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1 **Participation in work and leisure activities after stroke: A national study**

2

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26

27 **Abstract**

28 **Background.** Stroke is a common and debilitating neurological disorder having a negative
29 impact on quality of life.

30 **Objectives.** We aimed to compare differences in participation in work and leisure activities
31 between patients with and without a self-reported stroke at the national level in France.

32 **Methods.** This study used cross-sectional data from the Disability Health Survey that was
33 administered in people's homes (DHH) in 2008 and in institutions (DHI) in 2009. Stroke
34 history and levels of participation in work and leisure activities were collected by interviews.
35 The levels of participation in these activities were compared between participants with and
36 without a history of stroke.

37 **Results.** Among the 33,785 interviewed participants, 1,725 reported a history of stroke. After
38 weighting, this represented a mean (SD) of 766,641 (36,650) people among 49 million adults
39 living in France. After adjustment, as compared with people without stroke, those with stroke
40 were less likely to work (odds ratio 0.19 [95% confidence interval 0.13-0.27]), use the
41 telephone (0.21 [0.17-0.25]) and drive (0.25 [0.21-0.32]). In the age group 19-59 years, as
42 compared with people without stroke, those with stroke less frequently worked (35.9% vs
43 72.2%), drove (54.3% vs 81.3%) and participated in sports (26.6% vs 55.8%).

44 **Conclusions.** Overall, our study indicates that people with a history of stroke report more
45 difficulties in participating in work and leisure activities than those without a history of
46 stroke.

47

48 **Introduction**

49 Approximately 80 million people in the world have a history of stroke [1]. The prevalence of
50 stroke is about 1.6% in the general population in France, and this figure is greater than 10% in
51 men aged 85 years or older [2]. At the individual level, stroke is associated with physical
52 morbidity [3], psychological distress [4] and mortality [5]. Stroke also has a substantial
53 impact at the national level, with high health care costs [6].

54 Although stroke is frequent and is known to be one of the major causes of disability
55 worldwide [7], only few studies have focused on the impact of stroke on leisure activities [8–
56 12]. In addition, most previous studies were based on small sample sizes, did not include
57 control groups and did not analyze the different leisure activities separately (e.g., sports, arts,
58 board games). Numerous studies have recently been published regarding work activities, but
59 findings are often difficult to generalize because the rate of return to work varies widely
60 among countries and settings [10,13,14]. Decreased participation in work and leisure
61 activities was found associated with poor quality of life in individuals with a history of stroke
62 [15,16]. Therefore, investigating the participation of stroke survivors in these activities may
63 be important for improving the care of these patients at the chronic stage of the disease.

64 The aim of this national study conducted in France was to compare the participation in
65 work and leisure activities between individuals with and without a history of stroke.

66

67 **Material and methods**

68 *Disability Health surveys*

69 The Disability Health surveys have been described in previous studies [2,17,18]. Briefly, the
70 aim of the Disability Health surveys, coordinated by the French Institut National de la
71 Statistique et des Études Économiques (INSEE; National Institute of Statistics and Economic
72 Studies) and the Direction de la Recherche, des Études, de l'Évaluation et des Statistiques
73 (Directorate of Research, Studies, Evaluation and Statistics) is to estimate the number of
74 dependent or disabled people in the general French population, describe the overall functional
75 health status of the population and document the incidence of different types of disability (i.e.,
76 physical, mental, cognitive, psychological). The secondary aim is, by using the International
77 Classification of Functioning, Disability and Health (ICF), to describe the environmental
78 factors favoring or limiting activities of daily living. Therefore, these detailed surveys explore

79 social participation (i.e., work, family, social relations, leisure activities), discrimination and
80 administrative recognition of disability, and human, technical and financial assistance. For the
81 present study, data from 2 parts of the survey were analyzed: Disability Health at Home
82 (DHH), performed in 2008, which covered the population living at home, and Disability
83 Health in Institutions (DHI), which covered the population living in long-term institutions in
84 2009. The study had a nationally representative design.

