

PERCEPTION OF DIGNITY IN MEN AND WOMEN WITH DEMENTIA**1 Perception of dignity in older men and women in the early stages of**
2 dementia: a cross-sectional study

3 Lucie Klůzová Kráčmarová^{a*}, Jitka Tomanová^b, Kristýna A. Černíková^a, Peter
4 Tavel^a, Kateřina Langová^b, Peta Jane Greaves^c, Helena Kisvetrová^b

5 ^a *Olomouc University Social Health Institute; Sts. Cyril and Methodius Faculty of Theology,*
6 *Palacky University Olomouc, Czech Republic*

7 ^b *The Centre for Research and Science, Faculty of Health Sciences, Palacký University*
8 *Olomouc, Czech Republic*

9 ^c *Department of Nursing, Midwifery and Health, Faculty of Health and Life sciences,*
10 *Northumbria University, Newcastle upon Tyne, United Kingdom*

11
12 *Correspondence concerning this article should be addressed to Lucie Klůzová
13 Kráčmarová, Olomouc University Social Health Institute, Faculty of Theology, Palacky
14 University Olomouc, Univerzitni 244/22, 771 11 Olomouc. Telephone number:
15 +420 739 228 117, Email: lucie.kluzova@oushi.upol.cz

16 Author note

17 Lucie Klůzová Kráčmarová  <https://orcid.org/0000-0003-3406-3176>

18 Jitka Tomanová  <https://orcid.org/0000-0002-2534-3742>

19 Kristýna A. Černíková  <https://orcid.org/0000-0003-3363-0431>

20 Peter Tavel  <https://orcid.org/0000-0001-7072-001X>

21 Kateřina Langová  <https://orcid.org/0000-0003-2387-0183>

22 Peta Jane Greaves  <https://orcid.org/0000-0002-3209-9960>

23 Helena Kisvetrová  <https://orcid.org/0000-0003-0174-5779>

PERCEPTION OF DIGNITY IN MEN AND WOMEN WITH DEMENTIA

24 **Perception of dignity in older men and women in the early stages of dementia: a cross-** 25 **sectional study**

26

27 **Abstract**

28 **Background:** Dementia is a serious problem in old age, that impacts an individual's ability to
29 function and may threaten personal dignity. Given the variable features of the illness and the
30 diversity of life experiences, many factors may contribute to the perception of dignity by men
31 and women with dementia. The purpose of the study was to explore the factors that contribute
32 to dignity and its domains in men and women with dementia.

33 **Methods:** This cross-sectional study involved 316 community-dwelling patients with early-
34 stage dementia (aged ≥ 60) (PwD). We assessed the participants' sociodemographic and
35 social involvement characteristics, health-related variables (pain, depression, physical
36 performance, visual and hearing impairments), attitude to aging, and self-sufficiency in the
37 activities of daily living (ADL). These factors were investigated as independent variables for
38 the perception of dignity and of its domains in men and women.

39 **Results:** Multivariate regression analysis showed that PwD experienced minor dignity
40 problems in the early stages of dementia. In both men and women higher rates of depression,
41 negative attitudes to aging, and pain were associated with reductions in the perception of
42 dignity. In men, but not in women visual impairment had a negative effect on overall dignity,
43 and on the associated domains of 'Loss of Autonomy' and 'Loss of Confidence'. In women,
44 lowered self-sufficiency in ADL contributed to reduced self-perception of dignity and in the
45 associated domains of 'Loss of Purpose of Life', 'Loss of Autonomy', and 'Loss of
46 Confidence'. Sociodemographic and social involvement characteristics, hearing impairment,
47 and physical performance did not influence the participants' self-perception of dignity.

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48 **Conclusion:** The results suggested that several common factors (depression, attitudes to
49 aging, and pain) contribute to the perception of dignity in both men and women. Other
50 factors, visual impairments in men, and self-sufficiency in ADL in women, appear to be more
51 gender specific. These differences might relate to their specific gender roles and experiences.
52 The self-perception of dignity in PwD can be helped by supporting the individual, to the
53 extent that their illness allows, in maintaining activities that are important to their gender
54 roles, and that preserve their gender identity.

55 **Trial registration:** NCT04443621

56

57 **Keywords:** activities of daily living, attitude to aging, dementia, depression, dignity, gender,
58 older adults, pain, visual impairment

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73

74 **Introduction**

75 *Dignity in People with Dementia*

76 Dementia is a neurodegenerative disease characterized by progressive, irreversible,
77 and (as yet) incurable cognitive decline. People with dementia (PwD) retain their positive
78 personality traits and character, however, as the illness progresses, symptoms such as memory
79 loss; speech impairment; disorientation; dependency in the activities of daily living (ADL);
80 and self-neglect, are common (1). In the early stage of dementia, patients are able to reflect on
81 their disease. Awareness of a deteriorating condition and related symptoms increases the risk
82 of depression, anxiety, and reduced quality of life (2). It can also lead to a reduced perception
83 of their dignity (3).

84 Dignity can be defined as a multidimensional construct that includes perception,
85 knowledge, and emotions related to competence or respect (4). It is a subjective experience of
86 individuals' own self-worth and self-esteem, as well as the respect and esteem that others
87 show them (5, 6). Nordenfelt (7) suggested that the dignity of identity is particularly crucial in
88 the context of illness and old age. In older adults, frailty, dependence, sensory impairments,
89 and cognitive decline tend to compromise dignity (8). Based on these assumptions, it would
90 be appropriate to address the area of dignity specifically for older adults with dementia.
91 However, regarding dementia, dignity has most often been examined from the point of view
92 of health professionals or other caregivers (9). The limited number of studies that have
93 focused on the issue from the point of view of the people with dementia (PwD) found that a
94 threat to dignity existed, to varying degrees, in both PwD living in institutional care (10, 11),
95 and those living in their own home (3, 9, 12, 13).

