Quality until we die: quality of life and quality of dying in nursing home residents with dementia

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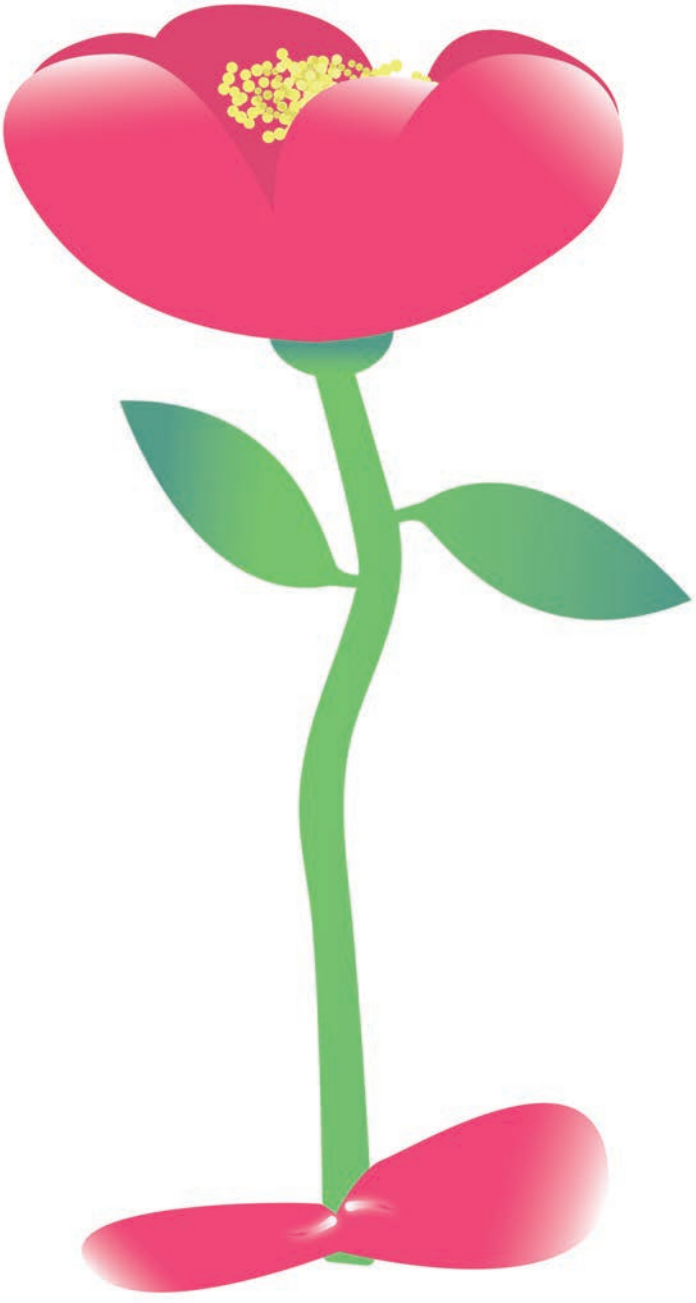

Chapter 3

Change in QOL after a multidisciplinary intervention for people with dementia

A randomized controlled trial

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Abstract

Objective
The objective of this study was to examine whether implementation of a stepwise multicomponent intervention (STA OP!) for challenging behavior and pain affects quality of life (QoL) of nursing home residents with moderate to severe dementia after 3 and 6 months.

Methods
A cluster randomized controlled trial was conducted in 12 nursing homes. Both control (n=140) and intervention group (=148) received training, the intervention group was also treated using the STA OP! intervention. At baseline, 3 and 6 months QoL was assessed using the six QUALIDEM domains applicable to moderate and severe dementia. Linear mixed models were used to compare changes in QoL domains between the two groups over time.

