Original Research Article

Factors Related to Rejection of Care and Behaviors Directed towards Others: A Longitudinal Study in Nursing Home Residents with Dementia

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Abstract

Aims: The aim of this study was to analyze factors related to rejection of care and behaviors directed towards others in nursing home residents with dementia. ***Methods:*** The relationship of lack of understanding, depression, psychosis and pain with rejection of care and behaviors directed towards others was explored using four assessments from the Minimum Data Set (MDS) within a period of 15 months on 1,101 residents with dementia in Dutch nursing homes. Presence of depressive symptoms was ascertained using a validated MDS scale, and presence of lack of understanding, rejection of care, psychosis and pain through the individual MDS items. A structural equation modeling approach and latent growth models were used to investigate the longitudinal relationship between changes in rejection of care and physical or verbal behaviors directed towards others, and changes in lack of understanding, pain, depression and psychotic symptoms. ***Results:*** Changes in lack of understanding predicted changes in rejection of care, and there was also a relationship between changes in depression and rejection of care. Changes of behaviors directed towards others were related to changes in lack of understanding and depression. Pain and behaviors directed towards others were unrelated, and psychosis was rather stable throughout. A mediation model suggested that the relationship of lack of understanding with behaviors directed towards others was mediated by rejection of care. ***Conclusion:*** These results indicate that lack of understanding and depression are important factors in development of rejection of care and behaviors directed towards others. The relationship between lack of understanding and behaviors directed towards others is mediated by rejection of care. Improvement in communication between residents and caregivers, and perhaps also effective treatment of depression may prevent or ameliorate these behaviors directed towards others.

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Introduction

The course of progressive dementias may be characterized as a gradual loss of independence. Development of apraxia and other cognitive deficits requires help of others with activities of daily living. Unfortunately, the person with dementia sometimes does not cooperate with family or professional caregivers but actually resists care or exhibits behaviors during care that may be labeled abusive [1]. These behaviors may be difficult to handle by family caregivers and may lead to institutionalization [2, 3]. In an institution, rejection of care and behaviors directed towards others may lead to injuries of the resident or staff and to staff burnout. A survey of nursing home physicians showed that the most common problem that they treated in residents with dementia was rejection of care [4].

There are several studies that investigated methods for management of behavioral symptoms of dementia. Some of them investigated the effectiveness of pain control [5], others used personalized psychosocial interventions based on the unmet needs theory [6] for treatment of agitation and found positive results. However, the problem with these studies is that they consider all behavioral symptoms to be agitation and do not differentiate between agitation and rejection of care. This is due to using the Cohen-Mansfield Agitation Inventory [7] or Neuropsychiatric Inventory [8] in which the item Agitation/Aggression is actually measuring rejection of care [9]. Similar problems are also present in drug trials investigating effects of antipsychotics and other medications [10, 11]. Therefore, we decided to study specifically rejection of care that is a highly relevant problem in clinical practice [12].

We have previously described strong correlations between rejection of care and lack of understanding, depression and psychotic symptoms [13]. Behaviors directed towards others were strongly correlated with rejection of care, depression and delusions. However, these findings were based only on cross-sectional data. In this study, we performed longitudinal analyses to further explore the relationships of these modifiable factors with rejection of care and behaviors directed towards others of nursing home residents. Our hypothesis was that longitudinal data would support causal relationships between these modifiable factors and rejection of care.

Material and Methods

Subject Population

We used Minimum Data Set-Resident Assessment Instrument (MDS-RAI) data collected by 8 Dutch nursing homes and 10 residential homes. We included the data of residents within a 12-month time window for each facility separately, resulting in a range from April 4, 2007, to December 1, 2008. Of the records of 2,705 residents available from the 18 facilities, we selected the last records of 1,101 residents aged over 65 with Alzheimer or other dementia (I1q or u), who were dependent in decision making (B4 not equal 0) and who were not comatose (B1 equal 0) [14]. Four assessments from the MDS within a period of 15 months were used for the analyses. Four assessments were completed for all patients.