96 Some of these studies have also suggested which variables might be related to the
97 perceived dignity of PwD (10, 12). Reduced self-sufficiency in ADL and increased dependence

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98 on caregivers were among the factors influencing the dignity of PwD living in nursing homes
99 (10). In community-dwelling PwD, dignity correlated positively with a higher degree of self-
100 sufficiency in ADL, a lower level of depression, and better attitudes to aging (12). Attitudes to
101 aging are social constructs that are culturally and historically situated, and individually
102 interpreted (14). They relate to physical and social losses and gains in the past and present, and
103 psychological growth, which can then be reflected in the sense of personal dignity (15). ~~Women~~
104 ~~generally have more concerns about aging (16), and more negative attitudes to aging and old~~
105 ~~age (17). The study of Kisvetrová et al. (12) suggested that attitudes to aging are also related to~~
106 ~~gender in PwD. In their study~~ In the study of Kisvetrová et al. (12), women with dementia
107 associated aging with psychosocial loss (experience of loneliness), social exclusion, and the
108 gradual worsening of physical self-sufficiency. How gender contributes to the domains of the
109 Patient Dignity Inventory (PDI), which is used to assess dignity in PwD (18), was not examined
110 in their study (12). The domains assessed in the PDI might however, contribute differently to
111 the overall perception of dignity, and these associations may be gender sensitive.

112 *Specifics of Dignity in Men and Women with Dementia*

113 The differences in dignity between men and women with dementia are worth
114 addressing if only because dementia itself differs between both groups (19). Women are more
115 likely to suffer from dementia than men, and their disease usually progresses more rapidly
116 (20). ~~There are few studies of differences in education, mental health, caregiving, and other~~
117 ~~roles, where factors relating to sex~~ The differences in a prevalence, course or outcomes of
118 dementia might be associated with factors relating to sex (biological attributes of physical
119 body of male or female (21), such as different physiological factors, which might be
120 associated with dementia (22)) and gender (complex patterns of social roles, identities, norms,
121 values and behaviours of male, female and gender-diverse persons (~~18, 21~~), such as different

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122 ~~roles in society or education of men and women (22)).~~ ~~.) may contribute to differences~~
123 ~~between men and women with dementia.~~

124 Although ~~differences in the factors associated with dignity may exist between older~~
125 ~~men and women with dementia, to our knowledge~~, no previous research has been done to
126 clarify ~~these~~ ~~the association between~~ ~~n PwD. To better understand the association of~~ gender
127 ~~with and~~ perceptions of dignity ~~in PwD, we need to look at~~ research findings in other groups
128 of older patients ~~can provide us some insight~~. In a previous study in individuals at the end of
129 life (23), it was found that ~~sociodemographic characteristics, including female~~ gender, have
130 ~~more~~ influence on ~~how people perceive their~~ ~~reduced sense of~~ dignity. ~~than does health status.~~
131 ~~Female gender, younger age, absence of a partner, and a lack of importance of religion were~~
132 ~~related to a reduced sense of dignity.~~ Women considered that psychological factors (e.g., the
133 inability to think clearly, feelings of depression and anxiety) and social factors (a person
134 feeling that they are a burden on others, a sense of loss of privacy) had a greater impact on
135 their dignity than ~~did problems with physical health~~ ~~their health status~~. In comparison, in a
136 study of nursing home residents (24), some physical and/or long-term care items were rated as
137 more likely to impact negatively upon their dignity by male than by female respondents. In
138 contrast, gender did not show a significant association with dignity in a study of patients with
139 terminal cancer (25). Therefore, the relationship between perceived dignity and gender is
140 unclear in older-adult patients. Since research is limited in the area of dignity of PwD, and the
141 gender perspective must be taken into account in order to fully understand the factors related
142 to the perception of dignity (4, 26, 27), the goal of the present study was to discover ~~any~~
143 factors that affect dignity differently in men and women.

144 **Cultural Specifics of the Czech Men and Women.**

145 ~~As our study is carried out on the Czech population, it is essential to mention some~~
146 ~~cultural issues that may influence gender roles.~~ In the Czech Republic there are differences in

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147 family, societal and employment life, average level of education, and representation in
148 decision-making (such as political representation or managerial positions) between men and
149 women (28).

150 In terms of family life, the Czech Republic supports maternal and parental leave for
151 child-care up to 4 years of age. There is limited access to day-care facilities for children under
152 three years. Almost exclusively, it is the mother, who stays at home with the children. Long
153 career breaks affect women's position in the labour market (29), and deepen the employment
154 and pay gap between men and women, which is among the highest in Europe (28). Taking the
155 impact of lower pensions (30) and longer life expectancy together, older Czech women
156 experience poverty and social exclusion much more than men.

157 In later life Czechs often continue to work and also take on the responsibility of caring for
158 their aging relatives, as trust in institutional care is not very strong in the post-socialist Czech
159 Republic (31). The family caregivers are mostly women (32). Men also look after their
160 parents, but not as frequently, nor as intensely, and when the older-adults' needs grow the
161 men's involvement in care decreases (32). There is limited research on men's gender roles in
162 Czech society. In a recent qualitative study conducted with grandfathers (33), the participants
163 indicated and endorsed differences in gender roles between men and women. They consider
164 that caring for their relatives is their responsibility that constitutes an important part of their
165 personal identity, gender role, and duty (31). ~~Men also look after their parents, but not as~~
166 ~~frequently, nor as intensely, and when the older-adults' needs grow the men's involvement in~~
167 ~~care decreases~~ (32). ~~There is limited research on men's gender roles in Czech society. In a~~
168 ~~recent qualitative study conducted with grandfathers (33), the participants indicated and~~
169 ~~endorsed differences in gender roles between men and women. They~~ Men perceived the men'
170 their role to be as a breadwinner during productive lives and as grandparents, they taught their
171 grandchildren masculine roles (33), whereas women consider caring for their relatives as their

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172 gender role, their responsibility that constitutes an important part of their personal identity,
173 and duty (31). In a society with traditional division of gender roles, men do not often talk
174 about their problems, and they avoid requesting help (34). This might be related to the idea of
175 male identity being based on self-reliance, physical and mental strength, which, in older
176 Czech men, might be reinforced by experience of compulsory military service (35). These
177 specifics may be important in understanding how Czech men and women differently perceive
178 their dignity.

