

2024-03-19

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<https://pearl.plymouth.ac.uk/handle/10026.1/21799>

10.1159/000536012

Neuroepidemiology

Karger Publishers

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Dementia screening in rural Kenya: The prevalence and impact of screening positive for dementia

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Short Title: Dementia screening in rural Kenya

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Number of Tables: 3

Number of Figures: 0

Word count: 2,842

Keywords: Dementia, older adults, prevalence, loneliness, Kenya

1 **Abstract**

2 **Introduction:** In Kenya, there is a lack of data on the number of people with dementia. In this article,
3 we aim to estimate the number of community-dwelling older adults (aged 60 years and above) that
4 are potentially living with dementia in rural Kenya.

5 **Methods:** Recruitment of older adults occurred through adopting a convenience approach based on
6 the catchment areas served by trained ten Community Health Workers (CHWs). Screening was
7 conducted using the Brief Community Screening Instrument for Dementia (CSI-D), in which
8 prevalence ratios were reported. Regression analyses were run to understand the association
9 between screening outcome and wellbeing, social isolation, and employment status (adjusted for
10 age, sex, literacy, geography, and social status).

11 **Results:** Of the 3,546 older adults who were screened for dementia, 652 screened positive (0.18,
12 95%CI 0.17 to 0.20). Back estimating screen positives based on established sensitivity and specificity
13 of the tool against a gold standard (clinical diagnosis), yielded a prevalence of 9.4% (0.09, 95%CI
14 0.08 to 0.11). Screening positive for dementia was associated with poorer quality of life (B = -0.17,
15 $p < 0.001$) and loneliness (B = 0.28, $p < 0.001$).

16 **Conclusion:** There is potentially 258,000 older adults living with dementia in Kenya, who likely have
17 poorer outcomes. We need to encourage a timely diagnosis and develop better ways to support
18 people living with dementia in Kenya and other resource-limited settings.

19

20 **Introduction**

21 The Kenyan census done in 2019 revealed that 11% of the population were aged 60 years and older
22 [1], surpassing the projected 2050 population estimates (10.6%) [2]. Dementia has a profound impact
23 on those living with the condition and is associated with older age; as such modelling suggests that
24 the number people with dementia in Kenya will grow to 361,000 in 2050 [3]. Underdiagnosis and lack
25 of comprehensive surveillance in the region makes making conclusions on the basis of health records
26 alone problematic.

27 It is essential that we are able to generate localised evidence about the number of people with
28 dementia, in part because of potentially unmeasured risk factors that could lead to country-level
29 variation. For example, in Kenya there is potentially higher numbers of HIV-neurocognitive
30 impairment [4] indicating HIV infection as a significant risk factor for dementia etiology. Generating
31 in-country prevalence estimates may also be more palatable for policy makers [5], and provides the
32 best current basis for resource allocation of dementia care and service planning. Despite this, there is
33 still a lack of data on the number of people living with dementia in Kenya [6]. The best quality data is
34 derived from non-representative cross-sectional estimates (17.9% of probable dementia) identified
35 through care and health systems [7].

36 Just as importantly, we need to understand how living with dementia impacts people's lives. To date,
37 much of the evidence is derived from small samples of caregivers or health professionals, perhaps
38 reflecting that many people diagnosed with dementia do so at the later stages of the condition.
39 Irrespective, the limited research highlights that living with dementia in Kenya is difficult. For
40 example, stigma surrounding dementia can lead to neglect and abuse [8]. It is also important to
41 recognise that for dementia there are non-standardised initial care pathways [9] and lack of available
42 support for people with dementia and their families in Kenya [10]. Whilst we can make inferences
43 about such data based on geographically or demographically similar countries, there are usually
44 dramatic differences between health and care systems, finances, attitudes and culture.

45 At present, we are no closer to generating robust estimates of dementia prevalence in Kenya, but we
46 can start to understand the numbers of community-dwelling older adults that are potentially living
47 with dementia through exploring those who screen positive for dementia. Comparisons between
48 those who screen positive and negative for dementia, better allow for us to understand potential risk
49 factors but also how living cognitive impairment impacts the lives of older Kenyans.

