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Original Study

Being Treated With Respect and Dignity?—Perceptions of Home Care Service Among Persons With Dementia

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A B S T R A C T

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Objective: Studies on the quality of home care services (HCS) offered to persons with dementia (PwDs) reveal the prevalence of unmet needs and dissatisfaction related to encounters and a lack of relationships with staff. The objective of this study was to enhance knowledge of the perceptions of PwDs regarding their treatment with dignity and respect in HCS over time.

Design: A mixed longitudinal cohort study was designed to study trends in the period between 2016 and 2018 and compare the results between PwDs (cases) and persons without dementia (controls) living at home with HCS.

Setting and Participants: Persons aged 65 years and older with HCS in Sweden.

Methods: Data from an existing yearly HCS survey by the Swedish National Board of Health and Welfare (NBHW) was used. The focus was on questions concerning dignity and respect. NBHW data sets on diagnoses, medications, HCS hours, and demographic information were also used. We applied GEE logistic and cumulative logit regression models to estimate effects and trends of interest after controlling for the effects of age, gender, self-rated health, and number of HCS hours.

Results: Over the study period, 271,915 (PwDs = 8.1%) respondents completed the survey. The results showed that PwDs were significantly less likely (3%-10% lower odds and cumulative odds) than controls to indicate that they were satisfied in response to questions related to dignity and respect. Both groups experienced a decrease in satisfaction from 2016 to 2018. Females, individuals with poor self-rated health, and individuals granted more HCS hours were found to be more dissatisfied.

Conclusions and Implications: The HCS organization needs to shift from a task-oriented system to a person-centered approach, where dignity and respect are of the utmost importance. The HCS organizations need to be developed to focus on competence in person-centered care, and leadership to support staff.

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With a rising older population, the number of persons with dementia (PwDs) is predicted to increase from 47 million worldwide in 2015 to 75 million by 2030. This increase will place serious demands on society in terms of the ability to provide high-quality care.¹ The global policy of “aging in place”^{2,3} suggests that older people should be

able to grow old where they wish (commonly in regular homes) and where they feel safe and in good circumstances, regardless of disability.⁴ In Sweden, in recent years, the number of beds in residential settings has decreased, meaning that PwDs have remained in their regular homes with home care service (HCS) and family carers as care providers to a greater extent than in previous years.^{5–7}

In Europe, in the northern countries, home care is commonly provided by the municipality, whereas in southern countries, home care is more commonly provided by informal carers.^{8,9} In Sweden, municipalities are responsible for ensuring that their inhabitants receive the support they need as regulated by the Social Services Act.⁴

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Anyone who considers themselves to be in need of support has the right to apply for assistance. The municipalities have care managers who are responsible for assessing the need for support from HCS,¹⁰ and who make decisions based on the individual's needs.¹¹ The care managers examine the needs individually, but the decision is usually made using standardized assessment tools, which according to research limit the individual's wishes and the quality of care,¹² and a PwD has difficulty participating in the needs assessment process.¹³ The public authorities are financially responsible for HCS, which can be provided by the municipality or outsourced to private agencies. HCS offers support with domestic tasks and personal care, which can include assistance with household tasks such as cleaning, shopping, and cooking, as well as with personal care such as bathing and dressing.¹⁴ Therefore, HCS should be provided by staff with the appropriate education and experience.⁴ In Sweden in 2019, most of the staff working most closely with the care recipients were assistant nurses and care assistants.¹⁵

Studies of the views of PwDs on HCS are sparse. Previous research shows that unmet needs and dissatisfaction are commonly related to encounters and a lack of relationship with staff. Furthermore, the support received does not match identified needs.¹⁶ Black et al¹⁷ found that unmet needs were common among PwDs and were related to safety, general health, and daily activities, and were correlated with lower quality of life and more neuropsychiatric symptoms, lower education levels among HCS staff, and fewer hours of HCS. Another study showed that PwDs whose needs were met also experienced higher well-being and higher quality of life.¹⁸ Moreover, PwDs living in regular housing had more social support and less functional impairment but worse health and more neuropsychiatric symptoms than PwDs in residential care.¹⁹