85

86 *DHH survey*

87 Before the DHH survey, a preliminary survey, called the Daily Life and Health survey, was
88 administered in 2007. A questionnaire was sent by mail to 127,200 homes that were randomly
89 drawn from all over France. The questionnaire consisted of 26 questions, of which 13 were
90 related to functional limitations, 1 to global activity limitations and 1 to the perception of
91 disability. The response rate was 80% (102,000 homes, including 238,000 individuals). The
92 database was then built from the responders of the preliminary survey. It consisted of 4 strata
93 according to the severity of the reported level of disability (i.e., no disability and slight,
94 moderate, and severe disability). To over-represent disabled people, participants with
95 disability had a higher weight than those without disability in the statistical analyses. The
96 survey was declarative and administered by face-to-face interview (with the help of family or
97 caregiver if the interviewee was not able to answer alone). The level of participation in the
98 interviews was 77%.

99

100 *DHI survey*

101 This complementary survey was carried out in institutions for older people (i.e., long-term
102 health care units, establishments for dependent older people, retirement homes), institutions
103 for disabled adults as well as psychiatric institutions and centers for social reintegration.

104 Among the 1,567 institutions sampled in France, 97% agreed to participate in the survey. The
105 level of participation of institutionalized individuals was 90.9%.

106

107 *Ethics statement*

108 This study was planned as a research project. It was performed in collaboration with DREES.
109 This study was declared of public interest by the Conseil National d'Information Statistique
110 and was approved by the Commission Nationale de l'Informatique et des Libertés (French law
111 no. 78–17). According to French law in 2007, written informed consent was not required for
112 this type of study. The data used were taken from the Disability Health surveys and were
113 anonymized before analysis.

114

115 *Study variables*

116 The interview questionnaire was practically identical between both surveys. Participants were
117 asked about their medical history. A list of 50 diseases was proposed (i.e., stroke) and the
118 question was “Do you have or have you ever had any of these diseases or health problems?
119 Subsequent questions focused on participation in work and leisure activities. For example, the
120 following question was asked: “In the past 12 months, have you been to the movie theatre?”,
121 with yes and no answers. Fifteen activities were included in this study: playing board games,
122 going to concerts, going to the movie theatre, reading, listening to music, watching television,
123 doing arts, knitting, tinkering, playing sports, going to the museum, using the telephone, using
124 the computer, driving the car, and working. Demographic variables collected included age and
125 sex.

126

127 *Statistical analysis*

128 A database including the variables of interest was constructed for each survey. Individuals
129 under 18 years of age were excluded. The databases (DHH and DHI) were then merged to
130 represent the overall French adult population living at home and in institutions. This was a
131 nationally representative study, and weights were calculated for both the DHH and DHI
132 surveys. Adjustment variables included age and sex. All statistical analyses involved using
133 statistical procedures adapted for complex survey plans (proc surveyfreq and proc
134 surveylogistic, SAS Enterprise Guide v4.3), with stratifications and weights taken into
135 account. Proportions of stroke survivors and controls participating in work and leisure
136 activities were compared by using partial Wald tests. Age- and sex-adjusted odds ratios (ORs)
137 with 95% confidence intervals (CIs) were further computed. The level of significance was set
138 at $p < 0.05$.

139

140 Results

141 Among the 33,785 interviewed participants, 1,725 had a history of stroke. After weighting,
142 this represented a mean (SD) of 766,641 (36,650) people among 49 million adults living in
143 France. Participation in work and leisure activities (except for board games and art) was less
144 likely with than without a self-reported history of stroke, with age- and sex-adjusted ORs
145 ranging from 0.19 to 0.77 in the overall population (see Table and Figure). The 3 activities
146 that were the most affected by stroke were working (OR=0.19 [95% CI 0.13-0.27]), using the
147 telephone (0.21 [0.17-0.25]) and driving (0.25 [0.21-0.32]). The mean (SD) prevalence of
148 work activity was 8.1% (1.3%) and 54.2% (0.4%) with and without a history of stroke and
149 was 35.9% (4.8%) and 72.2% (0.5%), respectively, for participants 19 to 59 years old. The
150 mean (SD) prevalence of driving was 38.7% (2.4%) and 76.1% (0.3%) with and without a
151 history of stroke and was 54.3% (4.5%) and 81.3% (0.4%) for individuals 19 to 59 years old.
152 The mean (SD) prevalence of sport activities was 16.9% (2.1%) and 49.2% (0.4%) with and

153 without a history of stroke and was 26.6% (4.4%) and 55.8% (0.6%) for individuals 19 to 59
154 years old.