50 **Materials and Methods**

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51 **Design:** The Integration and Evaluation of a Community-Level Dementia Screening Programme in
52 rural Kenya (DEM-SKY) was a cross-sectional project primarily designed as an evaluation study of the
53 programme over a 6-month period.

54 **Study setting:** Makueni County is a rural county located on the south-eastern part of Kenya whose
55 main economic activity is agriculture [11]. It hosts a population of 988,000 individuals, of which
56 86,000 are over the age of 60 years old [12]. At the age of 60, males have an average life expectancy
57 of 13.8 years and females have an average life expectancy of 16.5 years [12]. The county contains
58 six sub counties with one County referral hospital, 11 sub-county hospitals, 47 health centers and
59 178 dispensaries [11]. Makueni county has only one psychiatrist based at the County referral
60 hospital. Our study was conducted in the central part of Makueni, close to the county headquarters
61 in order to target participants who have access to the referral hospital with a mental health unit.

62 **Participants:** Participants were older adults (aged 60 years and older) living in Makueni County,
63 Kenya. All older adults were required to have an informant (e.g., family member or friend) who could
64 also participate in the informant reported section of the screening tool. Recruitment occurred
65 through adopting a convenience approach based on the catchment areas served by ten Community
66 Health Workers (CHWs). The CHWs would however regularly meet with the research team to reflect
67 on the demographics (e.g., education, social status, gender, and literacy) of those screened to ensure
68 that the sample was not homogenous. No formal criteria were used to assess homogeneity.

69 **Procedure:** CHWs were trained by the research team on consenting and administration of the
70 assessment measures over a period of one week. The training involved a role-playing component and
71 feedback session. After the training, older adults in the community were approached by CHWs in
72 their homes to participate in the dementia screening program. All participants were offered to
73 participate in the dementia screening as part of their usual healthcare and were highlighted the pros
74 and cons of dementia screening. Participants were informed that they could participate in the
75 dementia screening without participating in the research components. Following informed consent,
76 CHWs asked a series of questions related to sociodemographics, loneliness and quality of life (QoL)
77 prior to completing the dementia screening tool with the older adult and the informant. The older
78 adult was then informed about the outcome of the dementia screening process and those who
79 screened positive were supplied a referral letter to seek a diagnosis, if they so wished. The entire

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80 screening process (from consenting to completion of the last measure) took approximately 30
81 minutes.

Measures

83 **Sociodemographic factors:** Older adult age, literacy, sex, people, geographic region of recruitment,
84 employment—activity to produce goods or services to earn an income (as defined by the
85 International Labour Organization [13])— and subjective socioeconomic status (MacArthur Scale of
86 Subjective Social Status [14]).

87 **Dementia screening outcome:** The Brief Community Screening Instrument for Dementia (CSI-D). The
88 measure is composed of both cognitive items (asked to the older adult; Brief CSI-D cognitive scale)
89 and a combination of cognitive and functional items (asked to the informant; Brief CSI-D informant
90 scale). The Brief CSI-D informant scale is subtracted from the Brief CSI-D cognitive scale (range -6 to
91 9). Based upon the original paper tested in non-western settings (i.e., Latin America, India, China and
92 Nigeria), a score of <5 has the best sensitivity and specificity for detecting dementia [15].

Other Outcomes:

94 UCLA-3-item measure of loneliness [16], is a widely used measure of loneliness. Higher scores
95 represent greater loneliness. The measure has previously been shown to have good internal
96 consistency ($\alpha=0.72$) [16]. The measure has been used internationally to generate national estimates
97 of loneliness in older adults, albeit not within Africa [17]. However, the measure has been used in
98 Ghanaian older adults (aged 50 years and older) with good internal consistency ($\alpha=0.81$) [18]. Within
99 the present study the UCLA-3-item measure of loneliness demonstrates good internal consistency (ω
100 = 0.82, 95% CIs 0.81 to 0.83).

101 The EUROHIS-QOL-8 [19] is an 8-item measure of QoL. It has good internal consistency ($\alpha = 0.83$), and
102 is one of the most widely used measures older adult QoL within Africa [20]. Within the present study
103 the EUROHIS-QOL-8 demonstrates adequate internal consistency ($\omega = 0.79$, 95% CIs 0.77 to 0.81).