Results
After both 3 and 6 months there was no change, and no difference in change, between the two groups in the domains Care relationship, Positive affect, Negative affect and Social relations.
Between 0 and 3 months a positive effect was seen in the domain Restless tense behavior with a regression coefficient of β: 0.95 (95% confidence interval, CI, 0.36;1.54). Between 3 and 6 months a negative effect was seen on the domain Restless tense behavior β: -0.98 (95% CI -1.60; -0.36) and a positive effect in the domain Social isolation, β: 0.64 (95% CI 0.12;1.17).

Conclusion
The stepwise intervention STA OP! affects the QUALIDEM domains in different ways: there was a lowering of Restless tense behavior in the short term which reverted back to the initial level in the longer term, and a lowering of Social isolation in the longer term.

Key Points
- There is an urgent need for evidence-based interventions to improve the quality of life in people with dementia living in nursing homes
- After a stepwise multicomponent intervention (STA OP!) for challenging behavior and pain, two domains of quality of life, Restless Tense Behavior (between 0 to 3 months) and Social isolation (between 3 to 6 months) showed a positive effect
- The other domains (Care relationship, Positive affect, Negative affect, Social relations) showed no significant change in quality of life between 0 to 3 and 3 to 6 months post-interventions. The domain Restless Tense Behavior showed a negative effect on quality of life 3 to 6 months post-intervention

Introduction

With the global increase of ageing populations, dementia has become a major concern. One challenge is how to care for people who have lost the ability to take care of themselves and may need specialized care and/or admission to a nursing home. As there is no cure for dementia, quality of life (QoL) is an important and appropriate goal. In the general population, QoL can vary depending on different characteristics such as age, gender, marital status and morbidity.[1,2] Fortunately, more knowledge has become available regarding how to measure and follow the course of QoL, both at home and in a nursing home.[3,4] Various theoretical models form the basis of the development of these QoL instruments and, for many, a multidimensional concept has been used.[3] To observe a change in QoL it is important to look for differences within these different domains of QoL.
Several scenarios have been found regarding the course of QoL in dementia over time, ranging from a decrease in QoL, a stable QoL but also an increased QoL.[5,6,7,8,9,10,11] A higher QoL rating has been shown in people with dementia living at home compared to those in a nursing home, also after stratifying for dementia severity.[12,13] These results indicate that there is room for improvement and, therefore, a need for implementation of interventions that can improve QoL for people with dementia living in a nursing home.

A relation has been found between the various factors that can influence the measured QoL in people with mild cognitive impairment and dementia, living at home or in a nursing home.[14,15,16-18] Studies on neuropsychiatric symptoms also show a large influence on QoL of people with dementia, and the need for effective non-pharmacological interventions is clear.[16,19,20,21] The implementation of a stepwise multicomponent intervention (STA OP!) showed an overall effect on lowering challenging behavior, observed pain, depression, and a reduction in the use of psychotropic medication.[20,21] Both challenging behavior and depression are mediators of QoL and both may influence QoL domains such as relationships or affect. Therefore, the present study explores whether implementation of the STA OP! intervention improves the domains of QoL of nursing home residents with moderate to severe dementia over time.

Methods

Setting and study population

The STA OP! study is a cluster randomized controlled trial in which 12 nursing homes participated (trial registration NTR-1967). The STA OP! study assessed the implementation of a stepwise multidisciplinary intervention to address pain and challenging behavior.[20] Participating nursing homes had to meet the following inclusion criteria: at least one dementia ward willing to participate, and no major organizational changes or building activities planned or performed during the study period.[20,23]

The attending elderly care physician assessed the severity of dementia with the Reisberg Global Deterioration Scale (Reisberg GDS).[24] Residents with a Reisberg GDS score of 5 (moderate dementia), 6 (moderately severe dementia) or 7 (severe dementia) were eligible to participate. Furthermore, participants were eligible to participate when having a behavioral problem or an indication of being in pain and screened for the absence of a psychiatric diagnosis. The sample size was calculated based on one of the primary outcomes of the STA OP! study, the Cohen-Mansfield Agitation Inventory (CMAI), a behavioural observation scale. To detect a 15% difference between the intervention and control condition with an α of 0.05 and a β of 0.80, also taking into account a 50% dropout rate and design effect (cluster randomisation) of 1.5, 168 participants were needed. Details on the study design, the steps of the STA OP! intervention and the inclusion criteria is provided elsewhere.[23] STA OP! is based on the Serial Trial Intervention in the USA.[25] For all participants, written informed proxy consent was obtained from the family/caregivers. The study protocol was approved by the Medical Ethics Review Committee of the VU University Medical Center Amsterdam.

