.

Instruments

Starting from the domains of quality of life that are considered important by people with dementia as investigated in earlier research⁸ (Table 1), the working group Quality of Life in dementia designed a questionnaire to register for each domain the degree to

which professional caregivers actually focus on this domain in their daily working routine. To operationalize the different quality-of-life domains, the exact words and examples mentioned by people with dementia with respect to those domains were used.⁸ The goal of the questionnaire was clarified in the accompanying instructions, which emphasized that the respondent should indicate the specific focus of her care-giving activities, rather than the domains she considered important for quality of life in dementia in general. The respondent could indicate on a 5-point scale whether in her work she focuses on the domain to a very limited degree (1), a limited degree (2), some degree (3), a high degree (4) or a very high degree (5). The item was scored (0) if the respondent felt the domain was not applicable in her work.

Analyses

For each quality-of-life domain the mean score was calculated, specifying the degree to which 24-hour care staff working on psychogeriatric residential units in nursing homes on the one hand, and professionals who offer daytime activities at psychogeriatric nursing home units, day care, and meeting centers on the other hand, indicated they focus on it in their daily work.

Results

A total of 374 of the 793 distributed questionnaires were filled out (a 47% response rate). Only 16 of the possible 4488 answers were missing (0.37%). Ninety-five percent of the respondents were female, and the mean age was 38 (range 17-62). The mean number of years of experience working as a caregiver for people with dementia was 11 (range 0-38). The mean amount of hours worked per week was 26 (range 4-40).

The respondents were grouped. The first group, the 24-hour care group, consisted of 280 members of nursing staff who work in 24-hour care. They were all some type of nursing assistant (nursing assistant, $n = 153$; primary responsible nursing assistant, $n = 60$; assistant, $n = 44$; trainee/student, $n = 6$; and team leader, $n = 17$). The second group, the daytime activities group, consisted of 76 professionals who provide activities. Forty-one of them were activity therapists, 25 were nursing assistants, 8 were program-coordinators, and 2 were team leaders. Eighteen respondents did not indicate their profession and could not be included in any of the groups.