104 All measures were forward- and back-translated into Kamba by two multilinguists and concepts and
105 inconsistencies checked by a team consisting of clinicians, psychologists and community health
106 officers to ensure the intended meaning had been maintained.

Analysis

108 The percentages of who screened positive for dementia based on the Brief CSI-D were reported for
109 the whole sample, and then split by age (5-year categories), sex and literacy (able to read and write).
110 Prevalence estimates and 95% CIs were reported for each. We then re-analysed the whole sample

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111 following weighting data based on surveillance data from Kenya on the distribution of the population
112 by age and sex [21]. The analysis was first weighted based on proportions from Makueni County, and
113 subsequently the whole of Kenya. See Appendix A for weightings.

114 In recognition that dementia screening is likely to overestimate true prevalence, we also applied a
115 method of back estimating screen positives based on established sensitivity and specificity of the tool
116 against a gold standard, adopting a similar approach to that reported elsewhere [22,23].

117 Whilst the cohort was cross-sectional in nature, we looked for associations based on variables that
118 are theoretically likely to; 1) be risk factors dementia (age, sex and literacy), and 2) be a consequence
119 of dementia (QoL, Social isolation, employment status). For risk factors, prevalence ratios (Poisson
120 regression, 95% Wald Confidence Intervals) were calculated for those who screen positive against
121 age (reference group: 60-64 years old), literacy (reference group: illiterate) and sex (reference group:
122 female). These analyses were re-run with all independent variables entered into the model. For
123 consequences of dementia, regression models were generated to understand the association
124 between screening outcome and wellbeing, social isolation, and employment status (1=employed).
125 In addition, we dichotomised social isolation outcome to facilitate interpretation, utilising the
126 commonly employed ≥ 6 criteria which represents being 'lonely' [17]. Within each model, age, sex,
127 literacy, geography (1=Makueni subcounty), and social status was adjusted for.

128

129 **Results**

130 Of the 3,546 older adults who were screened for dementia, participants were on average 70.5 years
131 old, and predominantly female (58.3%). Nearly all identified as being Kamba (99.7%). See Table 1 for
132 further details.

133 **Screen positive**

134 652 screened positive (18.4%, 95%CI = 17.1 to 19.7). Percentage of positive cases split by age, sex
135 and literacy are reported in Table 2.

136 **Back estimation of prevalence**

137 Back estimation of the screening outcome based on the Brief CSI-D yields a prevalence of 9.4%
138 (95%CI 7.9 to 10.8) translating to about 258,000 older adults potentially living with dementia in
139 Kenya.

140 **Risk factors associated with screening positive.**

141 Screening positive for dementia was associated with older age, with the oldest age group (100 years
142 old +) being 5.31 times more likely to screen positive than the 60–64-year-old group. The only
143 comparison that was not statistically different was the comparison between the 65–69-year and the
144 60–64-year-old groups. Those who were illiterate, and female were associated with screening
145 positive for dementia. After adjusting for all other demographic factors, similar associations were
146 reported, but females were no longer significantly associated with screening positive for dementia
147 ($p=0.07$). As shown in Table 3.

148 **Outcomes associated with screening positive for dementia.**

149 Descriptive data of outcomes, split by screening positive and negative are reported in Table 4. People
150 who screened positive with dementia was associated with poorer QoL ($B = -0.17$, 95%CI -0.22 to -
151 0.12; $p < 0.001$) and loneliness ($B = 0.28$, 95%CI 0.13 to 0.43; $p < 0.001$) after adjusting for other
152 demographic factors. There was also a trend for people who screened positive for dementia to not
153 be in employment ($aOR = 0.72$, 95%CI 0.51 to 1.03; $p = 0.08$) in the adjusted model. People who
154 screened positive were also associated with dichotomised loneliness ($n = 236$, 36.2%) compared to
155 those who screened negative ($n = 878$, 30.5%) ($aOR = 1.22$, 95%CI 1.01 to 1.47; $p = 0.04$).