Data were provided or collected by research assistants, elderly care physicians and registered nurses. Both the intervention and control teams received training on challenging behavior in dementia and pain management. The multidisciplinary intervention team received additional training during the first 3 months on: working with the stepwise component method, the STA OP! assessments and methods to enhance communication. The goal at the start of the protocol was to identify pain and challenging behavior. The care teams determined the order of inclusion of each of the participants.[22,23] The STA OP! intervention contains the following steps: Step 0: perform a basic care needs assessment and determine whether basic care needs are fulfilled. Step 1: perform a pain and physical needs assessment including an observational Pain Assessment Checklist (PACSLAC-D). Step 2: perform affective needs assessment that focuses on the needs of people with dementia. Step 3: administer a trial of non-pharmacological comfort treatment. Step 4: administer a trial of analgesic agents but also administer the prescribed as-needed analgesic agent. In Step 5, either a consultation was initiated with other disciplines, or a trial of prescribed as-needed psychotropic drugs was started. The STA OP! process stopped when behavioral symptoms decreased by 50% or more. If behavioral symptoms continued after completion of the 5 steps, the process was repeated. The trial was single blinded. An independent researcher allocated the nursing homes for the intervention or control condition using a computer-generated sequence program. The intervention was multidisciplinary and training was given to the nursing home staff. The research assistant that interviewed the staff was unaware of the randomization and blinded.

Outcome measures

Quality of life

At baseline, and at 3 and 6 months, QoL was assessed using the QUALIDEM: this is an observational instrument to measure QoL in people with moderate to severe dementia.[26-29] The QUALIDEM describes observable behavior in nine domains: Care

relationship, Positive affect, Negative affect, Restless tense behavior, Positive self-image, Social relations, Social isolation, Feeling at home, and Having something to do. The QUALIDEM does not provide a validated calculated total score.
The QUALIDEM (total of 37 questions) is based on an observation window of one week.[28] The response options are: never, rarely, sometimes, and frequently. For the present study we used the 6 domains (Care relationship, Positive affect, Negative affect, Restless tense behavior, Social relations, and Social isolation) that include 18 questions that are also applicable to very severe dementia (GDS 7) [17,27,28] In the domain Care relationship question 7, 14, 31 were used, in the domain Positive affect question 5, 8, 21, 40, in the domain Negative affect question 6, 23, in the domain Restless tense behavior question 2, 19, 22, in the domain Social relations question 3, 12, 25, and in the domain Social isolation question 16, 20, 32. The individual item scores for each domain were processed such that a higher domain score reflects a better QoL.

Functioning
The Katz Index of Independence in Activities of Daily Living (Katz ADL) was used to measure ADL functioning. The Katz ADL is a reliable and valid instrument to assess functional status. [30,31] The index ranks adequacy of performance and scores on each function are summed (total range: 6-24). A higher score indicates a lower ADL function, i.e.a higher dependence on care.

Pain
The Dutch version of the Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC-D), a reliable and valid observational pain instrument, was used to assess pain. [32-34,35]

Neuropsychiatric symptoms
Behavioral and psychological problems were scored using the reliable and valid Neuropsychiatric Inventory-Nursing Home Version (NPI-NH), which scores 10 behavioral and psychological areas and two types of neurovegetative changes. [36,37,38]

Statistical analysis

Descriptive statistics included means and standard deviations (SD) for normally distributed variables, and median and interquartile range (IQR) when non-normally distributed. Differences at baseline between control and intervention group items were analysed using chi-square test for categorical variables, the T-test for normally distributed variables, and the Mann-Whitney U-test for non-normally distributed variables. [20,22] To account for clustering of measurements within individuals and nursing home units, a linear mixed model analysis was performed, with time (categorical), intervention and their interaction as fixed effects, and individual and nursing home unit as random effects. The final model 2 is also adjusted for the Reisberg GDS and the Katz index because of a significant difference between the two groups at baseline.

