

## RESEARCH PAPER

# Changes in symptom burden from 2019 to 2021 amongst community-dwelling older adults in Finland

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## Abstract

**Background:** Symptom burden causes suffering amongst older adults and is associated with healthcare visits and prognosis.

**Aims:** We evaluated the prevalence of 10 symptoms and changes in symptom burden amongst home-dwelling older adults in 2019 and 2021 using Finnish cohort data. We analysed factors associated with symptom burden increase during follow-up.

**Methods:** Altogether 1,637 people aged 75+ participated in the Helsinki Ageing Study postal survey in 2019, where they reported the presence of 10 common symptoms over the past 2 weeks. Of them, 785 participated in a follow-up in 2021, where the same symptoms were queried. We compared the prevalence of various symptoms and symptom burden scores in the 2-year interval and evaluated factors associated with increased symptom burden during this time.

**Results:** Of participants, 33% reported at least one daily symptom in 2019 versus 44% in 2021. Symptom burden increased by a mean ratio of 1.29 between 2019 and 2021. The most common symptoms were joint pain, back pain, urinary incontinence and fatigue. The prevalence of four symptoms increased between 2019 and 2021: joint pain, urinary incontinence, dizziness and shortness of breath. Higher age, reduced functional capacity and comorbidities were associated with higher odds of symptom burden increase during follow-up. Psychological well-being (PWB) was strongly associated with lower odds of symptom burden increase in the logistic regression model.

**Conclusions:** Symptom burden increased in our cohort aged 75+ between 2019 and 2021 before and during the COVID-19 pandemic. PWB was associated with lower odds of acquiring additional symptoms over time.

**Keywords:** symptom burden, community-dwelling older adults, home-dwelling older adults, Helsinki Ageing Study, COVID-19

## Key Points

- Symptom burden increased during the COVID-19 pandemic amongst community-dwelling older adults.
- The most common symptoms were joint pain, back pain, urinary incontinence and fatigue.
- Psychological well-being was associated with lower odds of increasing symptom burden.

## Introduction

Ageing often comes with comorbid conditions and multiple symptoms that affect the quality of life of older adults. Older people seek help in healthcare for symptoms rather than diseases, and therefore symptoms may serve as indicators of health care use [1]. About half of health care visits are due to symptoms [2]. Pain and lack of energy have been amongst the most common symptoms in older populations [3–6]. The overall symptom burden amongst older adults is associated with well-being, functional status and even mortality [3, 7]. Symptom burden gives detailed information about subjective health different from self-rated health, another important patient-reported measure that associates with important health outcomes [8]. Furthermore, even though symptom burden is associated with the number of comorbidities, it has independent prognostic value beyond comorbidities [3, 6, 7].

Symptoms have been shown to be significant in old age regarding health and well-being, but knowledge is lacking about factors affecting symptom burden over time. Very few studies have examined temporal changes in symptom burden in older adults. Eckerblad *et al.* [9] analysed pain trajectories and the stability of symptom burden; they showed that pain trajectories varied between individuals, but overall symptom burden scores did not change during follow-up. In cancer, repeated symptom assessment may have predictive value; the aggravation of certain symptoms, such as fatigue, pain and loss of appetite, has been shown to predict death amongst cancer patients [10]. In addition, persistent depressive symptoms appeared to be associated with a faster decline in cognitive scores than episodic depression in a cohort with a mean age of 65 years [11].

The aim of this study was to examine changes in symptom burden in community-dwelling cohorts aged 75+ years over a 2-year period between 2019 and 2021. We aimed to identify characteristics that would predict a negative outcome, that is, an increase in symptom burden during follow-up. We compared participants who reported at least one daily symptom at baseline with those who reported no daily symptoms. Furthermore, we analysed which participant characteristics were associated with symptom burden increase during follow-up. Identifying which patients are most at risk of acquiring multiple burdensome symptoms can improve preventive care for the ageing population.

## Methods

### Study design and participants

The Helsinki Ageing Study (1989–) is a cohort study with cross-sectional assessments every 10 years in random population samples aged 75+ years. It has collected information on medical diagnoses, medications, self-rated health, symptoms and functioning amongst community-dwelling older adults in Helsinki, Finland. The most recent study wave took place in 2019, when 2,789 people aged 75+ were invited to

take part in the questionnaire study. The participants were randomly chosen from the Finnish Population Information System according to age: 600 people aged 75, 80, 85 and 90 years, 389 people aged 95 years and 114 people aged 100+ years were invited. The estimated response rate was 74% after excluding those who had died, had moved or had been institutionalised before receiving the questionnaire. One reminder was sent to all who had not responded. Altogether 1,637 people answered the questionnaire in 2019.

