

1 **Wish to die among residents of Swiss long-term care facilities: A multi-site**
2 **cross-sectional study**

3 *Running title: Wish to die in Swiss long-term care residents*
4

5 Eve Rubli Truchard, MD^{a,b}; Stéfanie Monod, MD^c; Christophe Bula, MD^b; Anne-
6 Véronique Durst, MSc^b; Alessandro Levorato, MD^d; Claudia Mazzocato, MD^e; Thomas
7 Münzer, MD^f; Jérôme Pasquier, PhD^c; Pierluigi Quadri, MD^d; Etienne Rochat, PhD^g;
8 Brenda Spencer, PhD^c; Armin von Gunten, MD^h; Ralf J. Jox, PhD^{a,g}
9

10 ^a Chair in Geriatric Palliative Care, Palliative and Supportive Care Service and
11 Service of Geriatric Medicine & Geriatric Rehabilitation, Lausanne University Hospital
12 and University of Lausanne, Av. Pierre-Decker 5, 1011 Lausanne, Switzerland,
13 eve.rubli@chuv.ch

14 ^b Service of Geriatric Medicine & Geriatric Rehabilitation, Lausanne University
15 Hospital and University of Lausanne, Ch. de Mont-Paisible 16, 1011 Lausanne,
16 Switzerland

17 ^c Center for Primary Care and Public Health (Unisante), University of Lausanne,
18 Route de Berne 113, 1010 Lausanne, Switzerland

19 ^d Servizio di Geriatria dell'Ente Ospedaliero Cantonale, Viale Officina 3, 6500
20 Bellinzona, Switzerland

21 ^e [Palliative and Supportive Care Service, Lausanne University Hospital and University
22 of Lausanne, Av. Pierre-Decker 5, 1011 Lausanne, Switzerland](#)

23 ^f [Geriatrische Klinik St. Gallen, Rorschacher Strasse 94, 9000 St. Gallen, Switzerland](#)

24 ^g Institute for Humanities in Medicine, [Lausanne University Hospital and University of
25 Lausanne, Av. De Provence 82, 1007 Lausanne, Switzerland](#)

26 ^h Service of Old Age Psychiatry, Lausanne University Hospital, Route de Cery 1,
27 1008 Pilly, Switzerland
28

29 **Corresponding author**

30 Professor Ralf J. Jox, MD, PhD
31 Palliative and Supportive Care Service, Chair in Geriatric Palliative Care
32 Lausanne University Hospital (CHUV)
33 Avenue Pierre-Decker 5, CH-1011 Lausanne
34 Ralf.jox@chuv.ch, Phone: +41 79 556 62 58
35

36 **Key words:** wish to die, wish to hasten death, nursing homes, long-term care, old age

37 **Funding:** This work was funded by the Swiss National Science Foundation (NRP 67
38 on End of Life (No. 406740_139362)).

39 **Word count:** abstract 294 words, main text 3020 words, 3 tables, 2 figures, 42
40 references
41

42 **Acknowledgment:**

43 The authors thank Corina Fitze, Lea Siegman, Anne-Sylvie Martin Durussel, Lorenzo
44 Dorici and Myriam Lucia Di Marco for help with data collection, Camille Rochat for
45 help with data analysis, and the Palliative and Supportive Care Service of Lausanne
46 University Hospital as well as HéViva Association of Long-term Care Facilities in the
47 Canton auf Vaud for critical discussion of the results. Last not least, the authors are
48 grateful for all participating residents, LTCF and their staff.
49

50 **Wish to die among residents of Swiss long-term care facilities: A multi-site**
51 **cross-sectional study**

52

53 **ABSTRACT**

54 **Objectives:** The wish to die (WTD) in persons near the end of life is a clinically
55 important, ethically and practically complex phenomenon as demonstrated by the
56 intense debates on assisted dying legislation around the world. Despite global aging
57 and increasing institutionalization in old age, WTD among residents of long-term care
58 facilities (LTCF) is underexplored. We aimed to assess the prevalence of WTD and
59 identify its predictors in older LTCF residents.

60 **Design:** Multi-site cross-sectional observational study.

61 **Setting and participants:** 31 LTCF in the three major linguistic regions of Switzerland,
62 including residents 75 years or older, admitted to the LTCF 4-10 months before the
63 study, without severe cognitive impairment.

64 **Methods:** Between February 2013 and June 2017, trained research staff interviewed
65 residents to assess WTD using two validated instruments and collected information on
66 potential predictors including depressive symptoms, anxiety, demoralization, feeling to
67 be a burden, spiritual distress, symptom burden, multimorbidity, and drug use.
68 Demographic data were obtained by chart review. Descriptive statistics as well as
69 univariate and multivariate regression analyses were performed.

70 **Results:** From 427 eligible residents, 101 were excluded, 46 refused, and 280 were
71 included in the study (acceptance rate 85.9%). In general, residents readily and openly
72 addressed the topic of WTD. The prevalence of WTD was 16.0% and 16.2% according
73 to the two instruments, with all but one of the residents expressing a passive WTD.
74 The strongest independent predictors for a WTD were depressive symptoms (OR 7.45

75 and 5.77 for the two WTD assessment instruments) and demoralization (OR 2.62 and
76 3.66).

77 **Conclusions and implications:** The WTD is a relevant concern affecting about 1 in
78 6 LTCF residents. Further research is needed to investigate which sensitive
79 interventions could best address the potentially modifiable factors that were
80 associated with the WTD in this specific setting and population.

81 **Introduction**

82 With the increase in life expectancy and global aging, the last phase of life is
83 profoundly changing.¹ In the presence of age-related chronic health conditions,
84 functional decline and related suffering, older persons may develop a wish to die
85 (WTD). Qualitative research has established that WTD is a complex phenomenon of
86 variable intensity and meaning, ranging from the passive wish that natural death may
87 occur to the active seeking of ways to hasten death, such as suicide, assisted
88 suicide, or euthanasia.²⁻⁴

89 While the underlying definitions and assessment methods vary, studies reported
90 WTD prevalence ranging from 3 to 23% among community-dwelling older people,⁵⁻⁹
91 rising steeply with increasing age.⁵ In long-term care facilities (LTCF), where up to
92 one third of all citizens end their lives in many developed countries,¹⁰⁻¹² WTD
93 prevalence and the perspective of the residents has never been directly studied,
94 whereas the perspective of physicians has already been explored.¹³ On the one
95 hand, the general fear and avoidance of older people to be institutionalized in LTCF
96 may lead to higher WTD in this setting. On the other hand, social integration and
97 high-quality care in LTCF might mitigate WTD.