The WHO Global Action Plan on the Public Health Response to Dementia 2017–2025 (WAP2017)³ proposes that PwDs and their carers should live well and receive the care and support they need to fulfill their potential with dignity, respect, autonomy, and equality. This plan is well aligned with the Swedish national fundamental values for care for the elderly, which state that a person should be treated with dignity and respect, and that needs, values, and desires should be the main focus,⁴ which is also in line with the national guidelines for the care of PwDs in Sweden. These guidelines should be applied in all types of care settings for PwDs. The guidelines also stress that the care should be person-centered,²⁰ meaning that care is based on respect for the person's uniqueness by supporting and respecting their preferences and self-determination, becoming familiar with their situation and understanding their behavior.^{20,21} Reviews of previous research have also shown an improved quality of life for persons with dementia when the care has been person-centered.^{22,23} Person-centered care (PCC) is considered a prerequisite for high-quality dementia care⁷ and the Swedish strategy and guidelines are in line with WHO's WAP2017. Although it is too early to assess any progress in response to the WAP2017 or NBHW strategies, it is important to examine the direction that it is taking to have an early indicator of whether more attention needs to be paid to specific issues in order to comply with the vision. In addition, the Swedish National Board of Health and Welfare (NBHW)²⁰ and other previous European research^{24,25} have shown that, in general, HCS staff are poorly prepared to care for PwDs and seldom receive the necessary support at the organizational level to provide high-quality HCS.

Every year, persons 65 years and older who have been granted HCS are invited to participate in a national user survey conducted by the NBHW about their experiences with HCS.²⁶ However, the survey results are presented for the total sample without further analysis of the survey subgroups. The aim of this study was to enhance knowledge of the perceptions of PwDs regarding their treatment with dignity and respect in HCS over time. We use the 2016 results as the baseline for

comparison with the 2017 and 2018 results to determine whether there has been progress since the adoption of the WAP2017.

Methods

Study Design

The study population consists of individuals aged 65 years and older in the year 2018 who were granted HCS support at their regular housing in 2016, 2017, and 2018. With 3 years of data, we used a mixed longitudinal cohort study design²⁷ to assess differences between PwD (cases) and persons without dementia (controls) over the years in terms of feelings of being treated with respect and dignity. Because the WAP2017³ was adopted in 2017, we took 2016 as the comparison year to assess any progress compared to the year before the WAP2017 was adopted. This study was approved by the Ethical Review Board in Uppsala (2017/140).

Setting and Sample

Each year, the NBHW sends its survey to every individual who is granted HCS (approximately 145,000 individuals each year; see Figure 1). For individuals who cannot answer the questionnaire themselves, a relative (proxy response) is asked to respond. The overall response rate was approximately 60%. After accepting the proxy responses, we assumed that the nonresponse mechanism was missing completely at random (MCR).²⁸ Relying on the MCR assumption, we treated the data being analyzed as a random sample of the underlying population.

To identify PwDs, we used medical register data on diagnosis and medication, also maintained by the NBHW. We identified individuals who had been diagnosed with dementia using ICD-10 codes F00–F03 or had been prescribed medication using code N06D in 2016 as the cases (PwDs) and the remaining individuals as controls.

Data Collection

The NBHW survey consists of 25 questions covering the following areas: contact with the community; influence; the provision of support and help; treatment; security; social activities; availability; and overall perception of HCS.²⁶ Two questions are about being treated with respect and another 2 are about dignity, which we used as the response variables, and a question on overall health was used as an independent variable. Demographic data, such as date of birth, gender, and geographic location (with zip code), were collected from another database, because these variables were not part of the user survey. We supplemented the survey data with patient register data, the medical register, and the HCS register on granted service time. The questions and response options, including data sources, are presented in Tables 1 and 2. The independent variables in each model are presented in Table 2.

Statistical Methods

We used descriptive statistics to examine whether the survey respondents represented the underlying study population with respect to their backgrounds. As we do not have any information about those who did not reply to the survey questionnaire, these comparisons only provide us with an indication of possible violations of the MCR assumption. We fitted a cumulative odd (or proportional odds) ordinal logistic regression model for the ordinal responses and a logistic regression model for the binary responses. The same independent variables were used in all 4 models. To address the longitudinal nature of the observations, the models were fitted in R statistical software (R Foundation for Statistical Computing, Vienna, Austria, 2017) with the