179 *The present study*

180 To our knowledge, there are no published studies of whether men and women with
181 dementia differ in their experience of dignity. To examine factors that could be related to
182 dignity in men and women with dementia living in the community, the present study focused
183 on variables that have previously been suggested to relate to dignity in PwD. These were pain,
184 depression, attitudes to aging, self-sufficiency in ADL (12), sociodemographic characteristics
185 (such as age, education), and also the characteristics of social involvement of the participant
186 (e.g. living arrangements, involvement in social activities). We also included visual and
187 hearing impairments and physical performance as independent variables. Both are related to
188 health outcomes (36-38), quality of life (39, 40) and self-sufficiency in ADL (39) and thus,
189 we hypothesize a link between these variables and dignity. We expect to find different factors
190 contributing to dignity and its domains in men and women with dementia. Understanding
191 which factors affect self-perceptions of dignity in PwD can further pave the way toward more
192 effective dignity-conserving, community-based care.

193 **Methods**

194 *Participants*

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195 The research sample consisted of PwD living in the Czech Republic, and the research
196 was conducted in their native Czech language. We used a non-probability sampling method
197 combining criterion and convenience sampling. Firstly, we defined inclusion and exclusion
198 criteria. Secondly, we approached the criterion fitting patients on the basis of their
199 accessibility and availability. The inclusion criteria were as follows: (1) age \geq 60 years; (2)
200 living in the community rather than in residential care (3) diagnosed with any type of dementia
201 in an early stage (diagnosis according to the International Statistical Classification of Diseases
202 and Related Health Problems [ICD] -10 Version: 2019: F00, F01-F03; Mini-Mental State
203 Examination [MMSE] with a score of 20–25 points). The exclusion criteria for all
204 respondents were as follows: (1) permanent institutional care; (2) complete immobility; (3) a
205 severe psychological disorder (schizophrenia, bipolar affective disorder); (4) a severe sensory
206 disability (blind, deaf); and (5) terminal stage of an oncological or non-oncological disease.
207 We were interested in the community-dwelling patients because this group is less studied than
208 the older PwD living in institutions. For this group, it could also be assumed that their
209 difficulties with dignity would be related to the nature of the illness rather than to the situation
210 of living in the institution.

211 The respondents were approached through neurological and geriatric outpatient
212 departments, placed in different parts of the Czech Republic, where they were being treated
213 for dementia, so it was ensured that the person was indeed diagnosed with the illness. During
214 their regular check-up, they were offered the opportunity to participate in the study and it was
215 explained what questionnaires they would fill out. None of the respondents refused and all
216 signed informed consent before inclusion in the study. They were competent and independent
217 in their decision. Researchers explained to the participants how to complete the
218 questionnaires. The participants filled out the tools by themselves or with help of the

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219 researcher, as a structured interview, if it was preferred. The data was collected from June
220 2020 to June 2021 in three regions of the Czech Republic.

221

222 *Measures*

223 The cross-sectional study was conducted as part of the longitudinal study "Changes in
224 the perception of personal dignity over the course of dementia" (registered in Clinical
225 Trials.gov.; No. NCT04443621). Independent variables were the sociodemographic
226 characteristics of the participants and characteristics related to general physical and mental
227 health (pain, physical performance, sensory impairments, and depression), attitudes to aging
228 and self-sufficiency in ADL. Dignity and its domains were the dependent variables in our
229 study.

230 **Independent variables.**

231 Sociodemographic and social involvement information was gathered during structured
232 and standardized interviews. All variables, except for age, were dichotomized. An interviewer asked
233 about participants' level of education (dichotomized as lower [elementary school, vocational]
234 and higher [secondary school, university] education), and their living arrangements
235 (dichotomized as living alone, living with others). Regarding social involvement, participants
236 were asked when they participated in a social activity for the last time (more than 30 days ago
237 or 30 or less days before the interview), how long it had been from a friend or a relative
238 visited them (more than 30 days ago or 30 or less days before the interview), how long it was
239 from the last email or telephone contact with friends or relatives (more than 7 days or 7 or less
240 days before the interview), and how many hours a day does a participant spend alone
241 (dichotomized as whether the participant spent more than 8 hours or less hours alone daily.

242

243 *Pain.*

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244 Perceived pain was graphically assessed on the Horizontal Visual Analogue Scale
245 (HVAS), which consists of a continuous 10-cm line at which the patient records the level of
246 subjectively perceived pain (no pain to extreme pain) (41, 42). HVAS can be successfully
247 used in most PwD (41).

248 *Physical performance.*

249 To assess physical performance, we used the Short Physical Performance Battery
250 (SPPB, (43); Czech version (44)). The SPPB includes assessments of balance, gait speed, and
251 chair rises, that can be administered easily and quickly. The total score ranges from 0 to 12.
252 Higher scores indicate a higher physical performance. SPPB total score ≤ 6 points is rated as a
253 frail older adult (43).

254 *Self-sufficiency in activities of daily living.*

255 Participants' self-sufficiency in ADL was assessed by the Bristol Activities of Daily
256 Living Scale (BADLS, (45); Czech version (46)) that covers basic and instrumental ADL,
257 from completely independent to completely dependent. The questionnaire is completed by the
258 carer of the PwD, who evaluates the performance of 20 activities in the life of the patient (45).
259 The overall BADLS score ranges from 0 (completely independent) to 60 points (completely
260 dependent). In the Czech version (BADSL-CZ), the score is also converted into percentages
261 representing the range of self-sufficiency (0%–100%), where 100% means the complete self-
262 sufficiency in ADL of the person being evaluated (46).

263 *Visual and Hearing Impairments.*

264 Participants' visual and hearing impediments were estimated by a clinician using a screening
265 test of visual acuity for distance (optotype) and near vision, and a subjective hearing
266 examination (speech testing). They were dichotomized as no/minimum or medium/severe
267 impairment.