98 Previous studies in the older population have observed that higher age, depressive
99 symptoms, and lower quality of life are strong predictors of a WTD.^{7-9, 14} The role of
100 spirituality, however, is much less clear and scarcely studied,¹⁵ even though spiritual
101 wellbeing is closely linked to quality of life, especially in older persons,^{16, 17} and
102 spiritual distress is frequent in older patients.¹⁸

103 Switzerland is a particularly suitable country to study WTD in LTCF as it has one of
104 the highest percentages of its population living in LTCF.¹² Moreover, assisted suicide
105 has been legal in this country since 1942, right-to-die organizations such as “EXIT”
106 practice suicide assistance with the help of doctors and volunteers since the 1980s,

107 including in LTCF, and today these organizations count more than 150,000 members,
108 roughly 2% of the population.¹⁹ This may explain the broadly accepted notion of
109 assisted suicide as a civil right in Switzerland and suggest the hypothesis that people
110 talk relatively openly and freely about their WTD.^{14, 20}

111 The aims of our study were to assess the prevalence of WTD in the older population
112 in Swiss LTCF and to identify predictors of their WTD.

113

114 **Methods**

115 This was a multi-center, cross-sectional study conducted in a purposive sample of 31
116 LTCF located in the three major linguistic regions of Switzerland (specifically in the
117 cantons of Vaud, Ticino, and St Gallen), approved by the research ethics commission
118 of the Canton of Vaud (No. 304/2012) in line with the research ethics commissions of
119 the two other regions.

120

121 *Participants*

122 Residents of LTCF were included if admitted to the LTCF 4-10 months before the
123 start of the study (to avoid potential effects during the initial adjustment phase after
124 admission), aged 75 years or more, without severe cognitive impairment (defined as
125 a score ≤ 4 at the Cognitive Performance Scale, CPS²¹), fluent in one of the national
126 languages (German, French, or Italian), and able to consent to the study according to
127 the clinical judgment of the responsible physician. Written informed consent was
128 obtained.

129

130 *Measurements*

131 Between February 2013 and June 2017, a trained research psychologist experienced
132 in geriatric care collected data from the LTCF charts and from direct interviews with
133 residents, except for data on spiritual distress that was collected by trained spiritual
134 care professionals. The measurement instruments are detailed in Table 1. For the
135 validated scales we used the versions validated in the languages of the respective
136 geographic sites. Translation between these languages and English was performed
137 according to forward-backward translation using native language speakers.

138 The WTD was assessed using two instruments validated for the geriatric population:
139 the Categories of Attitudes towards Death Occurrence (CADO) and the Schedule of
140 Attitudes towards Hastened Death adapted to Seniors (SAHD-Senior).¹⁴ The CADO
141 is a 6-item numeric scale based on qualitative categories ranging from neither
142 readiness nor acceptance of death to the active wish to hasten death expressed by
143 specific plans. $CADO \geq 4$ signifies a WTD. The SAHD-Senior is a 20-item scale that
144 yields a robust summary score on the intensity of the wish to die, with a cut-off value
145 of ≥ 10 to be considered as significant WTD.

146 Spiritual distress was assessed using the 20-30 minute semi-structured Spiritual
147 Distress Assessment Tool (SDAT) in which unmet spiritual needs are identified in 5
148 sub-dimensions: meaning, transcendence, personal identity, decisional participation,
149 and feeling understood.²² The level of anxiety was investigated employing the
150 General Anxiety Disorder 7 (GAD-7) scale that asks people to rate the frequency of
151 seven symptoms of anxiety allowing categorization into minimal, mild, moderate, and
152 severe anxiety.²³ Depressive symptoms were measured using the Patient Health
153 Questionnaire 9 (PHQ-9), a self-report tool in which patients rate the frequency of
154 nine depressive symptoms.²⁴

155 A concept distinct from depression, yet still controversial, is demoralization,²⁵ which
156 was measured not by a validated scale, but by ratings of agreement with the
157 statements “My life does not seem to have sense” and “I feel discouraged by life”, as
158 well as disagreement with the statement “I am happy when I think of enjoyable
159 activities in the coming days”. We also assessed the participants’ feeling to be a
160 burden to others using a numerical rating scale ranging from 0 (“no feeling to be a
161 burden”) to 10 (“intolerable feeling to be a burden”), with scores ≥ 6 signifying a
162 feeling to be a burden.

163 Mobility was assessed using the 6 first items of the 10-item score on activities of daily
164 living.²⁶ Pain was assessed by using items 1-5 from the Patient Health Questionnaire
165 15 (PHQ-15), a self-rating score of 15 somatic symptoms, for which residents
166 indicated the extent to which they felt bothered over the previous four weeks.²⁷ The
167 Cumulative Illness Rating Scale for Geriatrics (CIRS-G), determines illness severity
168 in 14 organ systems.²⁸ As mentioned, CPS was used to measure cognitive
169 performance as part of the inclusion criteria.²¹

170 Other characteristics of residents, such as age, gender, diagnosis, current
171 medication, and functional capacities were retrieved from the LTCF records.

172

173 Insert Table 1 here

174

175 *Analyses*

176 Descriptive statistics such as mean, standard deviation (SD), median, interquartile
177 range, absolute and relative frequencies were calculated. Both univariate and
178 multivariate logistic regression analyses were performed. The two measures of the

179 WTD were used as dichotomous outcomes (dependent variables) with the following
180 cut-offs: CADO ≥ 4 and SAHD-Senior score ≥ 10 . For each dependent variable, the
181 following independent variables were considered: age (years), gender, pain (PHQ-15
182 sub-score), mobility impairment (ADL sub-score), cognitive performance (CPS),
183 depression (PHQ-9 score ≥ 10), anxiety (GAD-7), demoralization (3 questions
184 mentioned), spiritual distress (5 sub-dimensions of the SDAT used as separate
185 variables), feeling to be a burden (NRS score ≥ 6), marital status, and medication use
186 (5 drug types). Missing data were handled using multiple imputation by chained
187 equations. Analyses were performed using the R software and the mice package for
188 multiple imputation.^{29, 30}

189

190 **Results**

191 Among 769 residents screened, 427 fulfilled the inclusion criteria (Figure 1). Of these,
192 101 were excluded due to acute medical problems (n=51), discharge home or
193 transfer to other care institutions (n=11), or death before the start of the study (n=39).
194 Among the remaining 326 residents, 46 refused to participate in the study
195 (acceptance rate 85.9%) so that we included 280 residents as study participants. The
196 researchers who collected the data in the LTCF observed that the vast majority of
197 residents readily talked about the WTD and were grateful and relieved rather than
198 distressed by this communication.

199

200

Insert Figure 1 here

201

202 The characteristics of the study sample are detailed in Table 2. The participants
203 were predominantly women, widowed, and aged over 85 years. While more than 100

204 participants were recruited both from the French- and Italian-speaking regions of
205 Switzerland, the recruited sample in the German-speaking site was considerably
206 lower due to a change in the local study personnel. While the majority of participants
207 had only mild, borderline, or no cognitive impairment (according to CPS results),
208 about one third had moderate or moderately severe cognitive impairment. Results
209 suggested only limited psychological distress: more than half of participants had no
210 depressive symptoms, no anxiety, a very low level of demoralization, and a low level
211 of spiritual distress. Somatic symptoms were at the lower threshold of the mild
212 category (PHQ-15 median 5, mild somatic symptoms 5-9), whereas multimorbidity
213 was considerable (CIRS-G summary score 10). The most common illnesses were
214 vascular, psychiatric, cardiac, and musculoskeletal.