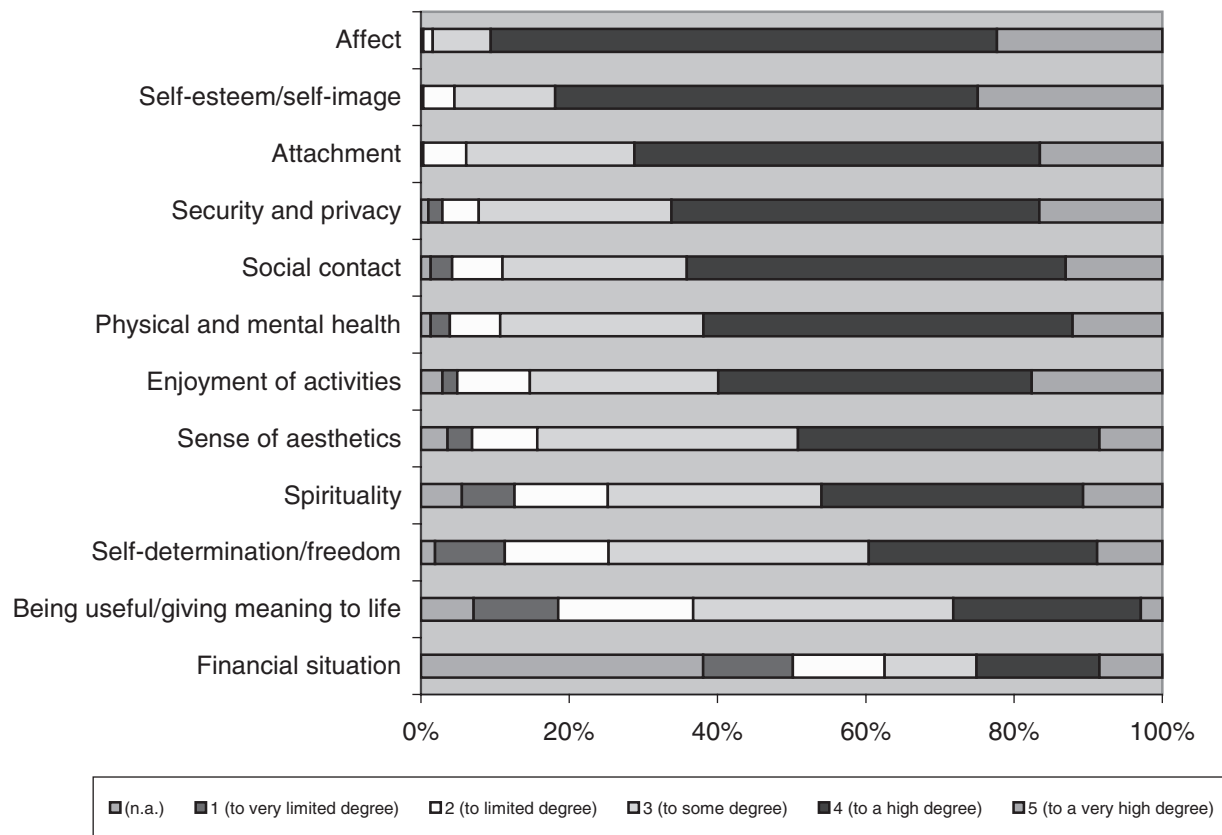


Figure 1. Distribution of the answers among the different response categories, per domain of quality of life.

Figure 1 presents the distribution of the different response categories. The categories 3 (to some degree) and 4 (to a high degree) were most frequently scored, with category 4 containing more than 50% of the responses on the first 6 domains. The domain “financial situation” shows a very different distribution in which the category “not applicable” is most often scored. In the other domains, this was the smallest category, and it was even absent in the first 3 domains.

Table 2 shows that the respondents reported focusing most on the domains of “affect” and “self-esteem/self-image” in their daily work (mean score > 4). The domain that received the least focus was “financial situation” (mean score = 1.89). The score on the domain “being useful/giving meaning to life” (mean score = 2.70) was also lower than on the other domains.

Generally, the responses of the 24-hour care group were similar to those of the total group, which is not surprising given its large proportion of the total group. The domains that received the least attention in the

24-hour care group (mean score < 3) were “financial situation,” “being useful/giving meaning to life,” and “self determination and freedom.”

The domains that had a mean score below 3 in the daytime activities group are “financial situation” and “spirituality.” The daytime activities group reported 2 additional domains on which they focus to a high degree (mean score > 4): “attachment” and “enjoyment of activities.”

The daytime activities group focused more than the 24-hour care group (mean score difference between groups > 0.5) on the domains “attachment,” “enjoyment of activities,” “sense of aesthetics,” and “being useful/giving meaning to life.” The difference between the groups was especially large in the latter domain (mean score = 2.50 in the 24-hour care group; 3.34 in the daytime activities group).

The 24-hour care group typically showed lower mean scores, implying they focus less on the different domains of quality of life than the daytime activities group.

Table 2. Mean Score of the Degree to Which the Caregiver Focuses on Each Domain

	Total Group n = 371-374*		24-hour Care n = 277-280		Daytime Activities n = 75-76	
	Mean	SD	Mean	SD	Mean	SD
Affect	4.11	0.61	4.05	0.63	4.33	0.50
Self-esteem/self-image	4.05	0.76	3.93	0.78	4.38	0.57
Attachment	3.84	0.80	3.71	0.82	4.21	0.62
Security and privacy	3.74	0.94	3.75	0.91	3.66	1.10
Social contact	3.61	0.98	3.62	1.00	3.55	0.96
Physical and mental health	3.59	0.96	3.58	1.01	3.58	0.85
Enjoyment of activities	3.56	1.14	3.34	1.11	4.41	0.66
Sense of aesthetics	3.30	1.11	3.18	1.16	3.78	0.62
Spirituality	3.14	1.27	3.21	1.21	2.91	1.35
Self-determination and freedom	3.10	1.16	2.99	1.13	3.41	1.19
Being useful/giving meaning to life	2.70	1.26	2.50	1.25	3.34	0.99
Financial situation	1.89	1.82	1.96	1.89	1.59	1.54

*The number of respondents varied slightly due to missing data.

Conclusions and Discussion

This explorative study firstly investigated the degree to which professional caregivers, more specifically 24-hour care staff and activity professionals, in their daily work, actually focus on the domains of quality of life that people with dementia consider important. Furthermore, it was determined if these groups of professionals differ in the domains they focus on. Most of the domains that persons with dementia consider important were reported by the professional caregivers as domains on which they focus strongly. However, professional caregivers concentrate less on the domains “financial situation” and “being useful/giving meaning to life.” With regard to the latter domain, this holds primarily for the 24-hour care staff. This group also does not concentrate much on “self-determination and freedom,” whereas the activity professionals focus less on “spirituality.” These results imply that the 2 disciplines differ in the domains of focus. People with dementia who live in a nursing home have contact with both disciplines, so the professionals can complement each other to some degree. Unfortunately, this is not possible for people with dementia who live at home.