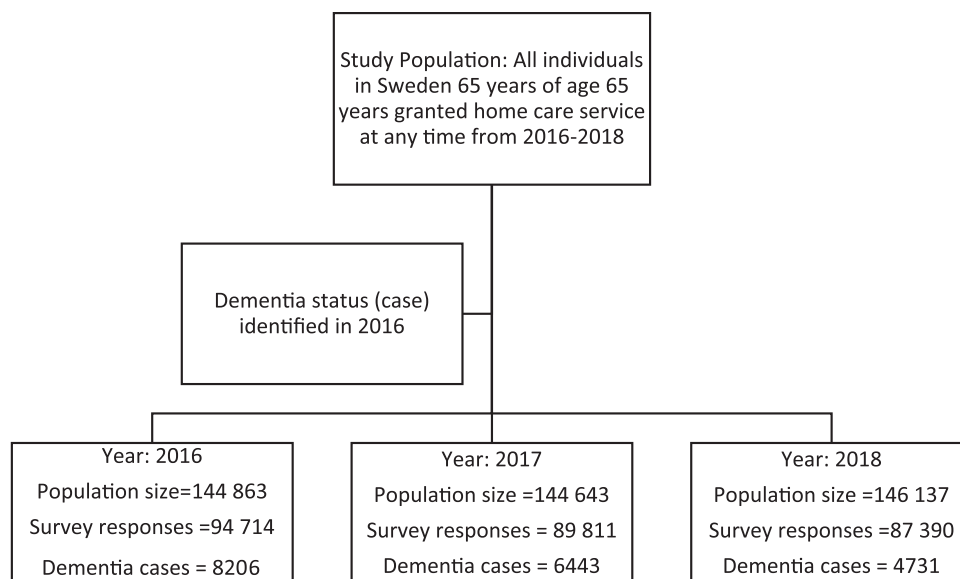


Fig. 1. Flowchart of the study design.

generalized estimation equations (GEEs) approach by using the “multgee”²⁷ package (for ordinal logistic model) and the “gee” package (for logistic regression).

Results

The descriptive statistics of the sample (Table 3) show that the prevalence of dementia in the comparison year (2016) was 8.7% (10.3% for all individuals who had been granted HCS in 2016), two-thirds of the sample were women (65% females among the PwDs in 2016), and the average age was nearly 85 years (84 years for the PwDs in 2016). Respondents, on an average, were granted 6.5 hours/wk of HCS in 2016 (vs 7 hours/wk in the population). These descriptive statistics do not indicate any real departure of the respondents’ backgrounds from

the respective population average. Therefore, the MCR assumption could be reasonable.

In most cases, the PwD responses indicated that they were less satisfied than the control individuals. The differences between PwDs and controls were marginal (Table 3). To consider all the ordinal response categories and adjust for any effects of confounding variables, we used cumulative odds logistic regression (Table 4).

The estimated (cumulative) odds ratios (ORs) for the 4 dependent variables in the 4 models (Table 1) are presented in Table 4. The results show that all the independent variables included in the 4 models (Table 4) were statistically significant (at the 5% level of significance). The results from model 1 show that PwDs had about 5% lower cumulative odds than the controls of providing a positive response (always treated with respect) rather than a negative response

Table 1
Presentation of Dependent Variables in the 4 Statistical Models

Models and Variables	Model Type	Question	Response Alternative
Model 1 Respect	Cumulative logit, GEE	Does the staff treat you well?	Ordinal response: 1 = Always treated well... 5 = Never treated well
Model 2 Respect	Logistic, GEE	No, I did not experience any of the following: Staff 1) did not show respect for your privacy, eg, did not knock on the door before entering your room. 2) made negative comments about you, your belongings, or your home 3) treated you disrespectfully in words or gestures 4) treated you like a child 5) denied your wishes for the help to be received 6) did not show respect in toileting, bathing, and dressing 7) was harsh about toileting, bathing, and dressing 8) kept distance in nursing 9) acted inappropriately in some other way	Binary response: Not experienced of any of the 9 listed negative incidents = 1, and 0 otherwise.
Model 3 Dignity	Cumulative logit, GEE	Does the staff take into account your opinions and wishes on how the assistance should be performed?	Ordinal response: 1 = Opinions about services were always respected, ..., 5 = Opinions were never respected
Model 4 Dignity	Cumulative logit, GEE	Could you influence the HCS service schedule?	Ordinal response: 1 = Yes, always, ..., 5 = No, never

Data on all the dependent variables are acquired from the NBHW Survey.