Measurements

For rejection of care, we used the MDS 2.0 item 'resist care' (E4eA). The terminology was changed by the introduction of MDS 3.0, which uses 'rejection of care' instead of 'resist care'. Other new, but equivalent, items in MDS 3.0 are 'physical behavioral symptoms directed towards others' instead of 'physical abuse' and 'verbal behavioral symptoms directed towards others' instead of 'verbal abuse' [15]. We use the new terminology in this article.

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Presence of rejection of care and behavioral symptoms directed towards others was obtained from MDS 2.0 section E with choices from 'not exhibited' to 'daily'. The variables 'physical behavioral symptoms directed towards others' (E4cA) and 'verbal behavioral symptoms directed towards others' (E4bA) were combined into one variable called 'behaviors directed towards others'. Ability to understand (C6) was rated as 'always', 'usually', 'sometimes' and 'rarely/never'. Psychotic symptoms [delusions (J1e) and hallucinations (J1i)] were combined into one variable, 'psychosis', whose values are number of symptoms.

Clinical diagnosis of depression was obtained from MDS item I1ee, and depression symptoms were assessed by the validated Depression Rating Scale using other MDS items: negative statements (E1a), anger (E1d), unrealistic fears (E1f), repetitive health complaints (E1i), sad expression (E1I) and crying (E1m; score 0–14) [16]. Presence of depression was indicated by a score of 3 or higher. This scale correlated well with the Cornell and Hamilton depression scales using 'at least mild depression' as a cutoff point, and with psychiatric diagnosis. It was also more sensitive and specific than the 15-item Geriatric Depression Scale in detecting depression in the nursing home population [16]. Data about presence of pain were obtained from the MDS item J2a with options of 'no', 'less than daily' and 'daily'. Demographic data were also obtained from the MDS.

Analyses

We investigated the longitudinal relationship between changes in rejection of care and behaviors directed towards others, and changes in lack of understanding, pain, depression and psychotic symptoms with the structural equation modeling approach. Within this approach, we used latent growth models, bivariate latent growth models and longitudinal latent growth mediation models. Since the studied variables were ordinal, we used latent growth models for categorical variables [17, 18] to study change within each variable. This model assumes the existence of latent or nonobserved trajectories, which are observed only indirectly through the repeated measures. The model allows the trajectories to differ by individual case. The intercept represents the initial level at the beginning of the study, and the slope represents the rate of change. The intercept is constant over time and is therefore fixed to one. The factor loadings for the slope represent the measurement points, and they were set to the values 0, 3, 6 and 9 that represent the months at which the measurements were taken.

First, we estimated separate latent growth models for each variable. Second, we used bivariate latent growth curve models [17–20] to study the relationships between rejection of care and understanding, and rejection of care and depression. These models combine two latent growth curve models that describe two separate longitudinal processes, and study the relationship between the initial level of the first process (Y, e.g. rejection of care) with the initial level and rate of change in the second process (X, e.g. lack of understanding), and the relationship between the rate of change in the first process with the initial level and rate of change in the second process (fig. 1, process Y and X). Single-headed arrows indicate the direction of the relationship. Bivariate latent growth curve models were also used to describe the relationship between behavioral symptoms directed toward others with rejection of care and behavioral symptoms directed towards others with understanding, and depression.

Frequency distributions of the variables psychotic symptoms and presence of pain remained stable through the whole measurement period, and the latent growth models showed no trend. Therefore, we did not use bivariate latent growth models but latent growth models that included these variables as time-dependent covariates. In the model for psychosis symptoms, we included only the measurements of the first and the fourth psychosis symptom because of the high correlation between the first and the second measurement, and the third and the fourth measurement.