All descriptive analyses were performed with SPSS statistical software, version 23, 2015 (SPSS Inc., IBM, USA) and linear mixed model analyses with the lme4 package within R statistical software, version 3.3.1, 2016. [39,40]

Results

Study population

In 12 nursing homes, 21 units were eligible for inclusion in the study. In these 21 units, 363 residents were eligible, and 288 residents were included in the STA OP! study: 148 in the intervention condition (11 units) and 140 in the control condition (10 units). [20]

Demographic and clinical characteristics of the participants are presented in Table 1. There was no significant difference between the groups in age, length of nursing home stay, marital status and gender. However, more participants in the intervention condition had less severe dementia, 115 participants Reisberg GDS 5 and 6 and 33 Reisberg GDS 7 in the intervention group compared to 93 participants Reisberg GDS 5 and 6 and 47 people Reisberg GDS 7 in the control group (p-value 0.04). Also, participants in the intervention group were less dependent regarding ADL with a median Katz score of 17 compared to the control group with a median Katz score of 19 (p-value 0.01).
Of the 148 residents in the intervention condition, 39% were actually assessed by the team with the stepwise component of the STA OP! protocol. The mean number of steps assessed was 2.8 (SD $\pm$ 1.2).
During the 6-month study period, 29 participants in the control group died and 30 in the intervention group were lost to follow-up (29 died, 1 was transferred to another unit/ institution). [20,22]

Quality of life

The median score on the six domains is presented in table 1. [28] At baseline, there were no significant differences between the two groups.

Change in Quality of life

After implementation of the STA OP! intervention, changes in QoL over time for the two 3 month-periods for each QUALIDEM domain were compared between the two groups; the results are shown in Table 2.

Short-term effect: first 3 months
In the domains Care relationship, Positive affect, Negative affect, Social relations and Social isolation, no effect was found on change in QoL between the two groups in the period 0 to 3 months. In the domain Restless tense behaviour, a positive effect was found between 0 and 3 months, with a regression coefficient, β, of 0.95 (standard error (SE) 0.30 and 95% confidence interval (CI) 0.36 to 1.54). Adjustment for the Katz index and Reisberg GDS (model 2) did not essentially change these results.

Long-term effect: second 3-month period
In the domains Care relationship, Positive affect, Negative Affect and Social relations no effect was found on change in QoL between the two groups in the period 3 to 6 months. In the domain Restless tense behaviour, a negative effect with a β of -0.98 (SE 0.32, 95% CI -1.60 to -0.36) was found. In the domain Social isolation a positive effect was found with a β of 0.64 (SE 0.27, 95% CI 0.12 to 1.17). Adjustments for the Katz index and Reisberg GDS (model 2) did not essentially change these results.

Discussion

This study shows that some aspects of quality of life improved after the STA OP! intervention compared to the control condition. In the domains Restless tense behavior and Social isolation, a positive effect was found in both the first and second 3 month periods, respectively, after start of the intervention. This indicates that an intervention in a nursing home that involves nursing/medical staff and using the stepwise method to manage pain/challenging behavior, can have a beneficial effect on several domains of QoL in people with dementia. This is relevant since dementia care should also aim to improve the QoL of people affected by this progressive and disabling syndrome. However, the positive effect was not maintained in the second 3-month period in the domain Restless tense behavior. Although the reason for this is unclear, it might be related to the end of the training of the teams after 3 months. However, there was a positive effect on the domain Social isolation after 3 months, which shows an emerging, delayed, longer-term positive effect in contact with other people. In this latter domain, two (out of three) questions relate to rejection by other people, or rejection of contact with other people. This effect might be explained by the effect of the stepwise component on lower observed pain and the changes in behavior; both of these can be followed by improvement in interaction with other people and result in an improvement in this specific domain of QoL in the longer term.