156 **Discussion/Conclusion**

157 Data from a dementia screening program in Kenya, provide us with the first estimate of prevalence of
158 those potentially living with dementia within the community in Kenya. The findings indicate that

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159 there are large numbers of older adults potentially living with dementia, which is associated with
160 poorer outcomes.

161 Previous estimates of cases screened positive for dementia using the Brief CSI-D (Combined cut-off
162 <5) appear to generate similar estimates as Uganda (20%) [23], Argentina (18%) [24] and South Africa
163 (17%) [22,25]. The consistency potentially indicates a level of robustness and cultural sensitivity. The
164 findings also appear to be not dissimilar to existing Kenyan data (i.e., 17.9%) generated within a
165 health and care setting, despite having profoundly different methodologies [7]. We need to be
166 vigilant that the cut-offs used here, may not be optimal for Kenya, despite the proposed cut-off being
167 found to be optimal across a number of different countries [15]. The common associations between
168 screening positive for dementia and age, sex and literacy, were also reported here, providing further
169 validity to our findings.

170 Weighting of analysis based on county-level demographics and country-level demographics did not
171 dramatically change the prevalence of screen positives. However, back estimation of dementia
172 prevalence revealed that the number of people living with dementia might be closer to 9%. If
173 accurate, this could mean over 258,000 older adults are living with dementia in Kenya, based on
174 2019 demography [1]. Whilst such a prevalence estimate would be considered elevated compared to
175 many estimates internationally, it does appear to align better with the limited evidence from Central,
176 Eastern and South Africa that have generated estimates of $\geq 6\%$ [26]. Such variability is likely to be
177 driven by variation in sampling, but in particular the criteria used for diagnosis.

178 The Kenyan older adult sample reported lower QoL compared to a broad geographic group of long-
179 term ill participants ($M=3.52$; $SD=0.63$) [19]. Our findings indicate that people who screen positive for
180 dementia were found to have statistically poorer QoL compared to those who screened negative. It is
181 unclear whether this difference is clinically meaningful. It should be recognised that QoL is not
182 exclusively determined by cognition and does not necessarily decline as the condition progresses
183 [27], thus having dementia should not necessarily result in poorer QoL.

184 The current sample indicates somewhat higher loneliness scores compared to samples from Spain
185 (65 years and older; $M=4.08$, $SD=1.55$) [28], Hong Kong (60 years and older; $M=3.9$, $SD=3.0$) [29],
186 Japan (65 years and older; $M=4.30$, $SD= 1.65$) [30], and Malaysia (60 years and older; $M=3.25$,
187 $SD=0.88$) [31], to name a few. Application of a cut-off indicates that close to a third of older adults'
188 sample were lonely, with those who screened positive for dementia being 22% more likely to be
189 lonely than those who screen negative. Due to the cross-sectional nature of the study and no ways to
190 ascertain the temporal relationship between the two, the way we interpret this association is difficult
191 because loneliness can also be seen as a risk factor for dementia [32]. Irrespective, we should be

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192 concerned about the presence of loneliness in this population because it could contribute to cases of
193 dementia, but also may have a subsequent effect on the lives of the older adults. Loneliness has been
194 found to be associated with other negative outcomes such as depression [33], functional decline
195 [34], hypertension [35,36], and death [34].

196 Our findings also indicate that older adults who screen positive for dementia are less likely to be in
197 employment, though this did not remain statistically significant after adjusting for other factors.
198 Kenyan pensions policy involves a series of old-age benefits available dependent on whether a
199 person was previously public/private sector or self-employed. Depending on the type of benefit,
200 pensions become available when a person reaches 50 or 60 years old, but typically require
201 employment to stop. There is also a universal pension for those aged 70 years and older, for those
202 who do not receive any other pension. Within our sample, there appears to be a cohort of older
203 adults who maintain work (7.7% over the age of 70) despite these financial support packages being
204 available, though it is unclear why. Those who were in employment did appear to be less satisfied
205 with their financial situation, as measured by the EUROHIS-QOL-8 item. In fact, recent reports
206 highlight that Kenyan retirees are some of the poorest internationally, and this typically means that
207 older adults have to remain in work to 'top up' their income [37]. Critique of policies that necessitate
208 or encourage older adults to remain in work fall outside the scope of this work. Irrespective, our
209 findings indicate that people who screen positive maybe more susceptible to further financial strain
210 as they are unable to keep working.