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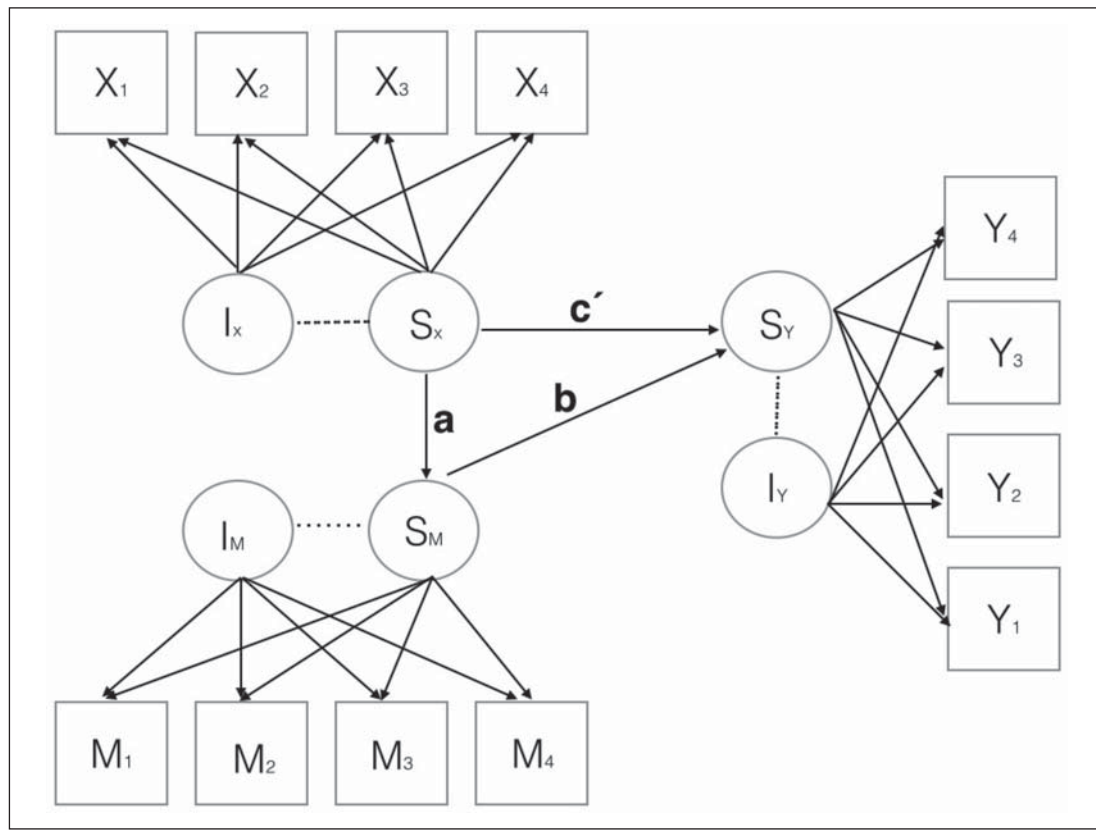
Fig. 1. Path diagram of a latent growth curve mediation model. Squares represent observed repeated measures, ovals represent latent intercepts (I) and latent slopes (S). One-way straight arrows represent both relationships between observed and latent variables and relationships between latent variables, and discontinuous lines represent correlations between latent variables. In the final models, X represents the independent variables, which are lack of understanding or depression, M represents the mediator, which is rejection of care, and Y represents the dependent variable, behaviors directed toward others. The relationship between X and M is described by a, the relationship between the M and Y is described by b, and the direct effect c′ describes the relationship between X and Y that is independent of the mediator M.

Finally, longitudinal mediation models [21] were used to study whether rejection of care mediated the relationship between lack of understanding and behaviors directed towards others, and whether it mediated the relationship between depression and behaviors directed towards others (fig. 1). This means that first changes in lack of understanding (depression) occurred, and they promoted changes in rejection of care. Next, changes in behaviors directed towards others occurred as a consequence of changes in rejection of care. Three sets of latent growth factors were specified, one set for the independent variable, one set for the mediator, and, finally, another set for the dependent variable. The mediation model examined whether the growth in the independent variable affected the growth trajectory of the mediating variable which, in turn, affected the growth trajectory of the dependent variable. The χ^2 value, the root mean square error of approximation (RMSEA), the comparative fit index (CFI), and the Tucker-Lewis (TLI) index were used to evaluate the model. A model achieves a good fit if the RMSEA is lower than 0.05, and fit is acceptable for values between 0.05 and 0.09. An RMSEA of 0.1 or more indicates a poor fit. A CFI and a TLI higher than 0.95 indicate a good fit. All the analyses were performed with the software package Mplus, version 7.1 [22]. Paired t tests were used to assess changes in medication.