Table 2
Independent Variables in all 4 Models

Variable	Description and Question	Response Options and Measurement Scale	Source
Year	Survey year	Categorical: 2016, 2017, and 2018	NBHW survey
Age	(Age in years – 65)/10	Continuous: unit = 10 y	NBHW survey
Gender	Gender of the respondent	Categorical: 1 = male, 2 = female	NBHW survey
Self-report	Who responded to the survey	Binary: 1 = self-report, 2 = proxy response	NBHW survey
Dementia status	Whether the respondent was diagnosed with or received medication for dementia in 2016	Binary, 1 = dementia, 0 = not dementia	Medical register data obtained from the NBHW
Overall self-reported health	How do you assess your overall state of health?	Ordinal response treated as categorical, 1 = very good ... 5 = very poor)	NBHW survey
HCS hours granted within 1 calendar year	Total number of HCS hours granted in a calendar year	Continuous, rescaled with 1/8784 to range from 0 to 1	Database on home care service hours. Data obtained from the NBHW

(sometimes or never treated with respect). The declining cumulative odds over 2017 and 2018 (Table 3) indicate declining satisfaction in respect over the years compared to 2016. This trend was found for both PwDs and controls. Respondents who answered the survey by themselves also had 36% higher cumulative odds of providing positive rather than negative responses than those for whom a proxy completed the survey. The results of model 2 (Table 4) show that PwDs had 7% higher odds than the controls of not reporting having experienced any of the 9 listed negative incidents that indicated a lack of respectful treatment. The decreasing (cumulative) ORs in 2017 and 2018 indicate that the prevalence of these incidents increased over the years. Furthermore, in model 2, those with fair to very poor self-rated health had significantly higher odds of reporting a negative incident than those with very good self-rated health.

Models 3 and 4 show that PwDs had 10% and 4% lower cumulative odds, respectively, than controls of providing positive (always) rather than negative (never) responses. This finding indicates that PwDs were more likely than controls to report not being treated with dignity. The decreasing cumulative ORs in 2017 and 2018 indicate a declining satisfaction level related to dignity over time.

The effects of the other covariates (Table 4) were more or less in the same direction across all models. In models 1 and 2 (respect), higher age was associated with higher cumulative odds of being treated with respect. In models 3 and 4 (dignity), for every 10-year increase in age, the cumulative odds of being treated with dignity decreased by 2% and 14%, respectively. All 4 models indicate that female respondents were less satisfied (between 3% and 12% lower odds and cumulative odds) than the male respondents. All 4 models revealed that the self-reported satisfaction levels were higher than those reported by proxy (cumulative OR > 1 for proxy variable). It was also found that more granted HCS hours was related to lower satisfaction levels (OR and cumulative OR < 0.1).

Discussion

The results reveal that PwDs were less satisfied than controls in terms of being treated with respect and dignity for 3 of the 4 questions. Furthermore, our results also showed that in both groups, the level of satisfaction with HCS declined sharply over the years. Persons with poor self-rated health or who had been granted more HCS hours were also less satisfied, as were those who answered the survey by

Table 3
Summary Statistics of the Key Variables

Variables	Years			
	2016	2017	2018	Overall
Independent variables				
Dementia, % (sample size, n)	8.7 (n = 94,714)	7.2 (n = 89,811)	5.4 (n = 87,390)	8.1 (n = 271,915)
Average age (SD)	84.6 (7.49)	83.7 (7.55)	83.5 (7.55)	83.9 (7.5)
Female, %	67.2	66.7	66.4	66.8
HCS hours/y, mean (SD)	376.03 (409.2)	362.64 (404.8)	364.23 (402.8)	367.81 (405.7)
Very good or good self-reported health, %				
PwD	30.3	32.4	31.1	31.2
Control	29.6	30.1	30.0	29.9
Dependent variables				
Staff always treated well, %				
PwD	72.5	72.8	70.6	72.1
Control	75.1	75.3	73.6	74.7
Experienced any of the listed 9 incidents, %				
PwD	14.2	14.5	15.3	14.6
Control	13.6	13.6	15.0	14.0
Opinions about services were always respected, %				
PwD	42.2	41.8	40.6	41.7
Control	46.6	46.4	45.1	46.1
Could always influence the HCS service schedule, %				
PwD	20.4	20.9	19.7	20.4
Control	21.8	20.9	20.3	21.0

For the ordinal response variables, only the prevalence of the first (positive) response category is presented. For self-reported health status, the first 2 response categories were combined.