215

216 Insert Table 2 here

217

218 The prevalence of the WTD was 16.0% and 16.2% as assessed respectively by the
219 CADO and the SAHD-Senior (Figure 2). In addition, the CADO revealed that among
220 residents expressing a WTD, almost all (44 out of 45; 98%) had a passive wish to die
221 (CADO category 4), while only one participant indicated considering hastened death
222 (CADO category 6). Half of all participants (n=141, 50.4%) did not feel ready to die
223 but would accept it (CADO category 2). According to the SAHD-Senior, 49.6% had
224 either no wish or only a low wish to hasten death (SAHD-Senior score 0-3), 34.4%
225 expressed a moderate one (score 4-9) and 16.0% a high one (score 10-20).

226

227 Insert Figure 2 here

228

229 Univariate and multivariate logistic regression analyses were performed to identify
230 potential predictors of a significant WTD according to each assessment instrument
231 (Table 3). In univariate analysis, residents with significant WTD by CADO (defined as
232 category ≥ 4) more frequently expressed higher score regarding depressive
233 symptoms (Odd's Ratio, OR, 10.35, 95%-CI 4.87-22.02), demoralization (OR 3.52,
234 95%-CI 2.21-5.62), pain (OR 3.26, 95%-CI 1.52-7.00), unmet spiritual needs in the
235 sub-dimension transcendence (OR 2.25, CI 1.08-4.69), and anxiety (OR 1.59, 95%-
236 CI 1.12-2.25). In addition, they were older (OR 2.24, 95%-CI 1.18-4.26) and more
237 likely to use analgesic medication (OR 2.37, 95%-CI 1.21-4.65). Similarly, residents
238 with significant WTD as measured by SAHD-Senior had higher scores regarding
239 depressive symptoms (OR 8.75, 95%-CI 3.91-19.57), demoralization (OR 3.83, 95%-
240 CI 2.25-6.52), anxiety (OR 1.68, 95%-CI 1.15-2.46), and had a higher age (OR 2.56,
241 95%-CI 1.20-5.47). In addition, increased odds were also found for female residents
242 (OR 4.03, 95%-CI 1.19-13.71), those who expressed the feeling to be a burden to
243 others (OR 3.97, 95%-CI 1.12-14.08), those with unmet spiritual needs in the sub-
244 dimension of meaning (OR 3.69, 95%-CI 1.07-12.72), and residents with impaired
245 mobility (OR 1.47, 95%-CI 1.02-2.10).

246 In multivariate regression analysis, three factors remained significant predictors of a
247 WTD as defined by CADO ≥ 4 : depressive symptoms (Adjusted Odd's Ratio, AOR,
248 7.45, 95%-CI 2.57-21.60), higher age (AOR 2.56, 95%-CI 1.07-6.08), and
249 demoralization (AOR 2.62, 95%-CI 1.44-5.13). A score of SAHD-Senior ≥ 10 ,
250 indicating a significant WTD, was also independently predicted by depressive
251 symptoms (AOR 5.77, 95%-CI 1.72-19.34) and demoralization (AOR 3.66, 95%-CI
252 1.67-8.04), as well as by two additional factors that had not been significant

253 predictors in the univariate analysis: more frequent use of antipsychotic drugs (AOR
254 3.92, 95%-CI 1.35-11.36) and a lower CPS score (AOR 0.41, 95%-CI 0.18-0.95).

255

256 Insert Table 3 here

257

258 **Discussion**

259 This study found that one in six residents living in Swiss LTCF reported a significant
260 WTD and identified those with depressive symptoms, evidence for demoralization,
261 and higher age as most likely to express such a wish. These results are important for
262 several reasons.

263 First, to our knowledge, the study is the first to specifically investigate the prevalence
264 of WTD in LTCF residents, a setting where up to one third of deaths occur in most
265 developed countries.¹⁰⁻¹² The study broadens our knowledge in showing that a
266 substantial minority endorse a significant WTD. Indeed, the 16% prevalence reported
267 in our LTCF population is substantially higher than those reported by two population-
268 wide studies: A study among 8174 community-dwelling Irish citizens aged 50 years
269 or older, using a single probing question for WTD, reported a prevalence of 3.5%.⁶
270 Another study among 1563 Dutch citizens aged between 57 and 99 years, using four
271 questions taken from two suicidal risk scales to assess WTD, reported a prevalence
272 of 4.0%.⁵ A third study, conducted among 232 medical inpatients in a Swiss
273 academic hospital that used the same instruments as in our study (CADO and
274 SAHD-Senior), found a WTD prevalence of 8.6%.⁷ In contrast, the higher prevalence
275 in our population is comparable to the 18% found in a Spanish palliative care
276 population.³¹

277 Second, findings from this study broaden our current knowledge in showing that,
278 although a significant WTD affected a notable minority of LTCF residents, most

279 expressed a 'passive' WTD that death may come naturally, albeit preferably soon.
280 Indeed, only one resident expressed an active WTD with a specific plan to hasten
281 death. This observation matches the fact that, for various reasons, assisted suicide is
282 still rarely practiced in Swiss LTCF (which has, of course, several causes): at the time
283 of the study, only 11.8% of all assisted suicides accompanied by the German-
284 speaking right-to-die organization "EXIT" happened in LTCF and 10.3% of assisted
285 suicides accompanied by the French-speaking organization "EXIT A.D.M.D."
286 occurred in LTCF.^{32, 33} The fact that 84% of all residents participating in our study did
287 not express any WTD also challenges the assumption, which is popular in
288 Switzerland, that LTCF would be places where residents only wait for their death to
289 come.

290 Third, a unique contribution of the current study is also to provide specific information
291 on characteristics of LTCF residents that were associated with a significant WTD.
292 This information is essential to better identify those residents most at-risk to express
293 significant WTD and to implement preventive or responsive strategies. Although
294 some characteristics, such as higher age, are not modifiable, others could be.
295 Addressing depressive symptoms, demoralization, and the burden of somatic
296 symptoms could certainly contribute to enhancing these residents' quality of life and
297 reduce their WTD. The results also raise the question whether depression and
298 demoralization may be under-diagnosed and under-treated in LTCF residents.³⁴

299 Finally, the observation that demoralization (as assessed by 3 non-validated
300 questions) and depressive symptoms (as assessed by a validated instrument) are
301 independently associated with the WTD underscores the hypothesis that these
302 psychological states are two conceptually distinct constructs.^{35, 36} The finding that
303 female gender predicted higher score of the SAHD-Senior requires more thorough

304 studies in the future in order to elucidate whether female gender influences WTD
305 indirectly and by what mechanisms.