We intended to include 800 participants in a follow-up study in 2021. Of a random sample of those answering the questionnaire, 785 people participated in the follow-up. The follow-up consisted of telephone interviews conducted by trained research nurses. Symptoms were inquired using identical questions in 2019 and in 2021; a written questionnaire was employed in 2019 and an oral interview in 2021. In our analysis, we included 776 subjects who participated in the study in both 2019 and 2021 and who reported their symptoms at both time points.

## Measures

### Participant characteristics

Participants' age and sex were gathered from their Finnish personal identity code. Participants reported their marital status ('Are you married or cohabiting/unmarried/divorced/widowed?'), school education (<8 years of schooling, secondary school or higher education) and income (good, moderate or poor). Self-rated functional capacity was reported on a four-step scale (good, moderate, poor or very poor), with the two last options subsequently classified as poor self-rated functional capacity. Self-rated health was reported on a four-step scale (healthy, moderately healthy, moderately unhealthy and very unhealthy), and the two first options (healthy and moderately healthy) were classified as good self-rated health.

The Charlson comorbidity index [12] was calculated from self-reported medical diagnoses. Participants reported whether they had been diagnosed with any of the 20 listed medical conditions such as diabetes, hypertension, coronary heart disease, cardiac insufficiency, stroke, dementia, chronic obstructive pulmonary disease (COPD), asthma, rheumatoid arthritis, osteoarthritis, psychiatric disorder (e.g. depression) and cancer. The participants also reported their regular prescription medications in the questionnaire.

### Psychological well-being

Participants' psychological well-being (PWB) was measured using a validated PWB score [13, 14]. The score was calculated from six questions in the questionnaire: (i) Are you satisfied with your life? (yes/no), (ii) Do you have a zest for life? (yes/no), (iii) Do you feel needed? (yes/no), (iv) Do you have plans for the future? (yes/no), (v) Do you suffer from loneliness? (seldom or never/sometimes/often or always) and (vi) Do you feel depressed? (seldom or never/sometimes/often or always). The dichotomous questions

yielded zero or one point, and the questions with a three-step scale yielded 0, 0.5 or 1 point; a more positive answer yielded a higher score. The summed points were divided by the number of questions that the participant had answered to yield the PWB score (score range 0–1).

### Symptoms and symptom burden

The Helsinki Ageing Study was designed in 1989 by experienced geriatricians who chose the symptoms in the questionnaire. The symptom list has undergone only minor changes since then. This study uses a list of 10 symptoms that were included in the Helsinki Ageing Study Questionnaire in 2019. Participants were asked to report whether they had suffered from any of the 10 listed symptoms over the past 2 weeks on a three-step scale: never, sometimes or daily. The symptoms included (a) dizziness, (b) joint pain that hinders activity, (c) back pain that hinders activity, (d) loss of appetite, (e) abdominal pain, (f) chest pain or discomfort in the chest, (g) shortness of breath, (h) fatigue, (i) anxiety and (j) urinary incontinence.

First, we compared the baseline characteristics of two groups of participants: those who reported at least one daily symptom in 2019 with those who reported no daily symptoms at baseline. Second, we compared the prevalence of each symptom in 2019 and in 2021. Third, we quantified symptom burden for each participant as the number of daily symptoms (range 0–10) in both 2019 and 2021. Finally, we examined factors associated with an increase in symptom burden during follow-up.

We have previously validated a symptom burden score containing eight symptoms, seven of which are present in the current score [7]. Three additional symptoms were added to the questionnaire in 2019, which resulted in the present 10 symptom score. We considered daily symptoms more burdensome than intermittent symptoms, as in our previous study [7], and limited our analysis to them.