Strengths and limitations

This randomized controlled trial in a large group of people with dementia in a nursing home setting, shows that the stepwise intervention STA OP! had a beneficial effect on the secondary outcome measure QoL. Although other intervention studies also reported a positive effect on QoL of people with dementia, it is difficult to make meaningful comparisons due to the different observational methods used and the different levels of dementia included in the studies. [41,42] In the present study, the positive effects on QoL were found in the domains Restless tense behavior and Social isolation; this is relevant, as this indicates that QoL can be improved in people with dementia living in a nursing home. This effect might be explained by providing medical staff with increased knowledge of pain and behavior in dementia, and the stepwise multicomponent intervention that provides directions for assessments as well as for interventions. Another strength is the high number of participating nursing homes, resulting in the inclusion of a large group of people with moderate to very severe dementia.

Table 1 Characteristics of the study population at baseline

	Control (n=140)		Intervention (n=148)		p-value
Demographic variables					
Female	100	71.4 %	107	72.3 %	0.87 [a]
Mean age in years (SD)	83.3	(6.9)	84.3	(7.4)	0.25 [b]
Median length of stay in months (IQR)	24.6	(12-42)	18.8	(10-40)	0.14 [c]
Marital status: Married	37	26.4 %	50	33.8 %	0.42 [a]
Functional variables					
Katz range 6-24 median (IQR)	19	(15-22)	17	(12-20.8)	0.01 [c]
Quality of Life					
QUALIDEM					
Care relationship range 0-9 median (IQR)	7	(5-8)	7	(5-9)	0.93 [c]
Positive affect range 0-12 median (IQR)	9	(7-11)	10	(7-12)	0.18 [c]
Negative affect range 0-6 median (IQR)	5	(4-6)	4	(3-6)	0.20 [c]
Restless tense behavior range 0-9 median (IQR)	5	(3-7)	4.5	(2-7)	0.53 [c]
Social relations range 0-9 median (IQR)	6	(5-8)	6	(4-8)	0.15 [c]
Social isolation range 0-9 median (IQR)	7	(5-9)	7	(5-9)	0.77 [c]
Disease specific measurements					
Dementia severity					
Reisberg GDS 5 and 6	93	66 %	115	78 %	0.04 [a]
Reisberg GDS 7	47	33 %	33	22 %	
Pain; PACSLAC-D range 0-24, median (IQR)	3	(1-6)	4	(1-7)	0.18 [c]
Behavior; NPI range 0-144, median (IQR)	12	(4-21)	12	(5-24)	0.24 [c]

SD=Standard deviation
IQR=Interquartile range
QUALIDEM; a higher score indicates a better QoL
Reisberg GDS=Reisberg Global Deterioration Scale
PACSLAC-D=Pain Assessment Checklist for Seniors with Limited Ability to Communicate-Dementia
NPI=Neuropsychiatric Inventory
p-value: [a] Chi-square, [b] t-test, [c] Mann-Whitney

Table 2 Average change in quality of life domains of the QUALIDEM at 3 and 6 months post of the intervention

	Model 1			Model 2		
	β	SE	95% CI	β	SE	95% CI
Care relationship						
0-3 months	0.19	0.21	-0.22 to 0.61	0.19	0.21	-0.22 to 0.61
3-6 months	0.03	0.22	-0.40 to 0.47	0.03	0.22	-0.40 to 0.47
Positive affect						
0-3 months	0.06	0.31	-0.55 to 0.66	0.05	0.31	-0.54 to 0.66
3-6 months	-0.21	0.32	-0.84 to 0.43	-0.20	0.32	-0.84 to 0.43
Negative affect						
0-3 months	0.27	0.18	-0.07 to 0.62	0.28	0.18	-0.07 to 0.62
3-6 months	-0.10	0.19	-0.47 to 0.26	0.10	0.19	-0.47 to 0.27
Restless tense behavior						
0-3 months	0.95	0.30	0.36 to 1.54	0.95	0.30	0.36 to 1.53
3-6 months	-0.98	0.32	-1.60 to -0.36	-0.98	0.32	-1.60 to -0.36
Social relations						
0-3 months	0.45	0.24	-0.02 to 0.91	0.45	0.24	-0.01 to 0.92
3-6 months	0.23	0.25	-0.26 to 0.72	0.23	0.25	-0.26 to 0.72
Social isolation						
0-3 months	0.01	0.26	-0.49 to 0.51	0.01	0.26	-0.49 to 0.51
3-6 months	0.64	0.27	0.12 to 1.17	0.65	0.27	0.12 to 1.17