306 Contrary to one of our initial hypotheses, no independent association was observed
307 between the global measure of spiritual distress and a significant WTD once
308 adjusting for covariates in the multivariate analysis. However, unmet spiritual needs
309 in two subdomains (transcendence and meaning) were associated with WTD in
310 univariate analysis. As spiritual distress is a rather new and complex concept, the
311 instrument we used for assessment (SDAT) may not be the most appropriate one for
312 this population and situation. Yet, the very concept of spiritual distress may also be
313 too closely linked to psychological distress, in particular depression, to be used as
314 independent predictor of WTD. Whether and how exactly spiritual distress and
315 related concepts influence WTD remains to be investigated more specifically.

316 Residents with a higher age appeared at higher risk to express a WTD (significantly
317 when assessed by the CADO). This finding has been shown elsewhere^{7, 14, 37} and
318 could be interpreted as reflecting their closer proximity to death. The association
319 between WTD (assessed by SAHD-Senior) and the use of antipsychotic drugs may
320 rather point to the use of these partially sedative drugs in residents with WTD than to
321 adverse effect of the drugs themselves.³⁸

322 This study has limitations: First, the WTD is a complex, multi-faceted construct
323 without a consensual gold standard measure yet. The results may therefore vary
324 depending on the assessment instrument employed. However, the use of two
325 validated instruments that provided very similar results is a strength of the present
326 study and corroborates the construct of WTD. As the concept of demoralization is not
327 yet formally established, we could not use a validated instrument to assess it. An
328 additional limitation is related to the inclusion of volunteering LTCF, which may
329 reduce generalizability of the results. Our findings may not be applicable to each

330 LTCF context and not be readily transferable to other countries with different cultural
331 and socio-economical traditions. Still, our sample recruited from several LTCF in all
332 three major cultural areas of Switzerland is concordant with published data on the
333 Swiss LTCF population regarding gender distribution³⁹ cognitive performance.⁴⁰
334 Slight intercultural variations due to the use of various languages and the translation
335 into English cannot be ruled out completely. Finally, our study sample was only a
336 specific subset of LTCF residents and excluded younger residents, residents recently
337 admitted or living in a LTCF for a long time, as well as residents with severe cognitive
338 impairment.

339 Beside the use of two validated instruments to measure WTD, an additional strength
340 of this study is the acceptance rate of 85.8%. This shows that residents in LTCF are
341 willing to talk about the WTD, as corroborated by the informal feedback from the
342 researchers who gathered data from the residents. Other strengths are the relatively
343 large sample size, and the extensive set of covariates that were collected to
344 investigate predictors of the WTD. Finally, the qualitative feedback of the researchers
345 that the residents were openly addressing WTD highlights that empirical research on
346 WTD in this population is feasible, even among residents with mild cognitive
347 impairment.

348

349 **Conclusions and implications**

350 Results from this study show that the WTD is a relevant concern in LTCF as it affects
351 about 1 in 6 residents. The readiness of residents to communicate about this topic
352 warrants specific educational and implementation programs to address WTD in
353 interaction with LTCF residents. Indeed, many factors that were associated with WTD
354 in this specific setting and population are potentially modifiable. Future studies should
355 investigate which sensitive interventions could best address these factors and open

356 up avenues for improving care for LTCF residents, such as improved diagnosis and
357 treatment of depression as part of a comprehensive and systematic geriatric
358 assessment. From an ethical perspective, however, the WTD may also be the
359 expression of an autonomous end-of-life preference and it may be appropriate to
360 respond by offering advance care planning to the resident.⁴¹ Using longitudinal data
361 from the study presented here, we are currently investigating whether the presence
362 of a WTD directly impacts mortality in the LTCF population. Finally, we would
363 welcome other researchers replicating our study in other cultural contexts, notably
364 after the dramatic effects of the Covid-19 pandemic on long-term care.

365 **Author contributions**

366 Study concept and design: SM, CB, CM, ER, AVD, BS

367 Acquisition of data: AVD, RJJ, ERT, ER

368 Analysis and interpretation of data: ERT, RJJ, and JP. All authors contributed to the
369 interpretation of data.

370 Drafting of the manuscript: ERT, RJJ. All authors critically revised it and approved the
371 final version.

372 All authors approved the final version of the article and agree to be accountable for
373 all aspects of the work.

374

375 **Funding**

376 The study was funded by the Swiss National Science Foundation in the context of the
377 National Research Program 67 on End of Life (No. 406740_139362).

378

379 **Conflicts of interest**

380 The authors report no conflicts of interest.

381 **References**

- 382 1. Voumard, R, Rubli Truchard, E, Benaroyo, L, et al. Geriatric palliative care: a
383 view of its concept, challenges and strategies. *BMC Geriatr* 2018;18(1):220.
- 384 2. Schroepfer, TA. Mind frames towards dying and factors motivating their
385 adoption by terminally ill elders. *J Gerontol B Psychol Sci Soc Sci*
386 2006;61(3):S129-139.
- 387 3. Balaguer, A, Monforte-Royo, C, Porta-Sales, J, et al. An International
388 Consensus Definition of the Wish to Hasten Death and Its Related Factors.
389 *PLoS One* 2016;11(1):e0146184.
- 390 4. Rodriguez-Prat, A, Balaguer, A, Booth, A, et al. Understanding patients'
391 experiences of the wish to hasten death: an updated and expanded
392 systematic review and meta-ethnography. *BMJ Open* 2017;7(9):e016659.
- 393 5. Kox, RMK, Pasman, HRW, Huisman, M, et al. Current wishes to die;
394 characteristics of middle-aged and older Dutch adults who are ready to give up
395 on life: a cross-sectional study. *BMC Med Ethics* 2021;22(1):64.
- 396 6. Briggs, R, Ward, M, Kenny, RA. The 'Wish to Die' in later life: prevalence,
397 longitudinal course and mortality. Data from TILDA. *Age Ageing*
398 2021;50(4):1321-1328.
- 399 7. Bornet, MA, Rubli Truchard, E, Waeber, G, et al. Life worth living: cross-
400 sectional study on the prevalence and determinants of the wish to die in
401 elderly patients hospitalized in an internal medicine ward. *BMC Geriatr*
402 2020;20(1):348.
- 403 8. Rurup, ML, Deeg, DJ, Poppelaars, JL, et al. Wishes to die in older people: a
404 quantitative study of prevalence and associated factors. *Crisis* 2011;32(4):194-
405 203.
- 406 9. Ayalon, L. The prevalence and predictors of passive death wishes in Europe: a
407 2-year follow-up of the Survey of Health, Ageing, and Retirement in Europe.
408 *Int J Geriatr Psychiatry* 2011;26(9):923-929.
- 409 10. Pivodic, L, Pardon, K, Morin, L, et al. Place of death in the population dying
410 from diseases indicative of palliative care need: a cross-national population-
411 level study in 14 countries. *J Epidemiol Community Health* 2016;70(1):17-24.
- 412 11. Dasch, B, Blum, K, Gude, P, et al. Place of Death: Trends Over the Course of
413 a Decade: A Population-Based Study of Death Certificates From the Years
414 2001 and 2011. *Dtsch Arztebl Int* 2015;112(29-30):496-504.