211 There are, however, several limitations to consider. First, the data generated does not represent
212 actual dementia prevalence, not least because the Brief CSI-D tool does not claim to be a diagnostic
213 tool and does not seek to exclude other comorbidities that might cause cognitive and functional
214 impairment. Through adopting backward estimates of prevalence, based on existing knowledge of
215 sensitivity and specificity against diagnostic gold standards, we may get a better understanding of
216 what the prevalence might be. Irrespective, the study was not designed to generate definitive
217 prevalence estimates, and thus the convenience sampling may introduce sources of bias. For
218 example, our sample predominantly originates from a single ethnic group (Kamba people) from a
219 single region (Makueni subcounty). In line with this, application of weightings may amplify
220 unmeasured sampling bias, however, weighting did not ultimately change screen positive ratios
221 outside the 95% CIs reported initially. Second, due to the cross-sectional nature of the research,
222 associations between factors does not tell us the direction of any effect. Third, all participants
223 screened agreed to participate in the research. As such, the screening process included additional
224 data collection (e.g., QoL, demographics) prior to screening process. Although the length of the

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225 whole process is still modest, we should consider that the increased length of testing may influence
226 fatigue and performance on cognitive tasks [38]. Finally, the research is limited to older adults with
227 an informant that who could also participate in the dementia screening, as such, the most isolated of
228 society maybe missing from our cohort and there could be greater numbers of loneliness.

229 The study highlights that approximately 18% of older adults in Kenya have symptoms indicative of
230 dementia, based on a dementia screening tool. Through adopting back estimation, this would equate
231 to 258,000 older adults that could be living with dementia. Whilst it is important to ensure people
232 receive a timely diagnosis, there is perhaps a more pressing issue to ensure sufficient support for
233 those experiencing dementia-related symptoms, as ultimately, they have poorer outcomes. Further
234 research is needed to understand how these outcomes change over time, particularly where
235 diagnosis and formal support are not common.

236

237 **Statements**

238 **Acknowledgement**

239 The authors would like to acknowledge Makueni County for the support given during the research
240 period through availing community health workers as well as healthcare workers and granting a
241 supportive environment. The authors would also like to acknowledge Africa Mental Health Research
242 and Training foundation for serving as the host institution for the research project.

243 **Statement of Ethics**

244 Study approval statement: This study protocol was reviewed and approved by Maseno University
245 Ethics Review Committee (MUSERC), approval number MUSERC/01102/22 and by National
246 Commission for Science, Technology and Innovation (NACOSTI), approval number
247 NACOSTI/P/22/19392.

248 Consent to participate statement: Written informed consent was obtained from all participants in the
249 study.

250 **Conflict of Interest Statement**

251 The authors have no conflict of interest to declare.

252 **Funding Sources**

253 This research was funded by the Davos Alzheimer's Collaborative

254 **Author Contributions**

255 All authors made substantial contributions to the conception and design of the work, in writing and
256 reviewing the manuscript. All authors have approved this version for publication and are accountable
257 for all aspects of the work.

258 **Data Availability Statement**

259 The data that support the findings of this study are available from the corresponding author upon
260 reasonable request.

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Tables

Table 1. Sample demographics

	Missing	N (%)	Mean (SD)
Age	3		70.5 (8.61)
Sex: Male	0	1480 (41.7%)	
Literacy: Able to read and write	9	2409 (67.9%)	
Ethnicity: Kamba	0	3534 (99.7%)	
Residence: Makueni subcounty	2	3375 (95.2%)	
MacAuthur Scale of Subjective Social Status (↑ Higher social status)	18		2.7 (1.34)

Table 2. Cases and prevalence of screen positive for dementia in those over the age of 60. Data is also split by age, sex and literacy.