A comparison with the results of our first study⁸ shows that the domains that professional caregivers did not mention as being relevant for the quality of life of people with dementia (“sense of aesthetics,” “financial situation,” and “being useful/giving meaning to life”) are domains that they do report to focus on in their work, albeit to a limited or some degree.

Of the domains that are not included in existing conceptual approaches and measurement instruments for quality of life in dementia, that is, “security and privacy” and “self-determination and freedom,” the latter is a domain the respondents focus on only to a limited degree. “Security and privacy,” however, is a domain they do focus on. Indeed, this domain is also represented in instruments for quality of life that are developed for the general nursing home population (eg, references 13 and 14). The results of this study suggest that caregivers in day care also see a task in this domain. The finding that caregivers focus to a limited degree on the domain “financial situation” comes as no surprise. In the first study, only a few people with dementia mentioned “not having any financial worries” as important for their quality of life.

Putting the results in the perspective of person-centered and emotion-oriented care, the results are mixed. Although person-centered and emotion-oriented care have become major goals in long-term care facilities,¹⁵ it is not easy for care professionals and institutions to redirect their focus from supply-driven care to individual needs and preferences. The results of this explorative study may illustrate that this is partly succeeding. On the one hand, all caregivers, both 24-hour care staff and activity professionals, indicate they focus most on affect and self-esteem, which is in accordance with the objectives of care approaches that are aimed at preserving and reconstructing the personhood of the individual with dementia.^{16,17} On the other hand, the respondents do not focus intensely on the domains “being

useful/giving meaning to life” and “self determination and freedom.” This implies that further care interventions, which focus on staff behavior, are necessary.^{18,19} Although professionals who offer daytime activities focused more on these domains than nursing assistants on residential units, especially the domain “being useful/giving meaning to life” receives little attention. The magnitude of feeling useful for elderly people who are in need of assistance or care is mentioned in the literature on person-centered and relationship-centered care^{16,20} and quality of life,^{21,22} and is also present in theories on quality of life, for example in the Social Production Functions theory.^{23,24} In this theory, “behavioral confirmation” is 1 of the 5 main domains of quality of life, and it includes doing good things, doing things well, being a good person, being useful, contributing to a common goal, and being part of a functional group.²⁴ “Being useful/giving meaning to life” is, furthermore, a domain that holds many opportunities for the caregivers. Giving people with dementia tasks and roles in the day-to-day routine (eg, being made responsible for taking care of the plants, helping to prepare food, or assisting other clients) is a response to this need.

The scope of this explorative study does not allow the conclusion that the results have general validity. A convenience sample was used, and the recruitment procedure and relatively low response rate do not guarantee that the sample is representative for nursing assistants and activity professionals who work in nursing homes and day care facilities. Another limitation is the inclusion of only 2 groups of caregivers. Although 24-hour care staff and activity professionals may be considered the professional caregivers that have the most intense and regular contact with the persons with dementia, the focus of physicians, social workers, and psychologists is important as well.

However, in our opinion, the results give sufficient cause for further investigation of the discrepancy that was found between the domains that are important to the people with dementia, and the domains that their caregivers focus on in their daily work. First of all, the relevant domains that were found in our first study need to be confirmed. Furthermore, this study investigated what professional caregivers *report* they focus on. Further investigation could concentrate on the *actual activities* that caregivers *undertake* when they say they focus on a specific domain, thereby including other staff groups. A logical next step would then be to investigate whether neutralizing discrepancies would contribute to improving the quality of life of people

with dementia. In these investigations, the importance of each domain for the individual with dementia would need to be taken into account.

Finally, one should not assume that any measurement instrument for quality of life is automatically suitable to evaluate the effect of interventions on the quality of life of people with dementia. If the main focus in actual practice would be on aspects that cannot be measured with the measurement instrument in question, the effectiveness of the intervention cannot be assessed correctly.²⁵ This is a subject for further investigation, which might result in the development of new measurement instruments that are in line with the perspectives or objectives of the various users.

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