- 415 12. Hedinger, D, Braun, J, Zellweger, U, et al. Moving to and dying in a nursing
416 home depends not only on health - an analysis of socio-demographic
417 determinants of place of death in Switzerland. *PLoS One* 2014;9(11):e113236.
- 418 13. Rurup, ML, Muller, MT, Onwuteaka-Philipsen, BD, et al. Requests for
419 euthanasia or physician-assisted suicide from older persons who do not have
420 a severe disease: an interview study. *Psychol Med* 2005;35(5):665-671.
- 421 14. Durst, AV, Spencer, B, Bula, C, et al. Wish to Die in Older Patients:
422 Development and Validation of Two Assessment Instruments. *J Am Geriatr*
423 *Soc* 2020;68(6):1202-1209.
- 424 15. Bonnewyn, A, Shah, A, Bruffaerts, R, et al. Are religiousness and death
425 attitudes associated with the wish to die in older people? *Int Psychogeriatr*
426 2016;28(3):397-404.
- 427 16. Edwards, A, Pang, N, Shiu, V, et al. The understanding of spirituality and the
428 potential role of spiritual care in end-of-life and palliative care: a meta-study of
429 qualitative research. *Palliat Med* 2010;24(8):753-770.
- 430 17. Piderman, KM, Lapid, MI, Stevens, SR, et al. Spiritual well-being and spiritual
431 practices in elderly depressed psychiatric inpatients. *J Pastoral Care Counsel*
432 2011;65(1-2):3:1-11.
- 433 18. Monod, S, Martin, E, Spencer, B, et al. Validation of the Spiritual Distress
434 Assessment Tool in older hospitalized patients. *BMC Geriatr* 2012;12:13.
- 435 19. SDA-Keystone. Swiss organisation reports over 1,200 assisted suicides last
436 year. *Swissinfo.ch*; 2020. [https://www.swissinfo.ch/eng/society/exit_swiss-](https://www.swissinfo.ch/eng/society/exit_swiss-organisation-reports-over-1-200-assisted-suicides-last-year/45576694)
437 [organisation-reports-over-1-200-assisted-suicides-last-year/45576694](https://www.swissinfo.ch/eng/society/exit_swiss-organisation-reports-over-1-200-assisted-suicides-last-year/45576694)
438 (accessed on Aug 19, 2022). Accessed.
- 439 20. Vilpert, S, Borrat-Besson, C, Borasio, GD, et al. Associations of end-of-life
440 preferences and trust in institutions with public support for assisted suicide:
441 evidence from nationally representative survey data of older adults in
442 Switzerland. *PLoS One* 2020;15(4):e0232109.
- 443 21. Morris, JN, Fries, BE, Mehr, DR, et al. MDS Cognitive Performance Scale. *J*
444 *Gerontol.* 49. 1994/07/01 ed.; 1994:M174-182.
- 445 22. Monod, SM, Rochat, E, Bula, CJ, et al. The spiritual distress assessment tool:
446 an instrument to assess spiritual distress in hospitalised elderly persons. *BMC*
447 *Geriatr* 2010;10:88.

- 448 23. Spitzer, RL, Kroenke, K, Williams, JB, et al. A brief measure for assessing
449 generalized anxiety disorder: the GAD-7. Arch Intern Med 2006;166(10):1092-
450 1097.
- 451 24. Kroenke, K, Spitzer, RL, Williams, JB. The PHQ-9: validity of a brief
452 depression severity measure. Journal of general internal medicine
453 2001;16(9):606-613.
- 454 25. Kissane, DW, Clarke, DM, Street, AF. Demoralization syndrome--a relevant
455 psychiatric diagnosis for palliative care. J Palliat Care 2001;17(1):12-21.
- 456 26. Morris, JN, Hawes, C, Fries, BE, et al. Designing the national resident
457 assessment instrument for nursing homes. Gerontologist 1990;30(3):293-307.
- 458 27. Kroenke, K, Spitzer, RL, Williams, JB. The PHQ-15: validity of a new measure
459 for evaluating the severity of somatic symptoms. Psychosom Med
460 2002;64(2):258-266.
- 461 28. Salvi, F, Miller, MD, Grilli, A, et al. A manual of guidelines to score the
462 modified cumulative illness rating scale and its validation in acute hospitalized
463 elderly patients. J Am Geriatr Soc 2008;56(10):1926-1931.
- 464 29. R Core Team. R: A language and environment for statistical computing. R
465 Foundation for Statistical Computing, Vienna, Austria. ; 2018. [https://www.R-](https://www.R-project.org/)
466 [project.org/](https://www.R-project.org/) (accessed on May 3, 2022). Accessed.
- 467 30. van Buuren, S, Groothuis-Oudshoorn, K. mice: Multivariate Imputation by
468 Chained Equations in R Journal of Statistical Software 2011;45(3).
- 469 31. Belar, A, Martinez, M, Centeno, C, et al. Wish to die and hasten death in
470 palliative care: a cross-sectional study factor analysis. BMJ Support Palliat
471 Care 2021.
- 472 32. EXIT. Suizidhilfe in Heimen zunehmend ein Thema 2016.
473 <https://exit.ch/artikel/suizidhilfe-in-heimen-zunehmend-ein-thema/> (accessed
474 April 1, 2022). Accessed.
- 475 33. EXIT A.D.M.D. Suisse romande. Nombre d'assistances au suicide effectuées.
476 Bulletin 2016;64:9.
- 477 34. George, K, Davison, TE, McCabe, M, et al. Treatment of depression in low-
478 level residential care facilities for the elderly. Int Psychogeriatr
479 2007;19(6):1153-1160.
- 480 35. Costanza, A, Vasileios, C, Ambrosetti, J, et al. Demoralization in suicide: A
481 systematic review. J Psychosom Res 2022;157:110788.