Total	Cohort: n	Positive cases: n	Positive cases: Rate, % (95% CI)
60-64	1020	104	10.2 (8.4 to 12.2)
65-69	849	98	11.5 (9.5 to 13.9)
70-74	769	134	17.4 (14.8 to 20.3)
75-79	360	96	26.7 (22.2 to 31.6)
80-84	272	87	32.0 (26.5 to 37.9)
85-89	123	53	43.1 (34.2 to 52.3)
90-94	86	43	50.0 (39.0 to 61.0)
95-99	43	24	55.8 (39.9 to 70.9)
100 plus	24	13	54.2 (32.8 to 74.4)
Sex	Cohort: n	Positive cases: n	Positive cases: Rate, % (95% CI)
Male	1480	225	15.2 (13.4 to 17.1)
Female	2066	427	20.7 (18.9 to 22.5)
Literacy	Cohort: n	Positive cases: n	Positive cases: Rate, % (95% CI)
Total Literate	2409	320	13.3 (12.0 to 14.7)
Total Illiterate	1128	332	29.4 (26.8 to 32.2)

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Totals	Cohort: n	Positive cases: n	Positive cases: Rate, % (95% CI)
Grand total (Unweighted)	3546	652	18.4 (17.1 to 19.7)
Grand total (weighted, Makueni County)*	3572	665	18.6 (17.4 to 19.9)
Grand total (weighted, Kenya)*	3546	652	18.4 (17.1 to 19.7)

*Weighted based on census proportions of age and sex.

Table 3. Prevalence ratios (95% Wald CIs) of demographic factors associated with screening positive with dementia.

		Unadjusted	Adjusted *
Age	60-64	Ref	Ref
	65-69	1.13 (0.87 to 1.47)	1.10 (0.85 to 1.43)
	60-74	1.71 (1.35 to 2.17)	1.57 (1.23 to 2.00)
	75-79	2.62 (2.04 to 3.36)	2.38 (1.84 to 3.07)
	80-84	3.14 (2.44 to 4.03)	2.64 (2.02 to 3.45)
	85-89	4.23 (3.22 to 5.55)	3.41 (2.54 to 4.57)
	90-94	4.90 (3.71 to 6.48)	3.77 (2.79 to 5.09)
	95-99	5.47 (3.97 to 7.56)	4.15 (2.97 to 5.78)
	100 plus	5.31 (3.52 to 8.01)	4.16 (2.71 to 6.4)
Literacy	Literate	Ref	Ref
	Illiterate	2.22 (1.93 to 2.54)	1.47 (1.24 to 1.73)
Sex	Male	Ref	Ref
	Female	1.36 (1.17 to 1.58)	1.15 (0.99 to 1.34)

*Age was adjusted for literacy and sex. Literacy was adjusted for age and sex. Sex was adjusted for age and literacy.

Table 4. Descriptives of outcomes in those that screen positive and negative for dementia, based on the Brief CSID.

	Total		Screen negative		Screen positive	
	M (SD)	N (valid %)	M (SD)	N (valid %)	M(SD)	N (valid %)
EUROHIS-QOL-8 (↑ better quality of life)	2.6 (0.60)		2.6 (0.58)		2.4 (0.65)	
UCLA-3-item measure of loneliness (↑ more lonely)	4.8 (1.75)		4.7 (1.72)		5.1 (1.86)	
Employed: Yes		362 (10.2%)		323 (11.2%)		39 (6.0%)

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Appendix A: Weightings

Demographic data (gender and age) at a county-level (Makueni County) and country-level (Kenya) were derived from a single source (Kenya National Bureau of Statistics, 2019).

Weightings used within study, at a county-level and country-level.

Age	Makueni County		Kenya	
	Male	Female	Male	Female
60-64	1.0358	0.9696	1.203185	1.032472
65-69	1.067	0.9988	1.093558	0.9384
70-74	0.8722	0.8164	0.94383	0.809916
75-79	1.0253	0.9597	1.109371	0.951968
80-84	1.0726	1.004	1.05743	0.907398
85-89	1.3337	1.2485	1.302904	1.118043
90-94	1.5608	1.4611	0.903745	0.775518
95-99	1.3364	1.251	0.918753	0.788397
100+	1.3999	1.3104	0.825224	0.708138

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