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Table 1. Characteristics of the subject population at the beginning of the study (n = 1,101)

Age, years	84.2±7.1
Female	780 (70.8)
Diagnosis	
Alzheimer's disease	493 (44.8)
Other dementias	579 (52.6)
Both	30 (2.6)
Resists care	
None	690 (62.7)
1–3 days in last 7 days	316 (28.7)
4–6 days, but less than daily	95 (8.6)
Verbally behavioral symptoms	
None	759 (68.9)
1–3 days in last 7 days	241 (21.9)
4–6 days, but less than daily	101 (9.2)
Physically behavioral symptoms	
None	929 (84.4)
1–3 days in last 7 days	133 (12.1)
4–6 days, but less than daily	39 (3.5)
Clinical diagnosis of depression	136 (12.4)
MDS depression score	
0–2	539 (49.0)
3 or higher	562 (51.0)
Psychosis	
Delusions only	40 (3.6)
Hallucinations only	81 (7.3)
Both	46 (4.2)
Pain	
None	562 (51)
Mild	267 (24.3)
Moderate	237 (21.5)
Excruciating at times	35 (3.2)
Medications administered daily	
Antipsychotics	354 (32.2)
Antidepressants	206 (18.7)
Antianxiety medications	151 (13.7)

Values are presented as mean ± SD or n (%).

Results

The residents were mostly female, and some had diagnoses of both Alzheimer's disease and other dementias (table 1). Over one third of them exhibited rejection of care for at least some days, and almost one third exhibited verbal behavioral symptoms directed towards others, while about 15.0% exhibited physical behavioral symptoms directed towards others. About half of these residents (51.0%) exhibited significant symptoms indicating depression, but only 12.4% had a clinical diagnosis of depression. Psychotic symptoms were present in 15.1% of residents, while almost one half of them experienced some pain (table 1).

Most common medications used for treatment of residents with rejection of care and behaviors directed towards others were antipsychotics that were administered at the beginning of the study to 32.2% of subjects (table 1). Antidepressants were used in 18.7% of subjects, and antianxiety medications were used in 13.7% of subjects. Further, all three classes of psychotropic medications were used more often in residents with depressive symptoms than in residents without depression (antipsychotics 27.5 vs. 44.0%, antidepressants 13.0 vs. 27.4%, antianxiety 10.2 vs. 19.6%). The prevalence of psychotropic drug admin-

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Table 2. Longitudinal trajectories of measured variables

Variable	Model fit[1]				Slope					
	χ^2	d.f.	p	RMSEA	mean	SE	p	Var	SE	p
Lack of understanding	10.3	8	0.244	0.016	0.078	0.045	<0.001	0.014	0.001	<0.001
Depression	28.2	5	<0.001	0.065	0.06	0.01	<0.001	0.023	0.003	<0.001
Psychosis	–				–					
Pain	10.5	2	<0.001	0.062	0.023	0.015	0.111	0.057	0.019	0.003
Rejection of care	15.4	5	0.009	0.04	0.058	0.01	<0.001	0.026	0.003	<0.001
Behavior directed towards others (abusive behaviors)	26.0	11	0.006	0.035	0.014	0.04	<0.001	0.004	0.000	<0.001

Positive slopes indicate that these symptoms increase with time. The model for psychosis could not be estimated.
[1] CFI and TLI indices were equal to one for all models.

istration did not change during the study for antipsychotics (t = 0.22, p = 0.826) and antide-pressants (t = −0.81, p = 0.416), while the use of antianxiety medications increased (13.7 vs. 17.3%, t = −2.51, p = 0.012).

Longitudinal Trajectories of Each Process

Table 2 shows the longitudinal trajectories of all the variables analyzed with latent growth models to investigate the development of the symptoms over time. Based on the RMSEA criteria, the model fit was good for the lack of understanding, rejection of care and behaviors directed towards others, and acceptable for depression and pain. The CFI and TLI coefficients were equal to one for all the models. In table 2, positive slopes show that all these variables increased with time. However, the increase was not significant for pain. The latent growth model for psychosis symptoms could not be estimated because there were almost no cases with change in psychosis scores within the study period.