155

156 Discussion

157 To the best of our knowledge, this is the first national study investigating participation in
158 work and leisure activities in people with a history of stroke. Participation in these activities
159 was significantly lower in stroke survivors than people without stroke and was particularly
160 low for working, using the phone and driving.

161 Several studies have analyzed a return to work after stroke, and there is some
162 discrepancy in the findings of these previous analyses. For example, in 150 stroke survivors
163 from India, only 20.7% were employed after a stroke, whereas this proportion was 62.7%
164 before this neurological event [13]. More recently, a 2017 Swedish study found in 174 people
165 ≤ 63 years old that the rate of return to work was 74.7% after 6 years of follow-up [14]. In our
166 national study, the prevalence of participation in work was 35.9% in stroke survivors and
167 72.2% in controls aged 19 to 59 years. The discrepancy in the results from previous studies is
168 likely explained by major differences in the treatment, management and rehabilitation of
169 stroke survivors between these countries (i.e., India, Sweden, France), particularly between
170 developed and developing countries [19]. Also, the present study is the first study with a
171 national and cross-sectional design. Major predictors of a return to work after stroke seem to
172 be dependency at discharge, aphasia, sick leave and alcohol consumption before the stroke,
173 rehabilitation length of stay, anxiety, depression, and global functioning [14,20,21]. However,
174 unfortunately, these studies featured selection bias (e.g., post-rehabilitation studies). Finally,
175 little knowledge of predictors of a return to work are from large cohort studies, which needs to
176 be improved. The low rate of employment among individuals with a history of stroke in the
177 present study is of particular concern because lack of return to work in the post-stroke context

178 is associated with low occupational satisfaction, decreased quality of life and poor emotional
179 status [21–23].

180 We found that participation in leisure activities was less frequent with than without a
181 history of stroke, and these results agree with the literature. For example, previous research of
182 people with mild stroke found that the number of high-demand leisure activities (e.g.,
183 running, swimming, bicycling) decreased after stroke [24]. Later, a US study including a
184 sample of 156 patients found that only 30.8% of the population returned to driving 6 months
185 after stroke, and this reduced activity was significantly predicted by cognitive ability and
186 motricity of lower extremities [25]. Finally, in 60 chronic stroke survivors, Korean
187 researchers estimated that most had not returned to their pre-stroke level of leisure activity
188 participation and that the mean number of activities had decreased from 3.9 to 1.9 [26]. The
189 authors further showed that the most frequent barriers to participation in leisure activities
190 were weakness and poor balance, lack of transportation, and cost. Although these previous
191 studies have advanced the field, they feature several limitations that need to be acknowledged.
192 First, because most of these analyses focused on only a few leisure activities, identifying the
193 activities that are most affected by stroke is difficult. Second, these studies were based on
194 small sample sizes, and thus their findings cannot be generalized. In contrast, with the
195 inclusion of 15 activities (i.e., work, using the phone, driving) and with the use of weighted
196 samples, the present national study including more than 33,500 participants is
197 methodologically sound and sheds important light on participation in work and leisure
198 activities after stroke.

199 These findings suggest that the rehabilitation of stroke survivors should be
200 personalized and include leisure activities performed before the stroke as goal of
201 rehabilitation. Furthermore, participation in work and leisure activities may be improved at
202 the societal level by several public health measures such as increasing the number of

203 workplaces adapted to people with disabilities **after stroke**, favoring the development of cars
204 with personalized pedals and cruise control and increasing the number of financial aids for
205 family caregivers. Future studies should focus on the identification of predictors of
206 participation in work and leisure activities in stroke survivors.

207 The strengths of the study include the large sample size **and** the use of nationally
208 representative data and a control group. The use of a control group allowed us to define with
209 accuracy the standard participation in work and leisure activities among the general
210 population, and thus estimate the relative risk of non-participation in these activities among
211 stroke survivors.