Reference category for the intervention effect is the control condition. Regression coefficients (β) reflect the average differences in quality of life domains of the QAULIDEM 3 and 6 months after intervention.
SE=standard error, CI=confidence interval
Model 2 includes adjustment for Katz ADL index and Reisberg GDS.

A limitation of this study is that it was not possible to start the stepwise component in all patients in the intervention group at the same time, i.e. after 6 months, 39% were included in the stepwise component of the study. However, this indicates that, although only some of those were assessed utilizing several steps (mean 2.8) of the stepwise component, an effect was found on QoL for the entire group. This could mean that those people that were assessed first with the stepwise component, were monitored on pain, behavior and unmet needs in a more intensive way. In turn, this could have resulted in better overall skills that also benefited other persons on the unit. Another limitation lies in a potential bias due to lack of blinding of the control versus intervention condition. i.e. due to the more intensive training and evaluation of the stepwise component, the nursing staff were aware that they were working on the intervention unit. Although we cannot rule out the possibility that the results found in two domains are due to chance our results are in line with the other positive effects found on improved behaviour and less pain. [20,22]
In studies measuring QoL in people with dementia, different domains are often used, depending on the theoretical background of the different instruments used. Studies on the evaluation and use of the QUALIDEM show that six domains are applicable and often used for people with severe dementia. However, one study reported that Social relations have a low result on scalability, and that Negative affect is scalable but has a low reliability. [28] We found no effect of the STA OP! protocol on these two latter domains of the QUALIDEM. The scalability and reliability of the domain Restless tense behavior and Social isolation are acceptable. Others have used a total score of the QUALIDEM; however, since the reliability and interpretation of a total score has not yet been validated, it is debatable whether it should already be used in research.
It would be interesting to further compare the effect of interventions in different stages of dementia. Although some differences have been reported in stages ranging from mild to severe dementia [18], the groups in the present study were too small to allow meaningful comparisons.

Implications for practise

This study shows that an intervention that has an effect on challenging behavior, pain, and the use of analgesics/psychotropic medication can also lead to an improvement of QoL in people with advanced dementia living in a nursing home. [20,22] This type of intervention changes the knowledge, skills and approach of the entire multidisciplinary team towards people with dementia. (Pieper et al., manuscript under review). Therefore, we also recommend further use of this stepwise method for other nursing homes. We think that the regular application of a short and reliable QoL observational instrument can be used to improve the care for people with dementia. Scores in different domains, rather than a total score, may be more comprehensible for the caregivers, and help them better reflect on the intervention and its effects. The knowledge we get from this study can be used in other care settings in other countries because the effects found are the effects of a basic care assessment, a pain and physical needs assessment, an affective needs assessment, a trial of non-pharmacological comfort treatment(s) and sometimes a trial of analgesic agents or other disciplines. Most people never used step 5 (other disciplines)

and the first 4 steps are possible in all care settings if you train healthcare professionals. The STA OP! intervention is based on the Serial trial Intervention, which was successfully implemented in the US.

Conclusion

It is important to improve QoL for people with dementia in nursing homes. The present study shows that this stepwise intervention leads to lowered Restless tense behavior in the short term and less Social isolation in the longer term.

Conflict of interest
All the authors declare that there are no conflicts of interest. The work presented here has not been published elsewhere.

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