Combined Longitudinal Relationships

Next, bivariate linear latent growth models were used to study the relationships between evolution in rejection of care and evolution in symptoms related to rejection of care. For psychosis and pain, we fitted a model with these variables as time-dependent covariates because previously estimated latent growth models did not show evidence of change for these variables. The model fit columns in table 3 show low RMSEA values indicating a good model fit. The CFI and TLI coefficients were equal to one.

Table 3 also reports the relationship between the slopes. Changes in rejection of care were associated with or can be predicted by changes in lack of understanding and also by changes in depression. Finally, lower initial levels of pain were associated with a stronger increase in rejection of care (c = −0.009, SE = 0.004, p = 0.029).

The relationships between the intercepts or initial level of rejection of care and intercepts of the other variables are not reported in table 3 because intercept parameters depend on the measurement scale of the analyzed variables. The relationships between psychosis symptoms and pain, and initial levels of rejection of care are scale free and can be interpreted. We found a strong relationship between psychosis and initial levels of rejection of care, with higher initial levels of psychosis associated with higher initial levels of rejection of care (c = 0.207, SE = 0.053, p < 0.001). We also found that high initial levels of pain were associated with high initial levels of rejection of care (c = 0.116, SE = 0.045, p = 0.009).

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Table 3. Bivariate linear latent growth curve models

Predictors	Model fit[1]				Relationship between slopes		
	χ^2	d.f.	p	RMSEA	B	SE	p
Outcome: rejection of care							
Lack of understanding	36.4	25	0.066	0.020	0.699	0.167	<0.001
Depression	47.4	23	0.002	0.031	0.811	0.134	<0.001
Psychosis symptoms	15.8	7	0.003	0.034			
Pain	23.35	9	0.005	0.038			
Outcome: behaviors directed toward others (abusive behaviors)							
Rejection of care	59.2	28	0.005	0.032	0.718	0.093	<0.001
Lack of understanding	38.7	25	0.039	0.022	0.175	0.083	0.035
Depression	65.8	28	0.001	0.035	0.630	0.094	<0.001
Psychosis symptoms	33.8	13	0.001	0.038			
Pain	32.7	15	0.005	0.033			

Parameter estimates for pain and psychosis symptoms are not included in the table because these variables were included as time-dependent covariate in the model.

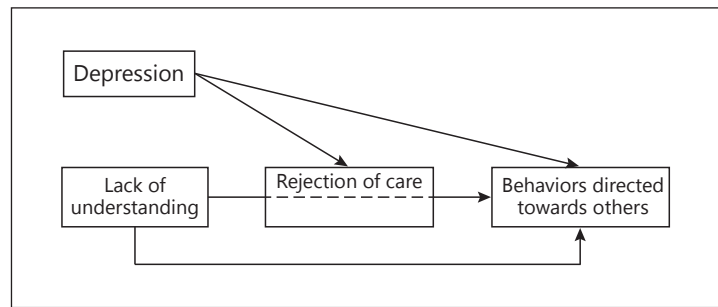[1] CFI and TLI indices were equal to one for all models.

Then, bivariate linear latent growth models were used to describe the relationships between evolution in behaviors directed towards others and evolution in symptoms related to those behaviors. A low RMSEA indicated a good model fit (see table 3). The columns reporting relationships between slopes show significant positive relationships between changes in rejection of care and changes in behaviors directed towards others. Changes in understanding and changes in depression were also associated with changes in behaviors directed towards others.

The relationships between intercepts for behaviors directed towards others are not reported in table 3 because of the same reasons explained above for the rejection of care analyses. Regarding the relationship between initial behaviors directed towards others and initial levels in pain or psychotic symptoms, we found a significant relationship between initial behaviors directed towards others and initial psychosis (c = 0.205, SE = 0.051, p < 0.001), indicating that initial psychosis was related to more frequent behaviors directed toward others.