### Statistical analysis

Data are presented as means with standard deviation (SD) or as counts (*n*) with proportion (%). Statistical comparison between the groups was performed using *t*-tests and Chi-square tests. Longitudinal changes in prevalence of daily symptoms were assessed with the McNemar test. Multiple logistic regression analyses were used to identify significant factors for symptom burden increase between 2019 and 2021. Symptom burden mean increase was analysed using a generalised estimating equation model (log link and Poisson distribution) with unstructured correlation structure. Hommel's adjustment was applied when appropriate to correct levels of significance for multiple testing. Hommel's adjustment was used because it is more powerful than options such as Bonferroni, Holm's and Hochberg's procedures [15]. In case of violation of assumptions (e.g. non-normality) for continuous variables, we employed a bootstrap-type method or Monte Carlo *P*-values (small number of observations) for categorical variables. The

normality of variables was evaluated graphically and using the Shapiro–Wilk *W* test. Stata 17.0 (StataCorp LP, College Station, TX, USA) was used for the analysis.

## Results

Altogether 776 participants were included in the study. Of these participants, 518 (67%) reported no daily symptoms in the 2019 questionnaire, whereas 258 (33%) reported one or more daily symptoms. Table 1 presents the baseline characteristics of these two groups. There were more women and people aged 85+ years in the daily symptom group ( $P < 0.001$ ). Lower education, living alone and lower income were associated with having one or more daily symptoms (Table 1). Functional status was rated as poor by 20% of participants in the daily symptom group compared with 3% in the no daily symptoms group. Of participants, 74% rated their health as good in the daily symptom group compared with 94% in the no daily symptoms group.

The Charlson comorbidity index was significantly higher in the daily symptom group (1.8 vs. 1.4,  $P < 0.001$ ). Coronary disease, cardiac insufficiency, COPD/asthma and musculoskeletal diseases were significantly more prevalent in the daily symptom group, whereas diabetes, stroke, dementia and cancer showed no significant difference between the groups. Those who had one or more daily symptoms were taking more daily medications, 5.8 drugs on average compared with 4.2 for those with no daily symptoms ( $P < 0.001$ ).

Those who did not suffer from daily symptoms had significantly higher PWB scores.

The proportion of participants reporting at least one daily symptom increased from 33% in 2019 [95% confidence interval (CI) 30–37%] to 44% in 2021 (95% CI 40–47%) ( $P < 0.001$  for change). Figure 1 compares the prevalence of daily symptoms in 2019 and in 2021. The five most prevalent symptoms were joint pain, back pain, urinary incontinence, fatigue and dizziness. Of all 10 symptoms, four showed a significant increase in prevalence (joint pain, urinary incontinence, dizziness and shortness of breath) after the Hommel procedure for multiple comparisons.

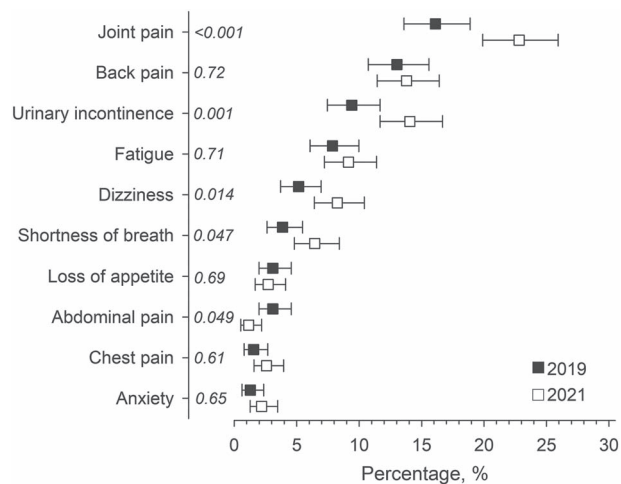
In total, <5% of the participants reported suffering from loss of appetite, abdominal pain, chest pain or anxiety. Abdominal pain was the only symptom that became less prevalent during follow-up.

Symptom burden distribution is shown in Figure 2. Mean symptom burden increased from 0.64 in 2019 to 0.83 in 2021, the mean ratio being 1.29 (95% CI 1.15–1.45,  $P < 0.001$ ) between 2021 and 2019. Very few participants had symptom burden scores of over 3.

Of participants, 30% (95% CI 26–33%) had a higher symptom burden in 2021 than in 2019. We employed multiple logistic regression to study the factors associated with an increase in symptom burden during follow-up. The variables associated with higher odds of symptom burden increase were age group 85–90 years [odds ratio (OR) 1.5 vs.