268 *Depression.*

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269 We estimated depression status by the Geriatric Depression Scale (GDS-15, (47) ; Czech
270 version (48)) containing 15 self-assessment items. The total GDS-15 score ranges from 0 to
271 15 points. The higher the total score, the greater the severity of depression (0-5 points are
272 considered normal, more than 5 points indicates depression). GDS-15 has 92% sensitivity and
273 89% specificity when evaluated according to diagnostic criteria and distinguishes depressed
274 patients from highly correlated non-depressive adults ($r = 0.84, p < 0.001$; (47)). It is a valid
275 and reliable tool for screening for depression that can also be used in PwD (49).

276 *Attitude to Aging.*

277 We used the Attitude to Aging Questionnaire (AAQ, (50); Czech version (51)), which
278 consists of 24 items that are divided into three domains: Psychosocial Loss, Physical Change,
279 and Psychological Growth (IRT [Item Response Theory] equivalents of Cronbach's values for
280 these domains: 0.81, 0.81, and 0.74, respectively). Each domain score is from 8 to 40 points.
281 The total AAQ score ranges from 24 to 120 points. Higher scores indicate more positive
282 attitudes to aging (50). The applicability of this scale in PwD was confirmed by a previous
283 study (52).

284 **Dependent variables.**

285 *Dignity and its domains.*

286 Dignity was estimated by *The Patient Dignity Inventory* (PDI, (18); Czech version PDI-CZ,
287 (53)), a 25-item questionnaire, which concentrates on understanding the problems connected
288 with patient dignity. The total score of the questionnaire ranges from 25 to 125 and it is a sum
289 of individual items. A higher score indicates a greater threat to dignity (18). The scores of the
290 PDI may be divided into four categories: 'mild' (25–49 points); 'moderate' (50–74 points);
291 'severe' (75–99 points); and 'very severe' (100–125 points) (54). The suitability of the PDI
292 for use for PwD has been demonstrated earlier (55). The Czech version, PDI-CZ, is based on
293 items divided into four subscales following a factor analysis ('Loss of purpose of life'; 'Loss

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294 of autonomy'; 'Loss of confidence'; and 'Loss of social support' [internal consistencies range,
295 Cronbach's α 0.58-0.90]; (53)). The Czech version was validated in PwD by a previous study
296 (12) We examined the total PDI-CZ (53) as the overall experience of dignity, and the four
297 domains of dignity as dependent variables in our study. The domain 'Loss of purpose'
298 consists of 13 items and it is related to life purpose in relation to illness, self-appraisal, and
299 future. 'Loss of autonomy' items are connected with self-care, dependency, and reactions
300 from the environment. The domain of 'Loss of confidence' is related to the mental and
301 existential insecurities. Questions relate to inability to think clearly, feelings of depression or
302 anxiety, and spiritual concerns. The domain of 'Loss of social support' consists of three items
303 mapping respondents feelings of being supported by friends, family or health care providers
304 and being treated with respect (53).

305 *Statistical analysis*

306 Ratio variables were presented using average, standard deviation, and minimum and
307 maximum values. Discrete variables were described using absolute and relative frequencies.
308 The differences between the two independent selections for discrete data were verified using
309 the Accurate Fisher Test. The differences between the two independent selections in
310 quantitative data were calculated using a two-sample t-test. The Mann-Whitney U test was
311 used for ordinal quantities. The ANCOVA method was used to distinguish the relationship
312 between gender and the physical performance of PwD from the influence of age. All tests
313 were carried out at the level of statistical significance $p = .05$.

314 The multivariate linear regression assessed the link of sociodemographic
315 characteristics, sensory impairments, pain, depression, physical performance, levels of self-
316 sufficiency in ADL, and attitudes to aging with the perception of dignity, individually for men
317 and women. Prior to the analysis, the regression diagnostics of linearity, multicollinearity, and
318 homogeneity, as well as the normality and independence of residues, were performed. The

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319 model was built using the ENTER method. IBM SPSS Statistics for Windows, Version 23.0
320 (IBM Corp., Armonk, NY, USA) was used for statistical processing.

321

322 **Results**

323 The sample consisted of 316 PwD (119 men and 197 women). Their demographic, social
324 involvement, clinical and psychological characteristics are presented in Table 1. The men
325 were significantly younger, had higher education, and were more likely to suffer from hearing
326 impairment. The women lived alone more often and had poorer physical performance.

327 Further, 52.3% of the women and 33.6% of the men were classified as frail older adults
328 (SPPB total score ≤ 6 points; $p = .0005$). Given the correlation of physical performance with

329 age found in this study, the relationship between gender and physical performance was

330 adjusted for the effect of age using ANCOVA. Even after performing ANCOVA, the

331 difference between men and women in physical performance remained significant ($p = .009$).

332 No statistically significant differences were found between men and women in perception of

333 dignity (PDI-CZ). The total PDI-CZ score (41.9 vs 43.1, $p = .493$) represented the category of

334 "mild problems" (54).

335 *[Please, place the Table 1 near here]*

336 ***Contributors to dignity in women with dementia***

337 None of the sociodemographic or social involvement characteristics showed a
338 significant association with dependent variables in women (Table 2). From physical health
339 related characteristics, pain contributed to the perception of dignity in the domains of 'Loss of
340 Purpose of Life' and 'Loss of Autonomy' and the overall PDI-CZ ($\beta = 0.722$, $p = 0.027$) in
341 women. The greater the pain the women reported, the worse they evaluated their dignity.

342 Physical performance or sensory impairments did not contribute to any dependent variable in

343 women. In women, depression contributed to the overall dignity (PDI-CZ) and in all domains

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344 of PDI-CZ (Table 2). The higher the level of depression, the worse the women rated their
345 dignity. Attitude to aging was related to the overall PDI-CZ and the domains of ‘Loss of
346 Purpose of Life’, ‘Loss of Autonomy’, and ‘Loss of Confidence’ of the PDI-CZ in women
347 (Table 2). Women, who had more positive attitude to aging rated their dignity better.