212 However, the study **has** several limitations. First, this was a cross-sectional analysis,
213 stroke was self-reported, and we had no information about the exact time **when** stroke
214 occurred, although **this** may have **affected** our findings. Second, our study could have
215 benefited from more detailed questions on work and leisure activities **before** and after stroke.
216 Finally, there was a lack of sociodemographic variables (e.g., income, education, type of
217 employment, marital status), and we were thus unable to investigate their impact on rates of
218 participation in work and leisure activities. **Several** of these variables are significantly
219 associated with risk of stroke [27,28], **and they** may have introduced a bias in the statistical
220 analyses.

221 **Overall, our study indicates that people with a history of stroke report more difficulties**
222 **in participating in work and leisure activities than those without a history of stroke.**

223

224 **About the data.** All files distributed within the frame of the Réseau Quetelet are distributed
225 free of charge for research purposes.

226 **Funding.** This study received financial support from IPSEN for analysis of the data and the
227 writing and translation of the manuscript.

228 **Conflict of interest.** None declared.

229 **Figure.** Participation in work and leisure activities in stroke survivors versus controls in an
230 ascending order. Odd ratios were adjusted for age and sex. All odds ratios are significant
231 except for playing board games and doing arts.

232

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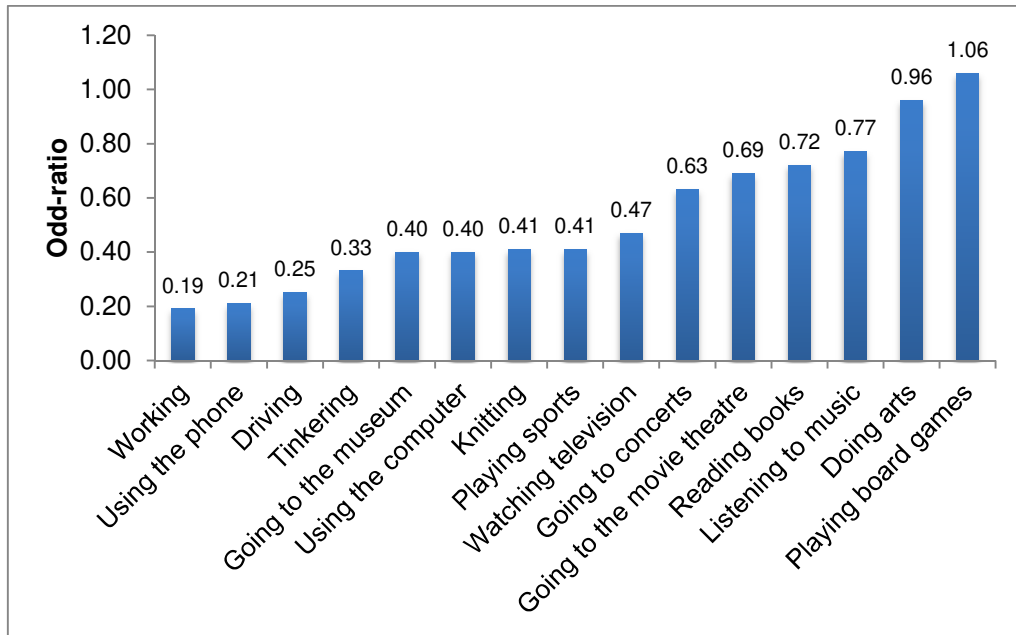
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1
2
3
4
5

Figure

1 **Table.** Participation in work and leisure activities by individuals with and without a history of stroke and by age group.