Table 4
OR and Cumulative OR Estimates From the Fitted Models of Respect and Dignity

Effect	Estimate (95% CI)			
	Model 1: Respect Cumulative OR	Model 2: Respect OR	Model 3: Dignity Cumulative OR	Model 4: Dignity Cumulative OR
Dementia: no	Ref.	Ref.	Ref.	Ref.
Dementia: yes	0.95 (0.92, 0.99)	1.07 (1.02, 1.12)	0.90 (0.87, 0.93)	0.96 (0.93, 0.99)
Year 2016	Ref.	Ref.	Ref.	Ref.
Factor 2017	0.92 (0.90, 0.93)	0.94 (0.92, 0.96)	0.91 (0.90, 0.93)	0.90 (0.89, 0.91)
Factor 2018	0.83 (0.81, 0.85)	0.84 (0.82, 0.86)	0.86 (0.85, 0.88)	0.86 (0.85, 0.88)
Age	1.14 (1.12, 1.16)	1.22 (1.20, 1.25)	0.98 (0.97, 0.99)	0.86 (0.85, 0.87)
Gender: male	Ref.	Ref.	Ref.	Ref.
Gender: female	0.92 (0.90, 0.94)	0.88 (0.86, 0.91)	0.97 (0.95, 0.99)	0.90 (0.89, 0.92)
Self-report: no, proxy	Ref.	Ref.	Ref.	Ref.
Self-report: yes, self	1.36 (1.34, 1.38)	1.20 (1.17, 1.23)	1.41 (1.39, 1.43)	1.32 (1.30, 1.34)
Overall health: very good	Ref.	Ref.	Ref.	Ref.
Overall health: good	0.54 (0.50, 0.58)	1.06 (0.98, 1.14)	0.51 (0.48, 0.53)	0.60 (0.57, 0.63)
Overall health: fair	0.34 (0.32, 0.37)	0.81 (0.75, 0.87)	0.32 (0.30, 0.33)	0.42 (0.40, 0.44)
Overall health: poor	0.23 (0.21, 0.24)	0.52 (0.48, 0.56)	0.22 (0.21, 0.23)	0.33 (0.32, 0.35)
Overall health: very poor	0.18 (0.16, 0.19)	0.38 (0.35, 0.42)	0.18 (0.17, 0.19)	0.29 (0.28, 0.31)
HCS hours granted/year	0.008 (0.007, 0.01)	0.004 (0.003, 0.005)	0.05 (0.04, 0.06)	0.11 (0.09, 0.13)

All the effects except "overall health = good" in model 2 were significant at the 5% level.

proxy. Our results reveal that HCS do not fulfill the Swedish national fundamental values in care of older people⁴ and are not in line with the Swedish national guidelines²⁰ or with WAP2017.³

There are several reasons for our results. Genet et al²⁹ suggest that it is particularly important for HCS staff to have adequate qualifications to respond to the complex needs of older people. Such qualifications require professional training and continuing education. Thus, our results are not surprising as previous research,^{24,25,30} as well as NBHW,²⁰ has indicated that staff generally lack the specific knowledge and prerequisites to provide individualized care in HCS. In fact, a survey from 2017 of the Swedish HCS showed that older people had an average of 15 different staff over a 14-day period,³¹ which meant that the continuity and possibility to nurture a relation, which is a requirement for PCC, was minimal. Furthermore, the focus in HCS is on the tasks to be completed rather than on building relationships. Other researchers³² have suggested that staff make choices about care action depending on their level of competence and operating conditions as well as social and professional support by leaders. Thus, a task-oriented approach requires knowledge of completing the task, but does not take into account competence for encounters, values, and ethics in the care, which might explain the lower ratings by PwDs than controls in terms of being treated with dignity and respect.

Dignity and respect are not the only components in the national fundamental values for care of older people and laws in Swedish health care. The components of PCC^{20,23,33–35} have also been described as fundamental for high-quality care, especially for PwDs. PCC includes respecting and preserving the person's uniqueness.³⁴ Thus, caring for PwDs requires knowledge about not only the disease but also about the importance of how to approach PwDs with a focus on what Kitwood described as helping the PwD experience the feeling of "being a person."³⁶