348 Self-sufficiency in ADL contributed to the overall PDI-CZ and the domains of ‘Loss
349 of Purpose of Life’, ‘Loss of Autonomy’, and ‘Loss of Confidence’. Women who had a
350 higher self-sufficiency in ADL perceived their dignity as better. In women, the determination
351 coefficient R^2 was highest for the model for the dependent variable "total PDI-CZ" – overall
352 dignity (explained 57.0% of variance), where pain, depression, attitude to aging and self-
353 sufficiency in ADL were significant contributors to the dependent variable. The lowest
354 coefficient R^2 was for the model for the dependent variable ‘Loss of social support’ (24.4% of
355 explained variance), where depression was the only significant contributor of the dependent
356 variable (Table 2).

357 *[Please, place the Table 2 near here]*

358 ***Contributors to dignity in men with dementia***

359 In men, none of the sociodemographic or social inclusion characteristics showed a
360 significant association with dependent variables (Table 3). From health-related characteristics,
361 pain and sensory impairment contributed to the dependent variables. Pain was a contributor to
362 the overall PDI-CZ ($\beta = 1.464, p < 0.0001$) and in all the domains of PDI-CZ except ‘Loss of
363 Social Support’ (Table 3). The greater pain the men perceived, the worse they evaluated their
364 dignity. Medium or severe visual impairment had a negative effect on the men’s experience of
365 dignity in the domains of ‘Loss of Autonomy’ and ‘Loss of Confidence’ and in the overall
366 PDI-CZ (Table 3). Physical performance and hearing impairment were not associated with
367 any of the dependent variables.

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368 In men, depression was a contributor to the overall dignity - PDI-CZ ($\beta = 2.220$; $p <$
369 0.0001) and to all domains of dignity (Table 3). The higher the level of depression, the worse
370 the men rated their dignity.

371 Attitude to aging influenced the overall PDI-CZ ($\beta = -0.269$, $p = 0.025$) and the
372 domain of 'Loss of Purpose of Life' (Table 3). If men had a better attitude to aging, they
373 evaluated their dignity better.

374 Self-sufficiency in ADL was associated only with the domain of 'Loss of Autonomy'
375 in men (Table 3). If men had better self-sufficiency in ADL, they evaluated their dignity
376 better. The coefficient of determination R^2 was the highest for the model for the dependent
377 variable "Total PDI-CZ" – overall dignity (73.9% of explained variance) with visual
378 impairment, pain, depression, and attitude to aging being significant contributors of the
379 dependent variable. The coefficient of determination R^2 was lowest for the model for the
380 dependent variable 'Loss of Social Support' (35.7% of explained variance) (Table 3), with
381 depression being the only significant contributor of the dependent variable.

382 *[Please, place the Table 3 near here]*

383 Discussion

384 This study focused on dignity, and its associated domains, in men and women in the
385 early stages of dementia. The results are in line with previous findings that suggested PwD
386 experienced reduced dignity or a threat to it (3, 5, 10, 12), regardless of gender. However,
387 both women and men exhibited only minor problems in dignity. One of the explanations is
388 that the participants lived in their own homes, which allowed them to keep their social role,
389 and control their life. This assumption is supported by a previous qualitative study that found
390 only minor issues with dignity described by PwD living in their homes (3). Although it seems
391 that continuing to live within the community may lead to better preservation of dignity, it has
392 previously been found that even in institutional care dignity may be preserved when older

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393 adults trust their professional caregivers, have control over their decision making, and feel to
394 be a part of a social network (56). Further study is needed to compare perceptions of dignity
395 in PwD living at home with those in institutional care. From a gender perspective, it is
396 possible that men did not want to admit their feelings of reduced dignity because this would
397 jeopardize their masculine identity (35). Women might downplay their problems because they
398 do not want to worry others – perceiving that they are the ones who are supposed to take care
399 of their loved ones. Their lifelong focus on caring for children and other relatives could also
400 distract them from paying attention to their own difficulties and needs, including the area of
401 dignity. It is also possible that PwD reported minor dignity issues because they perceived
402 other issues, such as physical symptoms and needs, as more pressing from their viewpoint.

403 Pain, depression, and the attitude to aging were common contributors to the overall
404 perception of dignity (PDI-CZ) in both women and men with dementia. The finding that pain
405 predicted a diminished perception of dignity was consistent with a previous study in
406 terminally ill patients (6), in which, the experience of pain was associated with loss of dignity
407 probably by affecting the individual's competence, autonomy, and sense of self-worth.
408 Lowered sense of competence or self-worth might be closely related to the domain 'Loss of
409 Confidence', which was associated with pain in men. Possibly, the perceived pain threatens
410 men's identity by reminding them of their weakening physical strength, which result in loss of
411 confidence. Our results showed that pain was also correlated with 'Loss of Purpose' and 'Loss
412 of Autonomy' in men and women. It may be that the reduced ability to perform both fulfilling
413 and routine everyday activities is the mechanism by which pain reduces dignity in these
414 domains. Family and professional caregivers should be informed that pain is often under-
415 recognized and undertreated in PwD and they should be taught how to recognize its
416 symptoms (57). Alleviating pain can have impact on overall wellbeing of PwD including their
417 improved perception of dignity.

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418 Depression was the only variable associated with both overall dignity and also with all
419 of its domains in both genders. Higher rates of depression predicted lower perception of
420 dignity. A link between dignity and depression has also been found in terminally ill patients
421 (6). Depression can deepen negative experiences in the areas of emotional or physical
422 dependence on others, feelings of shame, and feelings of being a burden. It also comes with a
423 decreased sense of self-worth and self-confidence and can thus lead to a reduced perception of
424 the persons dignity (58). Depression can promote negative experiences leading to a decrease
425 in dignity and also in overall quality of life (5). Hence, screening for the timely diagnosis of
426 depression in PwD and its effective treatment should be carried out not only to improve
427 mental health, but also to protect dignity.

428 A positive attitude to aging contributed to improved perception of dignity in both
429 women and men with dementia. The relationship between these variables has already been
430 pointed out, although that study considered dignity as a predictor of attitude to aging (12). In
431 addition to the overall PDI-CZ in women, the attitude to aging also contributed to the ‘Loss of
432 Purpose of Life’, ‘Loss of Autonomy’, and ‘Loss of Confidence’; in men, it was only
433 associated with the domain of ‘Loss of Purpose of Life’. The reason why attitudes to aging are
434 related to more dimensions of dignity for women than for men may be due to the fact that
435 aging is generally a more salient issue for women (16). They have more negative attitudes
436 towards aging than men and have more concerns about old age (16, 17). Attitude to aging in
437 women with dementia is associated with experience of loneliness, social exclusion and
438 gradual loss of physical self-sufficiency (12), which are closely related to the domains of
439 dignity.