- 482 36. Gan, LL, Gong, S, Kissane, DW. Mental state of demoralisation across diverse
483 clinical settings: A systematic review, meta-analysis and proposal for its use
484 as a 'specifier' in mental illness. *Aust N Z J Psychiatry* 2021;48:674-211060746.
- 485 37. Shim, EJ, Hahm, BJ. Anxiety, helplessness/hopelessness and 'desire for
486 hastened death' in Korean cancer patients. *Eur J Cancer Care (Engl)*
487 2011;20(3):395-402.
- 488 38. Kissling, W, Glue, P, Medori, R, et al. Long-term safety and efficacy of long-
489 acting risperidone in elderly psychotic patients. *Hum Psychopharmacol*
490 2007;22(8):505-513.
- 491 39. Federal Office of Statistics. Socio-medical institutions: number of clients
492 according to age and gender; 2022.
493 [https://www.bfs.admin.ch/bfs/de/home/statistiken/gesundheit/gesundheitswese](https://www.bfs.admin.ch/bfs/de/home/statistiken/gesundheit/gesundheitswesen/alters-pflegeheime.html)
494 [n/alters-pflegeheime.html](https://www.bfs.admin.ch/bfs/de/home/statistiken/gesundheit/gesundheitswesen/alters-pflegeheime.html) (accessed April 1, 2022). Accessed.
- 495 40. Huler, G, Wolf, H, Riese, F, et al. Cognitive Change at the End of Life in
496 Nursing Home Residents: Differential Trajectories of Terminal Decline.
497 *Gerontology* 2019;65(1):57-67.
- 498 41. Houben, CH, Spruit, MA, Groenen, MT, et al. Efficacy of Advance Care
499 Planning: A Systematic Review and Meta-Analysis. *J Am Med Dir Assoc*
500 2014;15(7):477-489.
- 501 42. Rosenfeld, B, Breitbart, W, Galietta, M, et al. The schedule of attitudes toward
502 hastened death: Measuring desire for death in terminally ill cancer patients.
503 *Cancer* 2000;88(12):2868-2875.
504

Tables and figure legends:

Table 1: Measurement instruments used			
Construct measured	Name of the assessment tool	Form of assessment	Results and signification
Attitudes towards death occurrence	CADO ^{2, 14}	Qualitative, categorical	Categories 1 to 6: 1 = I am not ready for death and don't accept it 2 = I am not ready for death, but I accept it 3 = I am ready for death, and I accept it 4 = I am ready for death, I accept it and I wish death would come 5 = I am considering hastening death, but I have no specific plan 6 = I am considering hastening death and I have a specific plan
Intensity of the wish to hasten death	SAHD-Senior ^{14, 42}	20-item psychometric scale (20 questions)	Score range 0 to 20 0-3 low wish to hasten death 4-9 moderate wish to hasten death 10-20 significant wish to hasten death
Cognitive performance	CPS ²¹	Multi-step algorithmic rating scale	Score range 0 to 6 0 = intact 1 = borderline intact 2 = mild impairment 3 = moderate impairment 4 = moderately severe impairment 5 = severe impairment 6 = very severe impairment
Depressive symptoms	PHQ-9 ²⁴	9-item psychometric scale	Values for each item: 0 = "never", up to 3 = "almost daily" Total score range 0 to 27 5-9: mild depressive symptoms 10-14: moderate depressive symptoms 15-19: moderately severe depressive symptoms 20-27: severe depressive symptoms
Anxiety	GAD-7 ²³	7-item psychometric scale	Values for each item: 0 = "never", up to 3 = "almost daily" Total score range 0 to 21 0-4: Minimal anxiety 5-9: mild anxiety 10-14: moderate anxiety 15-21: severe anxiety
Demoralization		3 questions	Values for each question: 0 = "strongly disagree", up to 4 = "strongly agree" Total sum range 0-12 (0 = none, 12 = highest demoralization)
Feeling to be a burden		Numerical Rating Scale 0-10	Score range 0 to 10 0 = no feeling to be a burden to others 10 = extreme feeling to be a burden to others
Spiritual distress	SDAT ^{18, 22}	15-item psychometric scale	5 sub-dimensions: meaning, transcendence, personal identity, decisional participation, respect of values: Values for each item 0 = "no unmet needs", up to 3 = "high unmet needs"; Total score range 0-15 (0 = no distress, 15 = highest distress)
Mobility impairment	ADL ²⁶ sub-score	6 items from 10-item scale	Values for each item: 0 = "independent", up to 4 = "total assistance" Total sub-score range 0-24

Pain	PHQ-15 ²⁷ sub-score	Items 1-5 from 15-item questionnaire	Values for each item: 0 = "not bothered at all", up to 2 = "bothered a lot" Total score range 0 to 10 (0 = "no pain" up to 15 = "maximum pain")
Comorbidity	CIRS-G ²⁸	14-item ordinal scale	Values for each item: 0 = "no problem", up to 4 = "severe illness" (1, 2, 3 and 4 = illness present) Total score range 0-56

506 ADL = Activities of Daily Living, CADO = Categories of Attitudes towards Death Occurrence, CIRS-G =
507 Cumulative Illness Rating Scale Geriatric, CPS = Cognitive Performance Scale, GAD = General
508 Anxiety Disorder, PHQ = Patient Health Questionnaire, SAHD = Schedule of Attitudes towards
509 Hastened Death, SDAT = Spiritual Distress Assessment Tool.

Table 2: Demographic and health-related characteristics of the study sample (n=280)

Variable	Value	Results	
Gender (n=280)	Female, n (%)	206 (73.6)	
	Male, n (%)	74 (26.4)	
Age (n=280)	Median (IQR) in years	88.1 (6.9)	
Marital status (n=277)	Married, n (%)	60 (21.7)	
	Widowed, n (%)	170 (61.4)	
	Divorced, n (%)	21 (7.6)	
	Single, n (%)	26 (9.4)	
Recruitment site (n=280)	Canton Vaud (French-speaking)	107 (38.2)	
	Canton Ticino (Italian-speaking)	117 (41.8)	
	Canton St Gallen (German-speaking)	56 (20.0)	
Cognition (CPS, n=280)	0 (intact)	82 (29.2)	
	1 (borderline intact)	66 (23.6)	
	2 (mild impairment)	38 (13.6)	
	3 (moderate impairment)	66 (23.6)	
	4 (moderately severe impairment)	28 (10.0)	
Depressive symptoms (PHQ-9, n=275)	Median (IQR)	4 (5)	
Anxiety (GAD-7, n=278)	Median (IQR)	2 (5.8)	
Demoralization (n=279)	Median (IQR)	3 (6)	
Spiritual distress (SDAT, n=217)	Median (IQR)	5 (6)	
Mobility impairment (ADL sub-score, n=275)	Median (IQR)	8 (9.3)	
Somatic symptoms (PHQ-15, n=2786)	Median (IQR)	5 (6)	
Pain (PHQ-15 sub-score, n=278)	Media (IQR)	2 (2)	
Comorbidity (CIRS-G, n=222)	Median (IQR)	10 (6)	
	Vascular illness present	n (%)	196 (79.4)
	Psychiatric illness present	n (%)	151 (70.9)
	Cardiac illness present	n (%)	148 (69.5)
	Musculoskeletal illness present	n (%)	139 (65.5)

510 ADL = Activities of Daily Living, CIRS-G = Cumulative Illness Rating Scale Geriatric, CPS = Cognitive
511 Performance Scale, GAD = General Anxiety Disorder, IQR = Interquartile range, PHQ = Patient Health
512 Questionnaire, SDAT = Spiritual Distress Assessment Tool.