**Table 1.** Baseline characteristics of the two groups: no daily symptoms/one or more daily symptoms in 2019

	No daily symptoms <i>N</i> = 518	One or more daily symptoms <i>N</i> = 258	<i>P</i> -value
Women, <i>n</i> (%)	307 (59)	202 (78)	<0.001
Age, years, <i>n</i> (%)			<0.001
75–80	306 (59)	103 (40)	
85–90	188 (36)	133 (52)	
95+	24 (5)	22 (9)	
Education, <i>n</i> (%)			0.003
<8 years	102 (20)	69 (27)	
Secondary school	150 (29)	84 (33)	
Higher education	264 (51)	104 (40)	
Married or cohabiting, <i>n</i> (%)	241 (47)	90 (35)	0.002
Income, <i>n</i> (%)			<0.001
Good	214 (41)	67 (26)	
Moderate	288 (56)	177 (69)	
Poor	16 (3)	14 (5)	
Functional capacity, <i>n</i> (%)			<0.001
Good	330 (64)	59 (23)	
Moderate	168 (33)	143 (57)	
Poor	15 (3)	51 (20)	
Good self-rated health, <i>n</i> (%)	483 (94)	186 (74)	<0.001
Charlson comorbidity index, mean (SD)	1.4 (1.4)	1.8 (1.6)	<0.001
Medical diagnoses, <i>n</i> (%)			
Diabetes	87 (17)	58 (22)	0.056
Coronary disease	82 (16)	57 (22)	0.032
Cardiac insufficiency	81 (16)	62 (24)	0.004
Stroke	55 (11)	34 (13)	0.29
Dementia	34 (7)	22 (9)	0.32
COPD/asthma	46 (9)	38 (15)	0.014
Musculoskeletal disease	237 (46)	191 (74)	<0.001
Cancer	143 (28)	75 (29)	0.67
Number of drugs, mean (SD)	4.2 (3.1)	5.8 (3.7)	<0.001
PWB score, mean (SD)	0.86 (0.18)	0.74 (0.24)	<0.001

**Figure 1.** Prevalence of daily symptoms in 2019 (in black) and 2021 (in white) presented with 95% CIs and *P*-values with the Hommel procedure for multiple comparisons.

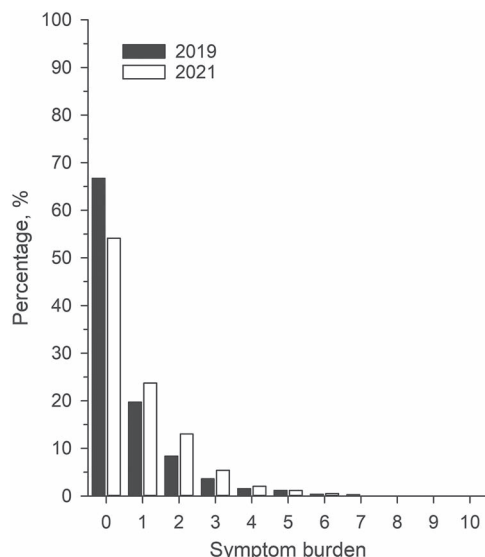
age group 75–80], moderate functional capacity (OR 1.71 vs. good functional capacity) and the Charlson comorbidity index (OR 1.21 for one unit increase, see Table 2). Two variables were associated with lower odds of symptom burden

increase: the PWB score (OR 0.17 for one unit increase) and symptom burden in 2019 (OR 0.59 for one unit increase). Sex, education, living alone, level of income or number of regular drugs did not affect odds of symptom burden increase in the logistic regression model.

## Discussion

An increasing trend in symptom burden emerged amongst home-dwelling older people during a 2-year follow-up between 2019 and 2021. Most had a symptom burden score of 0–2 (equivalent to 0–2 daily symptoms) in both years. The mean score increased from 0.64 to 0.83 between 2019 and 2021. Of the 10 symptoms, joint pain, urinary incontinence, dizziness and shortness of breath increased in prevalence during follow-up. Higher age (85–90 years), diminished functional capacity and higher Charlson comorbidity index were associated with higher odds of symptom burden increase during follow-up. Interestingly, higher symptom burden in 2019 and stronger PWB were associated with lower odds of symptom burden increase.

We report lower symptom prevalence numbers than previous studies [3,5,16–18], and this is affected by our choice



**Figure 2.** The bar chart shows symptom burden distribution in percentage in 2019 (in black) and in 2021 (white). Symptom burden score range was 0–10, with every daily symptom adding one point to the score.