440 A previous study suggested that a positive attitude to aging and, by extension, the
441 perception of old age as a meaningful stage of life, is a factor that may help to preserve
442 dignity (3). This found that PwD, who believe that their lives still make sense are better at

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443 maintaining a sense of personal dignity. Another study found a link between a positive
444 attitude to life and the perception of dignity in nursing home residents (24). Future research
445 should focus on the domains of the AAQ (Attitude to Aging Questionnaire) in relation to
446 dignity and its domains to better understand the differences between men and women.
447 Psychosocial interventions that could improve attitude to aging might be beneficial. They
448 could include socialization activities, counselling, or reminiscence therapy, which were shown
449 to improve attitudes to aging in PwD in previous research (59). Reminiscence therapy could
450 be focused on the individual's life-projects, personal skills, values, and former meaningful
451 work as these are important sources of self-worth and self-esteem (9).

452 In women, self-sufficiency in ADL was associated with overall dignity and with all
453 four domains of the PDI-CZ. In men, self-sufficiency in ADL contributed only to the PDI-CZ
454 domain of 'Loss of Autonomy'. A link between self-sufficiency in ADL and dignity has been
455 found also in previous qualitative (60-62) and quantitative (6, 12) studies. Maintaining self-
456 sufficiency in ADL, and therefore functional autonomy, is considered to be one of the central
457 conditions of dignity (61), and the idea of the loss of self-sufficiency is one of the major
458 concerns in relation to old age (60). The association between the self-sufficiency in ADL and
459 the 'Loss of Autonomy', which was found in both genders, was expected, since both variables
460 are relate to dependency and autonomy (45, 53) . We hypothesize that the decreased self-
461 sufficiency in ADL is, especially in women, associated with lower perception of dignity
462 because it may limit their customary gender roles. For example, the sudden change of
463 women's role from a care provider to a care recipient, may strongly challenge their gender
464 identity, and consequently their dignity. If self-sufficiency is reduced, their ability to care for
465 others) is probably limited. Because of relatively reduced access to affordable childcare
466 facilities in the Czech Republic (28), older women often take care of their grandchildren and
467 build a close relationship with them. Therefore, being a grandmother is important to women's

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468 identity and self-worth, and gives them a clear purpose for life in old age. Thus, we consider
469 that the relationship between experienced dignity and regular contact with grandchildren
470 would be worth further study. Reduced self-sufficiency in ADL might also be a barrier for
471 caring for one's own home. This task is not only more commonly performed by women but is
472 important to the identity of women with dementia, affecting their sense of competence, and
473 self-worth (13).

474 From a practical point of view, this study demonstrated that activities aimed at
475 maintaining the patient's autonomy or strengthening competencies that had not yet been
476 affected by the illness, might be important to supporting the perception of dignity in PwD.
477 With regard to gender, community caregivers should encourage activities related to men's or
478 women's roles. For example, they should support women's need for caring, show them how
479 they are still capable of taking care of others, and that they are needed by their social network.
480 It can be done through performing activities together but also, in the case of physical issues,
481 the caregivers can ask for advice, (e.g. an easy question "how to bake a cake" can make the
482 person feel needed). Future studies should focus on factors in both men and women that may
483 affect the relationship between the perception of dignity and self-sufficiency.

484 In men, overall dignity, 'Loss of Autonomy', and 'Loss of Confidence', were also
485 associated with a visual impairment. No study has been reported that supports this link in
486 PwD. Because there was no significant difference in the degree of visual impairment of men
487 and women in the study population, it is possible that men perceive its' impact on their
488 everyday life differently than women, in ways that have implications for their dignity.
489 Theoretically, visual impairment can prevent men from activities typical of their gender, and
490 male identity (e.g., driving a car, playing games, or solving crosswords). Regular eye tests
491 should be performed in PwD, as they help optimal correction of visual impairments, which
492 might have a positive impact on the perception of dignity. Patients and their caregivers should

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493 be educated about dealing with visual impairments (information on screen readers, interior
494 adjustments etc.). They could be offered assistive technology or equipment, and rehabilitation
495 for visually impaired if needed.

496 The results of the present study suggested that involvement in social life was not
497 related to the perception of dignity in PwD. However, a previous qualitative study, which
498 included PwD living in their own home (3), suggested that how they experienced their dignity
499 was related to their social environment. It is possible that women and men with dementia in
500 the present study did not experience much limitation of their social life as compared to their
501 previous lives or maintained as much social contact as they wished. This possibility was
502 supported by the fact that the participants reported the fewest difficulties in the ‘Loss of
503 Social Support’ compared with the other PDI-CZ domains. Nevertheless, we believe the
504 social environment and its associations with dignity in PwD deserves deeper attention in
505 future studies. In our study, we observed the frequency of contacts with others (visits or
506 phone/email), or participation in social activity and, in terms of living arrangements, we only
507 recorded whether the respondent lived alone or not. It is possible, that the frequency of
508 contacts alone is not as important to the perception of dignity as other aspects of social
509 involvement or the environment, such as the quality of the relationship, satisfaction with the
510 relationship, contact with grandchildren or marital status. Future study should focus on these
511 aspects in more detail.

512

513 *Limitations*

514 The present study was novel in providing valuable insights into the issue of dignity in
515 PwD in terms of gender. However, it is necessary to mention some of the limitations of the
516 study that should be considered when interpreting the results. The results could not be
517 generalized to the entire population of PwD because it includes only individuals living in their

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518 home environment and at an early stage of the disease, and makes no distinction between the
519 different types of dementia. The current study is also of a cross-sectional nature and thus we
520 cannot assess causality. Further studies should be longitudinal to clarify causal relationships.
521 This study did not look at other potential factors that could contribute to the dignity in PwD
522 including comorbidities, psychiatric treatment, emotional regulation, and distress or anxiety.
523 For example, we did not control for whether participants had been diagnosed with depression
524 before they were diagnosed with dementia. An important implication for future studies would
525 be looking at clusters of the various types of dementia, as they manifest different behavioural
526 and psychological symptoms (63), which may affect the subjective experiences and also
527 perception of dignity in PwD. The relationships found might also have been influenced by the
528 cultural context in which the study was conducted.