Table 3: Predictors of the wish to die

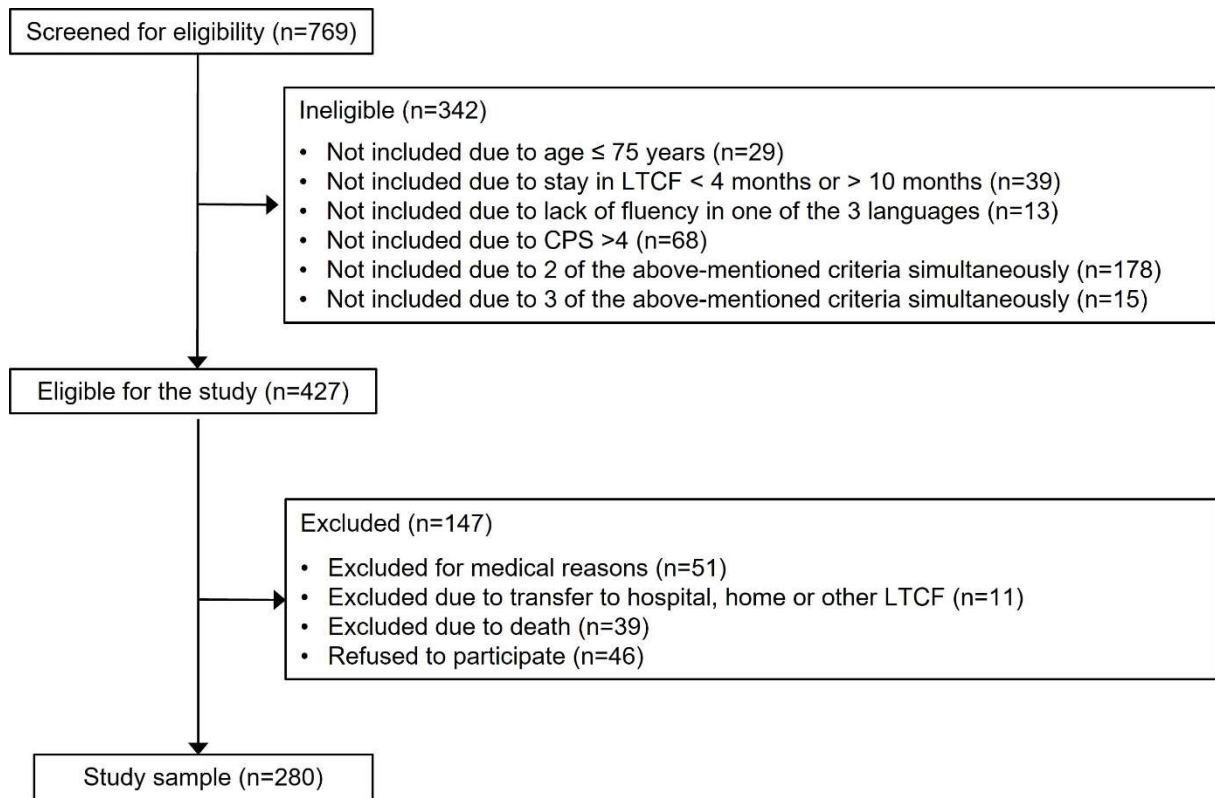
Explicative variable	CADO ≥ 4									SAHD-Senior ≥ 10								
	Univariate				Multivariate					Univariate				Multivariate				
	OR	95% CI		p-value	AOR	95% CI		p-value	OR	95% CI		p-value	AOR	95% CI		p-value		
Age	2.24	1.18	4.26	0.01*	2.56	1.07	6.08	0.03*	2.56	1.20	5.47	0.02*	2.76	0.97	7.87	0.06		
Mobility impairment	1.35	0.98	1.85	0.07	1.08	0.69	1.70	0.73	1.47	1.02	2.10	0.04*	1.37	0.81	2.33	0.24		
Low feeling to be a burden	2.06	0.98	4.32	0.06	1.37	0.48	3.94	0.56	1.67	0.69	4.04	0.25	0.92	0.25	3.42	0.90		
High Feeling to be a burden	2.67	0.77	9.25	0.12	0.82	0.17	3.95	0.80	3.97	1.12	14.08	0.03*	1.23	0.25	6.12	0.80		
Pain	3.26	1.52	7.00	<0.01*	1.74	0.58	5.22	0.32	2.27	0.96	5.40	0.06	1.24	0.31	5.01	0.76		
Female gender	1.92	0.85	4.34	0.12	1.19	0.40	3.51	0.75	4.03	1.19	13.71	0.03*	3.56	0.73	17.42	0.12		
Married	0.40	0.12	1.31	0.13	0.41	0.09	1.93	0.26	0.61	0.12	3.13	0.55	1.02	0.13	7.82	0.98		
Widowed	0.66	0.25	1.76	0.41	0.53	0.14	2.00	0.35	1.39	0.36	5.38	0.63	2.17	0.37	12.90	0.39		
Divorced	0.32	0.06	1.80	0.20	0.44	0.06	3.29	0.42	0.93	0.13	6.83	0.95	1.61	0.13	20.47	0.71		
Anxiety	1.59	1.12	2.25	0.01*	0.85	0.50	1.43	0.53	1.68	1.15	2.46	0.01*	0.93	0.51	1.69	0.81		
Depressive symptoms	10.35	4.87	22.02	<0.01**	7.45	2.57	21.60	<0.01**	8.75	3.91	19.57	<0.01**	5.77	1.72	19.34	<0.01**		
Spiritual distress: meaning	1.62	0.70	3.75	0.26	0.51	0.13	2.03	0.34	3.69	1.07	12.71	0.04*	4.09	0.66	25.52	0.13		
Spiritual distress: transcendence	2.25	1.08	4.69	0.03*	2.94	0.99	8.75	0.05	2.00	0.86	4.67	0.11	1.75	0.52	5.92	0.37		
Spiritual distress: values 1	1.38	0.67	2.84	0.37	0.84	0.24	2.87	0.78	1.11	0.50	2.46	0.79	0.32	0.09	1.19	0.09		
Spiritual distress: values 2	1.35	0.69	2.64	0.38	0.63	0.21	1.96	0.43	1.30	0.61	2.77	0.50	0.71	0.21	2.46	0.59		
Spiritual distress: identity	1.80	0.73	4.43	0.20	1.46	0.39	5.48	0.57	2.68	0.81	8.90	0.11	1.45	0.30	6.94	0.64		
Cognitive impairment	1.00	0.63	1.59	0.99	0.83	0.44	1.58	0.57	0.82	0.48	1.41	0.48	0.41	0.18	0.95	0.04*		
Demoralization	3.52	2.21	5.62	<0.01**	2.62	1.41	4.88	<0.01*	3.83	2.25	6.52	<0.01*	3.66	1.67	8.04	<0.01**		
Antipsychotic drugs	1.45	0.76	2.75	0.26	2.02	0.84	4.83	0.11	1.86	0.89	3.88	0.10	3.92	1.35	11.36	0.01*		
Antidepressant drugs	1.50	0.79	2.82	0.21	1.21	0.51	2.90	0.66	1.22	0.59	2.53	0.59	1.11	0.39	3.12	0.85		
Benzodiazepine drugs	1.47	0.67	3.25	0.34	1.36	0.49	3.74	0.55	2.13	0.91	4.96	0.08	3.09	0.95	10.01	0.06		
Z-drugs	0.92	0.41	2.04	0.83	0.75	0.26	2.20	0.60	0.85	0.33	2.19	0.74	0.76	0.22	2.64	0.67		
Analgesic drugs	2.37	1.21	4.65	0.01*	2.42	0.92	6.42	0.07	1.55	0.74	3.27	0.25	0.55	0.16	1.85	0.33		