Previous research has revealed that staff commonly do not have the prerequisites at an organizational level (eg, time and education) to practice PCC and that strategies at the organizational level are of utmost importance.^{37–39} Research in the Swedish context has shown that the workload in HCS is increasing, with an increasing number of severely ill persons to care for and an increasing number of persons per staff member per day.⁴⁰ The schedules of HCS staff are full of tasks to be completed and with a general amount of time provided for the tasks, which likely results in a PCC approach being deprioritized simply due to a lack of time. This may also influence the health of staff, as Strandell⁴⁰ revealed that mental exhaustion and work-related problems among HCS staff are increasing. Other research showed

perceived job strain among staff because of their inability to deliver good enough care.⁴¹

Our study also found that older persons receiving HCS (both PwDs and controls) reported being treated with decreasing levels of dignity and respect over the years from 2016 to 2018. This was especially true for PwDs with poor self-rated health, those who had answered the survey by proxy, and those who were granted more HCS hours. One explanation might be that these individuals became more vulnerable over time because of progress in their dementia and possibly the presence of more diseases. However, HCS should provide high-quality services regardless of an older person's conditions, particularly when a person is becoming frailer. Such provision of services is problematic as more people are going to be in need of HCS with the increasing population of older people. This trend places serious demands on municipalities. Our results should be seen as contributing at both an organizational and national level, as these issues may be resulting from care that fails to meet something as fundamental as being treated with dignity and respect in the older person's own home. As PwDs with HCS are in need of complex care, and as both our results and previous research indicate a lack of quality in HCS, the organizations need to be improved so that they provide high-quality care. The NBHW guidelines²⁰ and strategies⁷ regulate how the care of PwDs is to be carried out, but it is the municipality's responsibility to implement them. Sweden has 290 municipalities, and there are differences in the implementation. The NBHW has initiated online courses in dementia care in an attempt to improve the competence of staff. However, in order to fully improve the care and make it sustainable, care organizations need to employ more registered nurses specializing in the care of older people and the care of PwDs in order to support the development of staff and provide guidance in their work. In addition, registered nurses, in particular specialist nurses and master's-prepared nurses, have appropriate competence related to the diseases, quality of life, and well-being of older people, and need to be more involved in the care to be able to judge the need of different treatments or interventions. Several recent studies^{42–44} in hospital care conclude that high nursing competence (Bachelor's degree) and high amount of nursing staff decrease the risk of mortality and low patient satisfaction. In community care, results are vaguer because of methodologic issues. But previous studies show that older persons' safety depends on the availability of staff competence,⁴⁵ and that a greater number of nurses is associated with a better quality of care and satisfaction.⁴⁶ In addition, it could be argued that working conditions for HCS staff need to be improved to ensure both the quality of care and staff well-being to be able to retain and recruit workers. In fact,

the study by Aiken et al⁴² reported that a high nurse competence and staffing resulted in better work environment and less burnout.

Limitations

The primary strength of this study is the access to a large body of longitudinal survey data accompanied by register data on respondents' background characteristics, including their medication and diagnoses. The data do not include any information on the severity of dementia, which may be a limitation. Some respondents answered the survey by proxy, and we do not know the reason for that. It should also be noted that the proxy has reduced the survey's nonresponse rate, but this may not have fully revealed the perceptions of PwDs. The dementia status of the respondents was assessed in 2016 based on diagnosis and medication records. This approach may have led a PwD to be identified as a control because that person might have been neither diagnosed nor treated prior to 2016, but might have had dementia (but not asked for treatment) or been diagnosed (or treated) after 2016. This may lead to the control group containing a mixture of PwDs and controls. However, because the prevalence of dementia in the target population is very low (approximately 8%), and because the size of the control group was large, this might not be an important issue. Furthermore, the number of dementia cases decreased over the years, possibly because of death, transition to specialized care, or simple nonresponse, but we were not able to distinguish these cases from the data. The survey data had an approximately 40% nonresponse rate, which we treated as MCR. The descriptive statistics showed that the background characteristics of sampled individuals were in line with a previous register study,⁴⁷ also with data from 2016 in Sweden. However, the MCR assumption could not be statistically tested using the observed data. An analysis of the regional variations would also be interesting, which will be future work. We ran the models with 290 municipalities and found some variations between some municipalities, although this did not change our conclusions.

Conclusions and Implications

The HCS organization needs to change from a task-oriented approach to a person-centered approach to be able to provide high-quality care. In a PCC, dignity and respect are of the utmost importance. The guidelines stress this, but the organizations need to focus on competence in PCC and on leadership, preferably by including more registered nurses to lead and support the staff in their caring. This will require financial support from the government, but will be crucial for carrying out the Swedish dementia strategy and the WHO Global Action Plan.

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