529

530 **Conclusions**

531 The results of this study suggest that personal perceptions of dignity were associated
532 with attitude to aging, depression, and pain in both men and women. In women, a reduced
533 perception of dignity was also associated with reduced self-sufficiency in ADL. In men
534 reduced perception of dignity was associated with visual impairment. Physical performance
535 and the aspects of the social involvement investigated were not associated with perceptions of
536 dignity for either men or the women. The study showed that dignity could be compromised in
537 PwD who lived outside an institutional environment and that it was related not only to health
538 factors but also to psychological variables such as attitudes to aging or depression in men and
539 women. The research findings can be used in the provision of medical, psychosocial, and
540 nursing care to PwD.

541

542 **List of Abbreviations**

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543 AAQ – Attitude to Aging Questionnaire

544 ADL – Activities of Daily Living

545 BADLS – the Bristol Activities of Daily Living Scale

546 BADSL-CZ – the Czech version of the Bristol Activities of Daily Living Scale

547 GDS-15 – the Geriatric Depression Scale

548 HVAS – the Horizontal Visual Analogue Scale

549 PDI – the Patient Dignity Inventory

550 PDI-CZ – the Czech version of the Patient Dignity Inventory

551 PwD – People with Dementia

552 SPPB – the Short Physical Performance Battery

553 **Declarations**

554 *Ethics approval and consent to participate*

555 Research was performed in accordance with the Declaration of Helsinki and the study
556 protocol was approved by the ethics committee of the Faculty of Health Sciences at Palacký
557 University, Olomouc, the Czech Republic (UPOL-615/1040-2019). We paid special attention
558 to the ethical principles and preserving dignity of the participants. We followed these rules
559 before including the person in the research: 1. the patient understands the information about
560 the study; 2. he/she is able to decide about the participation; 3. he/she is able to understand
561 implications of his/her participation; and 4. is able to communicate his decision with the
562 researcher. The data were collected according to ethical principles with informed consent,
563 confidentiality, and the right to withdraw from participation at any time without presenting a
564 reason. All participants were at the onset of dementia, and they were able to consent to
565 participate in the study. None of the respondents refused to participate in the study and all
566 signed informed consent before inclusion in the study.

567 *Consent for publication*

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568 Not applicable.

569 *Availability of data and materials*

570 The datasets supporting the conclusions of this article are available from the
571 corresponding author on a reasonable request.

572 *Competing interests*

573 The authors declare that they have no competing interests.

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577 *Authors' contributions*

578 HK designed and supervised the study, JT played a major role in the data collection, KL
579 analysed and interpreted the data, LKK wrote the manuscript with input of HK, JT, KL, PT,
580 KAČ and PJG. All authors discussed the results and commented on the manuscript. All authors
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586

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746

Table 1*Sociodemographic and Clinical Characteristics of the Respondents*

Characteristic	Categories	Male (N = 119)	Female (N = 197)	<i>p</i> -value
Age Mean; SD (range)		80.8; 7.7 (60-97)	83.0; 7.2 (64-97)	.011 ^a
Education N (%)	Elementary	11 (9.2)	62 (31.5)	.0004 ^b
	Vocational	55 (46.2)	61 (31.0)	
	Secondary	35 (29.4)	67 (34.0)	
	Tertiary	18 (15.1)	7 (3.6)	
Social involvement				
With whom the older adult lives N(%)	Alone	20 (16.8)	95 (48.2)	< .0001 ^b
	With partner	87 (73.1)	69 (35.0)	
	With others	12 (10.1)	33 (16.8)	
Participation in social activities N(%)	> 30 days ago	38 (32.0)	78 (39.6)	.655 ^b
	≤ 30 days ago	70 (58.8)	101 (51.3)	
	Cannot be determined*	11(9.2)	18 (9.1)	
Visit of relatives/friends N(%)	> 30 days ago	9 (7.6)	12 (6.1)	.161 ^b
	≤ 30 days ago	110 (92.4)	185 (93.9)	
Contact with relatives/friends (phone, email) N(%)	> 7 days ago	18 (15.1)	30 (15.2)	.891 ^b
	≤ 7 days ago	101 (84.9)	167 (84.8)	

Time spent alone daily N (%)	≥ 8 hours	29 (24.4)	70 (35.5)	.217 ^b
	< 8 hours	90 (75.6)	127 (64.5)	
Clinical characteristics				
Hearing Impairment N (%)	No/Minimum	97 (81.5)	175 (88.8)	.024
	Medium/Severe	22 (18.5)	22 (11.2)	
Visual Impairment N (%)	No/Minimum	104 (87.4)	160 (81.2)	.098
	Medium/Severe	15 (12.6)	37 (18.8)	
Depression (GDS-15 score [Mean; SD])		4.9; 3.8	5.1; 3.9	.651 ^a
Self-Sufficiency in ADL (BADLS-CZ % [Mean; SD])		77.3; 20.5	76.7; 18.8	.788 ^a
Pain (HVAS score [Mean; SD])		2.1; 2.6	2.5; 2.7	.253
Physical Performance (SPPB total score [Mean; SD])		7.1; 3.7	5.6; 3.8	.001
Psychological characteristics				
Dignity (PDI-CZ total score [Mean; SD])		41.9; 15.5	43.1; 15.5	.493
Domains	Loss of Purpose of Life	22.5; 8.8	23.4; 9.1	.378
	Loss of Autonomy	8.7; 3.5	8.9; 3.9	.772
	Loss of Confidence	6.8; 2.8	7.2; 2.8	.288
	Loss of Social support	3.8; 1.8	3.7; 1.3	.342
Attitude to Aging (AAQ total score [Mean; SD])		73.7; 13.3	72.6; 10.0	.428