513 Univariate and multivariate linear regression analysis with various demographic and clinical variables as independent variables and both the CADO and
514 the SAHD-Senior as dependent variables. OR = Odd's ratio, APR = Adjusted odd's ratio. CI = confidence interval.*p < 0.05, **p < 0.01.

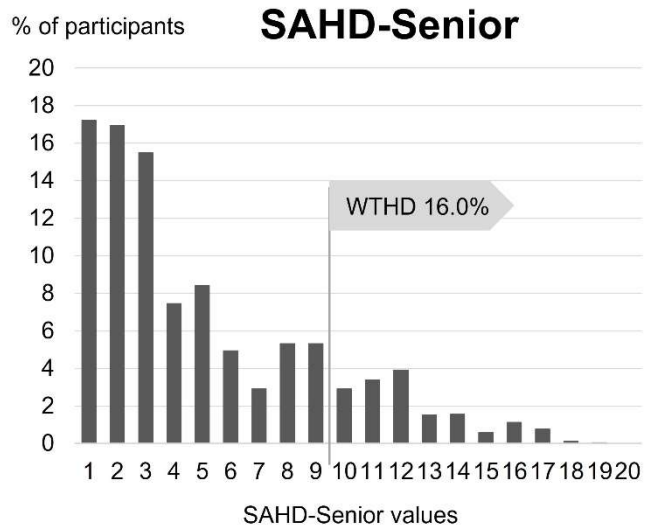
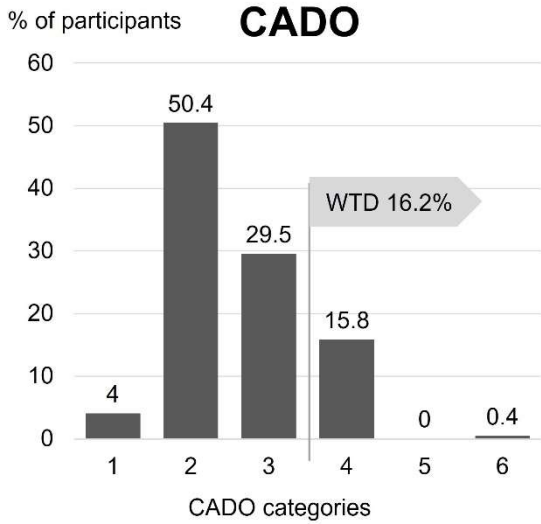
515 **Fig. 1: CONSORT flow diagram on study recruitment and inclusion.** CPS =
516 Cognitive Performance Scale. LTCF = long-term care facility.

517

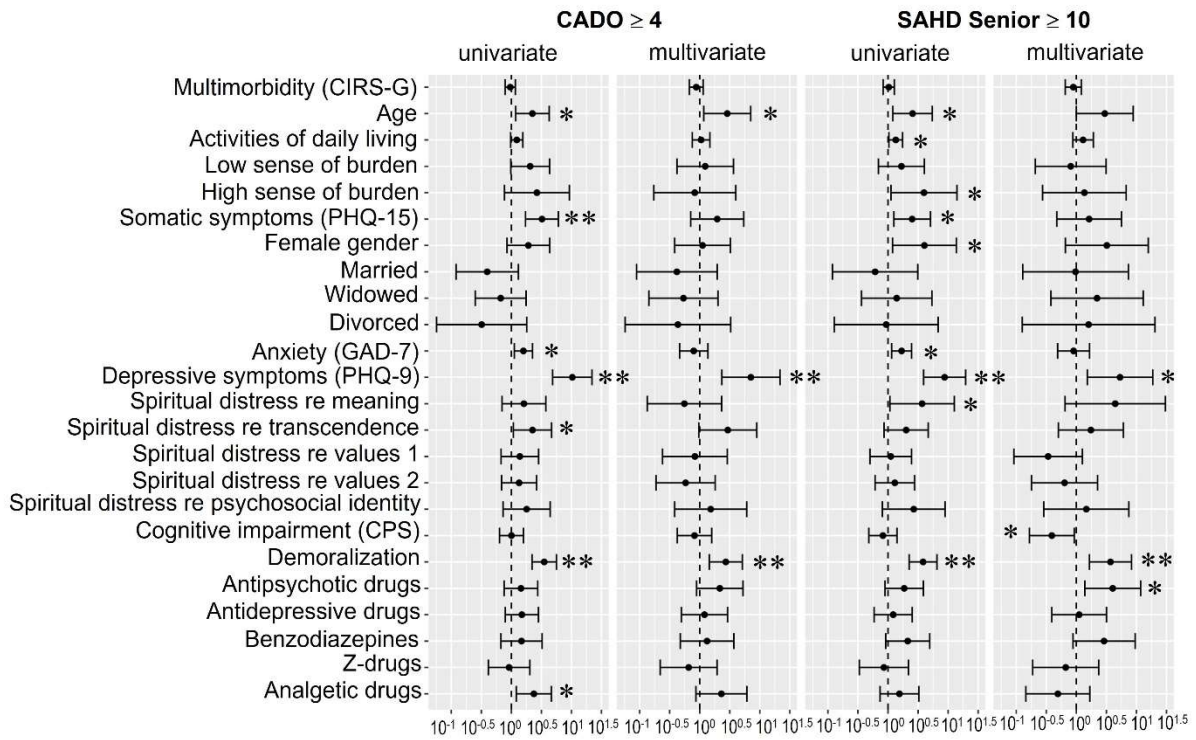
518 **Fig. 2: Prevalence of the wish to die.** CADO = Categories of Attitudes towards
519 Death Occurrence. The CADO categories are: 1: *I am not ready for death and don't*
520 *accept it, 2: I am not ready for death, but I accept it, 3: I am ready for death, and I*
521 *accept it, 4: I accept it and I wish death would come, 5: I am considering hastening*
522 *death, but I have no specific plan, 6: I am considering hastening death and I have a*
523 *specific plan.* SAHD-Senior = Schedule of Attitudes towards Hastened Death for
524 older persons. WTD = wish to die. WTHD = wish to hasten death.



525



526



527