**Table 2.** Multiple logistic regression model for symptom burden increases between 2019 and 2021

	OR (95% CI)	P-value
Male sex	0.83 (0.56–1.24)	0.36
Age, years		0.13 [Linearity]
75–80	1.00 (ref)	
85–90	1.50 (1.04–2.16)	
95+	1.05 (0.49–2.25)	
Education		0.69 [Linearity]
<8 years	1.00 (ref)	
Secondary school	0.95 (0.60–1.51)	
Higher education	0.91 (0.58–1.43)	
Married or cohabiting	1.25 (0.85–1.85)	0.26
Income		0.34 [Linearity]
Good	1.00 (ref)	
Moderate	1.37 (0.93–2.01)	
Poor	0.80 (0.30–2.10)	
Functional capacity		0.016 [Linearity]
Good	1.00 (ref)	
Moderate	1.71 (1.16–2.53)	
Poor	1.73 (0.85–3.50)	
Charlson comorbidity index	1.21 (1.08–1.37)	0.002
Number of drugs	1.04 (0.99–1.10)	0.12
PWB score	0.17 (0.07–0.42)	<0.001
Symptom burden in 2019	0.59 (0.49–0.73)	<0.001

ref = reference.

to report only symptoms that occurred daily. As in our study, pain and fatigue have been amongst the most common symptoms in earlier studies addressing symptom burden in older adults [3, 5, 16, 19]. Urinary incontinence has been rarely included in symptom burden scores in older adults; Whitson *et al.* [20] reported a prevalence of 22–36% in slightly younger cohorts during the previous month. In this study, urinary incontinence was amongst the most common

daily symptoms and its prevalence increased during follow-up, suggesting that incontinence poses a major burden on older adults aged 75+ years.

Our study adds to the scarce literature on symptom burden evolution over time amongst home-dwelling older adults. Eckerblad *et al.* [9] have previously shown that home-dwelling older people suffer from persistent high symptom burden, irrespective of a comprehensive geriatric assessment. We show a slightly increasing trend in symptom burden; however, the symptoms queried in our study were different from those of the Memorial Symptom Assessment scale used by Eckerblad and colleagues, which may contribute to the discrepancy between the results. Furthermore, the COVID-19 pandemic that began in spring 2020 might have contributed to a net increase in symptoms, as older citizens were encouraged to avoid all contacts, especially at the beginning of the pandemic. Lack of physical activity and loneliness may have increased the emergence and the self-monitoring of symptoms, thereby increasing symptom burden. On the other hand, symptoms may also have increased due to the ageing of our participants.

Several participant characteristics, such as female sex, higher age, low level of education, living alone, poor income, diminished functional capacity and poor self-rated health, have been shown to be associated with symptom burden [7], and the present study confirms this finding. When looking at symptom burden increase over time, only age, diminished functional capacity and the Charlson comorbidity index remained significant. It is encouraging to see that despite their advanced age most participants had relatively low symptom burden and those with higher burden were less likely to acquire additional symptoms. Furthermore, our study highlights the significance of PWB as a protective factor in health. To our knowledge, this is the first study to identify characteristics amongst older adults that predict symptom burden increase in a longitudinal setting.

Study strengths are that the cohort in the initial study in 2019 was randomly chosen and the response rate was good. Nearly half of the participants of the initial study were successfully recruited to the follow-up, where the same questions were used to ensure comparability. The items in our questionnaire have been the same for over three decades, and they have been shown to be easy for older people to understand. Furthermore, our study provides novel information about changes in older people’s symptom burden and well-being during the COVID-19 pandemic.

Some weaknesses must also be addressed. We cannot determine whether the higher symptom burden in 2021 is due to the ageing of our participants, social isolation and sedentary life during the COVID-19 pandemic or due to other factors. The follow-up study was performed via telephone interviews, as opposed to the written questionnaire in 2019, which may affect the way people perceived and reported their symptoms. In addition, some people participating in the questionnaire study were already deceased or in poor health during the follow-up study. Therefore, the findings apply to those who had a better prognosis at the

baseline in 2019. Finally, we only assessed the frequency of bothersome symptoms and not their intensity and are, therefore, unable to observe temporal changes in this respect.

## Conclusion

Symptom burden increased significantly amongst home-dwelling adults aged 75+ years in a longitudinal setting during the COVID-19 pandemic. Functional capacity, age and the Charlson comorbidity index were associated with increased symptom burden. PWB and higher symptom burden at baseline reduced the odds of increasing symptom burden. We conclude that there is a significant care debt amongst older people that should be addressed in health-care—especially in primary healthcare.

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**Data Availability Statement:** Data are available on reasonable request.

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