Note. *Category cannot be determined, excluded from the statistical comparison; ^aIndependent samples *t*-test; ^bMann-Whitney U-test;

^cFisher exact test

Table 2*Linear Regression Model – WomenFemales*

Variables	<u>Domains of PDI-CZ</u>								<u>Dignity</u> ←	
	Loss of Purpose of Life		Loss of Autonomy		Loss of Confidence		Loss of Social Support		<u>(PDI-CZ)</u>	
	β	p	β	p	β	p	β	p	β	p
Constant	29.333	.021	15.078	.006	6.683	.076	-0.646	.769	50.448	.015
Age	-0.028	.737	0.003	.923	-0.001	.980	0.012	.403	-0.013	.923
Education ^a	0.386	.726	0.188	.688	-0.254	.437	0.021	.911	0.342	.849
Living Arrangements ^b	0.968	.366	0.095	.835	0.570	.073	0.290	.121	1.923	.271
Participation in Social Activities ^c	1.996	.066	0.765	.098	0.518	.108	0.384	.053	3.663	.059
Visiting Friends ^d	-3.192	.234	-1.993	.081	-0.723	.362	0.144	.757	-5.764	.188
Phone/email Contacts ^e	-1.183	.475	-0.683	.333	-0.281	.567	-0.174	.547	-2.321	.391
Hearing Impairment	0.224	.888	0.773	.253	0.424	.367	0.404	.145	1.825	.481
Visual Impairment	-0.619	.642	-0.045	.936	-0.144	.716	0.137	.557	-0.672	.757
Pain (HVAS)	0.483	.016*	0.217	.011*	0.072	.222	-0.049	.154	0.722	.027*
Physical Performance (SPPB)	0.086	.654	0.010	.903	0.108	.058	0.016	.635	0.220	.482

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Depression (GDS-15)	1.166	<.0001***	0.277	.0001***	0.455	<.0001***	0.155	<.0001***	2.053	<.0001***
Attitude to Aging (AAQ)	-0.205	.002**	-0.061	.028*	-0.041	.034*	-0.015	.180	-0.321	.003**
Self-Sufficiency in ADL (BADLS-CZ)	-0.122	.002**	-0.097	<.0001***	-0.030	.013*	0.0004	.950	-0.248	.0002***
R ² /adjusted R ²	.564/.526		.547/.508		.575/0.539		.304/.244		.600/.565	
Durbin-Watson Test/VIF	1.763/1.523		2.006/1.523		1.856/1.523		1.941/1.523		1.792/1.523	

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$; ^a category dichotomized by the level of education into lower education (elementary, vocational) vs. higher (secondary, tertiary); ^b category dichotomized by the living arrangement into living alone vs. not alone (with partner or other people); ^c category dichotomized by the last time participated at social activity into > 30 days ago vs. <30 or less days ago; ^d category dichotomized by the last time visit of a friend/relative into > 30 days ago vs. 30 or less30 days ago; ^e category dichotomized by the last time of the phone/email contact with a friend/relative into > 7 days ago vs. <7 or less days ago. For each dichotomous variable, the first one listed was the reference category.

Table 3*Linear Regression Model – Menates*

Variables	Domains of PDI-CZ								Dignity (PDI-CZ) Total score	
	Loss of Purpose of Life		Loss of Autonomy		Loss of Confidence		Loss of Social Support		β	p
	β	p	β	p	β	p	β	p		
Constant	33.110	.008	6.611	.227	8.816	.034	8.627	.009	57.164	.006
Age	0.029	.665	0.021	.494	0.000	.997	-0.022	.215	0.027	.808
Education ^a	0.878	.411	0.495	.300	0.421	.242	-0.087	.759	1.707	.340
Living Arrangements ^b	-0.161	.903	-0.140	.812	0.302	.497	0.060	.864	0.061	.978
Participation in Social Activities ^c	0.239	.826	0.171	.725	0.144	.695	0.237	.414	0.791	.664
Visiting Friends ^d	-0.429	.882	0.865	.503	-0.493	.613	0.901	.243	0.845	.861
Phone/email Contacts ^e	-1.328	.461	-0.239	.766	-0.572	.345	-0.915	.058	-3.055	.311
Hearing Impairment	-0.120	.935	-0.339	.607	-0.244	.622	0.222	.571	-0.481	.845

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Visual Impairment	2.103	.165	1.898	.006**	1.025	.046*	0.337	.402	5.364	.036*
Pain (HVAS)	0.848	<.0001***	0.312	.001**	0.253	.0003***	0.052	.325	1.464	<.0001***
Physical Performance (SPPB)	-0.180	.342	-0.111	.190	-0.013	.840	-0.070	.167	-0.373	.239
Depression (GDS-15)	1.269	<.0001***	0.339	.0002**	0.474	<.0001***	0.137	.009**	2.220	<.0001***
Attitude to Aging (AAQ)	-0.169	.018*	-0.040	.207	-0.027	.253	-0.033	.080	-0.269	.025*
Self-Sufficiency in ADL (BADLS-CZ)	-0.006	.876	-0.048	.006**	0.001	.908	0.014	.181	-0.039	.543
R ² /adjusted R ²	.747/.709		.686/.639		.719/.676		.441/.357		.773/.739	
Durbin-Watson test/VIF	1.934/1.746		1.936/1.746		1.845/1.746		2.288/1.746		1.946/1.746	

* $p < .05$; ** $p < .01$; *** $p < .001$ ^a category dichotomized by the level of education into lower education (elementary, vocational) vs. higher (secondary, tertiary); ^b category dichotomized by the living arrangement into living alone vs. not alone (with partner or other people); ^c category dichotomized by the last time participated at social activity into > 30 days ago vs. <30 or less days ago; ^d category dichotomized by the last time visit of a friend/relative into > 30 days ago vs. <30 or less days ago; ^e category dichotomized by the last time of the phone/email contact with a friend/relative into > 7 days ago vs. <7 or less days ago. For each dichotomous variable, the first one listed was the reference category.