Activity	Overall population			19-59 years old		60-74 years old		75-84 years old		>85 years old	
	% Stroke	% No stroke	OR (95% CI)	% Stroke	% No stroke	% Stroke	% No stroke	% Stroke	% No stroke	% Stroke	% No stroke
Playing board games	29.3 (2.2)	36.1 (0.4)	1.06 (0.85-1.32)	34.8 (4.5)	37.9 (0.6)	27.5 (4.2)	32.4 (1.0)	31.7 (4.1)	30.5 (1.2)	22.1 (4.2)	28.6 (1.7)
Going to concerts	17.5 (2.0)	34.0 (0.4)	0.63 (0.47-0.84)	21.7 (3.9)	37.5 (0.6)	25.4 (4.9)	30.1 (1.0)	11.3 (2.7)	16.2 (1.1)	8.6 (2)	10.6 (1.3)
Going to the movie theatre	25.5 (2.0)	55.9 (0.4)	0.69 (0.54-0.88)	41.8 (4.6)	63.5 (0.5)	35.6 (5.0)	39.9 (1.0)	14.9 (3.0)	21.7 (1.2)	5.9 (1.5)	8.1 (1.1)
Reading books	45.5 (2.4)	58.8 (0.4)	0.72 (0.59-0.89)	46.2 (4.7)	60.4 (0.6)	54.9 (4.7)	58.5 (1.0)	40.7 (4.3)	49.2 (1.3)	35.7 (5.3)	42.3 (1.9)
Listening to music	52.1 (2.4)	81.3 (0.3)	0.77 (0.62-0.95)	73.1 (4.2)	89.5 (0.3)	62.5 (4.6)	67.9 (0.9)	40.1 (4.2)	48.3 (1.3)	29.4 (5.2)	33.5 (1.8)
Watching television	93.2 (0.8)	97.6 (0.1)	0.47 (0.35-0.62)	95.6 (1.3)	97.9 (0.17)	97.2 (0.9)	98.2 (0.2)	92.3 (1.7)	96.8 (0.3)	84.4 (2,6)	88.9 (0.9)
Doing arts	10.6 (1.7)	16.7 (0.3)	0.96 (0.66-1.40)	16.3 (3.9)	18.6 (0.5)	14.6 (3.8)	15.0 (0.8)	6.5 (3.1)	6.1 (0.6)	4.1 (1.5)	6.6 (1.1)
Knitting	14.6 (2.0)	22.7 (0.4)	0.41 (0.29-0.57)	14.9 (2.8)	20.3 (0.4)	20.6 (4.6)	32.0 (1.0)	11.3 (3,3)	27.4 (1.2)	9.1 (3.1)	15.7 (1.4)
Tinkering	40.8 (2.5)	65.8 (0.4)	0.33 (0.27-0.41)	48.2 (4.6)	67.5 (0.5)	53.9 (4.8)	72.7 (0.8)	32.9 (4.4)	48.2 (1.3)	21.6 (5.5)	23.4 (1.8)
Playing sports	16.9 (2.1)	49.2 (0.4)	0.41 (0.31-0.57)	26.6 (4.4)	55.8 (0.6)	21.5 (4.7)	41.4 (1.0)	11.9 (3.1)	16.9 (1.1)	5.4 (2.7)	6.3 (1.0)
Going to the museum	16.3 (1.9)	37.0 (0.4)	0.40 (0.30-0.53)	28.1 (4.3)	38.8 (0.6)	21.8 (4.2)	40.9 (1.0)	9.5 (2.7)	20.8 (1.2)	4.2 (2.6)	8.6 (1.3)
Using the phone	81.7 (1.3)	98.4 (0.1)	0.21 (0.17-0.25)	92.2 (1.6)	99.3 (0.1)	89.8 (1.7)	98.9 (0.1)	76.1 (2.8)	95.1 (0.3)	64.5 (4.1)	78.6 (1.1)
Using the computer	82.3 (1.4)	97.0 (+/-0.1)	0.40 (0.31-0.51)	90.4 (1.8)	98.7 (0.1)	88.1 (2.8)	96.3 (0.3)	78.9 (0.7)	89.3 (0.7)	67.7 (3.9)	76.2 (1.3)
Driving	38.7 (2.4)	76.1 (0.3)	0.25 (0.21-0.32)	54.3 (4.5)	81.3 (0.4)	51.4 (4.9)	75.6 (0.8)	30 (4.1)	45.3 (1.3)	12.1 (4.7)	18.8 (1.7)
Working	8.1 (1.3)	54.2 (0.4)	0.19 (0.13-0.27)	35.9 (4.8)	72.2 (0.5)	1.9 (1.0)	8.6 (0.6)	0	0.8 (0.3)	0.9 (0.8)	0.01 (0.01)

2 Data are mean (SD) unless otherwise indicated.

3 OR, odds ratio; 95% CI, 95% confidence interval

4 Playing board games was assessed with the following question: "In the past 12 months, have you played board games?". Similar questions were used for the other activities.

6 Odds ratios were adjusted for age and sex.