Mediated Effects

Finally, we built the two mediation models (fig. 1), one to investigate whether rejection of care mediated the relationship between lack of understanding and behaviors directed towards others, and the other to investigate whether rejection of care mediated the relationship between depression and behaviors directed towards others. We used the longitudinal growth mediation described in MacKinnon [21, chapter 8]. Consistent with the literature on statistical mediation [21], the parameters illustrating the relationships in figure 1 are called a, b and c′. Parameter a describes the relationship between the slope for the independent variable (X) and the slope for the mediator (M). Parameter b describes the relationship between the slope of the mediator (M) and the slope in the dependent variable (Y). Parameter c′ represents the direct effect, which is the part of the effect of X on Y that is independent of the mediator. This parameter has a prime sign to reflect the adjustment for the mediator.

The fit of the first model was good (χ^2 test = 88.6, d.f. = 61, p = 0.012, RMSEA = 0.021, CFI = 1.000, TLI = 1.000). The relationship between lack of understanding and rejection of

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Fig. 2. Path diagram describing the results obtained with the mediation models.

care was significant (a = 0.876, SE = 0.124, p < 0.000). There was a significant relationship between rejection of care and behaviors directed towards others (b = 1.249, SE = 0.337, p < 0.001), while the relationship between lack of understanding and behaviors directed towards others after adjusting for rejection of care was not significant (c′ = –0.645, SE = 0.465, p = 0.166). Therefore, this model suggests that the relationship between lack of understanding and behaviors directed towards others is mediated by rejection of care. To quantify the indirect effect, the product of the parameters a and b was calculated and tested with the Sobel test. We found a significant mediation effect (ab = 0.979, SE = 0.440, p = 0.026, with ab being the change in the outcome per one unit lack of understanding that goes through the mediator rejection of care; fig. 2).

The fit of the second model was also good (χ^2 test = 105.1, d.f. = 58, p = 0.0002, RMSEA = 0.027, CFI = 1.000, TLI = 1.000). The relationship between the slope for depression and the slope for rejection of care was significant (a = 0.828, SE = 0.138, p < 0.001), but there was not significant evidence that the slope in the mediator rejection of care was associated with the slope in behaviors directed towards others (b = 0.561, SE = 0.306, p = 0.067). The adjusted direct effect (c′ = 0.427, SE = 0.343, p = 0.214) and the indirect effect were also not significant (ab = 0.465, SE = 0.277, p = 0.094). Therefore, we cannot conclude that the relationship between depression and behaviors directed towards others is mediated by rejection of care. Since we did not observe changes in psychosis and pain, we did not consider mediation models for these processes.

Discussion

The results of this longitudinal study showed that changes in lack of understanding or depression commonly precede changes in rejection of care. Changes in behaviors directed towards others are related to changes in lack of understanding, depression and rejection of care. Furthermore, a mediation model suggested that the relationship between lack of understanding and behaviors directed towards others was mediated by rejection of care. Therefore, our results support conclusions of our previous cross-sectional study [13], which found that lack of understanding and depression are the two main risk factors for development of rejection of care and behaviors directed towards others. However, our results are more informative because longitudinal models provide more information regarding temporal relationships between the variables, and the mediation model provides information about the order in which the symptoms develop.

Initial psychotic symptoms and pain were also related to increased rejection of care, but we did not observe changes in the number of psychotic symptoms and pain within our study period. Regarding to the absence of observed changes in pain, Hendriks et al. [23] found a high

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proportion of patients with pain persistence. That precluded inclusion of psychotic symptoms and pain in the mediation model. A relationship of depression to resistive behavior (rejection of care) and aggression (abusive symptoms) was already reported by Lyketsos et al. [24] and by Leonard et al. [25]. They found, in agreement with our results, that psychotic symptoms play a minor role in the development of these behaviors.

The lack of understanding is caused by the progression of dementia, and it increases the prevalence of rejection of care [26]; this increase in rejection of care contributes to the increasing behaviors directed towards others. It may be improved by communication skills training of professionals and family caregivers that includes verbal skills, nonverbal and emotional skills, behavioral management skills, usage of tools and theoretical knowledge [27]. Such a program would be useful also in a hospital where many dementia patients are transferred [28]. The most important intervention is to teach the staff that most people with dementia are not aggressive; they just defend themselves against unwanted attention from the caregivers and may consider the caregivers to be the aggressors. Labeling somebody who is combative during care an 'aggressor' is blaming the victim. Similarly, this person should not be labeled as agitated. There is a clear-cut distinction between rejection of care and agitation [26], and the term agitation should be reserved for behaviors that occur when the resident is solitary, e.g. restlessness, repetitive movements, crying out [29].

We identified depressive symptoms using the MDS depression scale [16], which uses 7 MDS items. This scale correlated well with the Cornell and Hamilton depression scales using 'at least mild depression' as a cutoff point, and with psychiatric diagnosis. The MDS depression scale detected significant depressive symptoms in 51% of the subject population. This is comparable to 47.4% detected in a large study of a long-term care facility [30]. High prevalence of depression in individuals with Alzheimer's disease can be expected because Alzheimer's disease causes serotoninergic deficit, and some data indicate that this deficit may be related to aggressive behaviors [31, 32]. The relationship between serotoninergic function and aggressive behavior may not be unique to Alzheimer's disease because decreased serotoninergic activity is present also in frontotemporal dementia [33].

Our results suggest that depression contributes to both rejection of care and behaviors directed towards others and that the relation between depression and behaviors towards others is not mediated by rejection of care. Depression in dementia could be treated with psychological interventions as shown in a recent review [34]. Antidepressants could be the first line of medication for individuals exhibiting these behaviors directed towards others if psychotic symptoms are not present. Although some studies found improvement of behavioral symptoms after treatment with antidepressants [35, 36], other studies were negative. This was probably due to insufficient doses and duration of treatment. This was documented by the Depression in Alzheimer Disease Study, which found that treatment with sertraline decreased behavioral disturbance and caregiver distress only in patients whose depression responded to antidepressant treatment [37]. Antidepressant treatment was found effective in decreasing behavioral symptoms of dementia in a Cochrane data analysis [38] and in a recent citalopram study [10], but antidepressants may sometimes require augmentation with atypical antipsychotics [39].

The results of this study show that the psychotropic medications administered most frequently to the participants in this study were antipsychotics. It is possible that these drugs somewhat reduced rejection of care by their sedative effects. Similar prevalences of antipsychotic use were reported from a survey of nursing home physicians in the US [4] and a Dutch survey [40]. In that study, 32% of subjects received antipsychotics, which is comparable with reports from Sweden (38%) [41] and from Germany (32.5%) [42]. Antipsychotics are used frequently for treatment of behavioral symptoms of dementia despite multiple reports that found serious side effects including increased mortality in residents treated with these medi-

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cations [43]. Side effects of antipsychotics may be more serious in older men [44]. Efforts are made in several countries to decrease the use of antipsychotics in dementia. In the US, the prevalence of antipsychotic use in nursing homes is about 25% [45], and the use of antipsychotics was recently reduced by 9.1% [46]. In the UK, antipsychotic use in people with dementia decreased from 19.9% in 1995 to 7.4% in 2011, concomitant with an increase of antidepressants from 10.7 to 25.3% [47], indicating that antidepressants may be substituted for antipsychotics.

This study has several limitations. Our data were derived from MDS records that were completed mostly by nurses. However, these were experienced clinicians, and MDS data correlated well with other scales [48]. We have studied the relationship of only four factors in abusive behavior of nursing home residents with dementia. However, there are probably also other factors that may be involved, e.g. physical causes such as thirst, hunger or inappropriate environmental temperature. Using a discomfort scale [49] in future studies would provide information about the importance of these other factors. Our data could not evaluate these causes. A model with all predictors controlling for the influence of each variable would provide more evidence for causality than our models. Another limitation is that we did not have data about specific drugs and drug dosages that may have been modified in residents with rejection of care and behaviors directed towards others even when the prevalence of their use did not change.

Conclusions

The results of this study together with the results of previous investigations [13, 24–26] indicate that lack of understanding and depression are important factors in development of rejection of care and behaviors directed towards others, and that rejection of care may escalate into behaviors directed towards others. Initial psychotic symptoms and pain may also play a role. Furthermore, the relationship between lack of understanding and behaviors directed towards others may be mediated by rejection of care. Therefore, improved communication between caregivers and persons with dementia and perhaps also effective treatment of depression may prevent or ameliorate rejection of care and behaviors directed towards others.

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Disclosure Statement

The authors declare that they have no conflicts of interest.

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