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LETTER TO THE EDITOR

Life expectancy in cerebral palsy: Has the improvement continued?

Editor,

In our 2014 articles[1, 2] we reported on the survival of individuals with cerebral palsy (CP), using data from California for the period 1983 to 2010. We investigate here whether the trends in mortality and life expectancy have continued through 2019. Although mortality data for 2020 to 2021 were available, we chose to restrict attention to a period unaffected by the COVID virus.

The main question of interest is: after factors such as age, sex, and severity of disability are taken into account, has mortality continued to improve since 2010? In brief, the answer is no.

Our sample included 62 377 individuals with CP (56% male) contributing 994 971 years of follow-up. There were 12 067 deaths for an overall mortality rate of 12.1 per 1000 persons per year.

As previously, our unit of analysis was the *person-year*. We investigated whether – all else being equal – the probability of death during a given year improved since 2010. To determine this we again used Poisson regression and considered various groups defined by age, sex, and pattern of disabilities. For technical details, see our previous articles.[1, 2]

Overall, we found no significant indication of annual improvement during the period 2010 to 2019 (hazard ratio 0.994, 95% confidence interval 0.987–1.002, $p = 0.12$).

The reasons for this are not entirely clear. This result could reflect broader trends of stalling improvements in life expectancy observed empirically in the United States and other high-income countries.[3, 4] For individuals with very severe CP, at least some of the improvements we previously reported appeared to be the result of changing patterns in gastrostomy placement. That is, the apparent improvement in gastrostomy-dependent adults could be attributed to the increasing prevalence of gastrostomies in individuals with less severe disabilities. We found, however, that this prevalence stabilized during the 2010s which could explain the lack of improvement during this period.

TABLE 1 Probability (%) that a 4-year-old child with cerebral palsy will survive to various ages.

	Survival to age						
	10	**15**	**20**	**25**	**30**	**35**	**40**
Does not lift head in prone							
Tube fed	75	58	46	34	28	21	18
Fed orally by others	84	73	58	48	40	36	11
Self feeds orally	97	92	90	76	68	-	-
Lifts head but not chest in the prone position							
Tube fed	79	68	57	45	36	32	17
Fed orally by others	89	80	68	58	51	42	34
Self feeds orally	98	94	85	77	77	-	-
Lifts head and chest, partial rolling							
Tube fed	82	70	65	52	43	34	-
Fed orally by others	93	86	77	68	58	51	42
Self feeds orally	98	95	92	89	81	81	68
Full rolling, does not walk unaided							
Tube fed	90	86	79	73	65	63	54
Fed orally by others	96	93	88	83	78	72	64
Self feeds orally	99	98	96	94	91	88	83
Walks unaided							
Tube fed	97	95	92	90	90	68	-
Fed orally by others	97	97	95	93	86	86	86
Self feeds orally	100	99	98	96	95	94	92
General population (50% male, 50% female)	100	100	100	99	99	98	97

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TABLE 2 Life expectancy: additional years (standard error) for adolescents and adults with cerebral palsy.

	Cannot lift head			Lifts head or chest			Rolls/sits			Walks unaided[b,c]	General population
Sex/age	TF	FBO	SF	TF	FBO	SF[a]	TF	FBO	SF		
Female											
15	15 (1.1)	19 (1.0)	-	19 (1.3)	25 (1.0)	-	29 (1.6)	38 (1.0)	48 (0.8)	56 (0.7)	67.0
30	14 (0.7)	19 (0.8)	-	14 (0.7)	23 (0.8)	-	18 (1.5)	30 (0.8)	35 (0.6)	41 (0.5)	52.4
45	12 (0.9)	14 (0.7)	-	12 (0.9)	17 (0.9)	-	12 (1.0)	20 (0.7)	24 (0.4)	28 (0.4)	38.2
60	7 (0.8)	9 (1.0)	-	7 (0.8)	11 (0.6)	-	7 (0.8)	11 (0.6)	15 (0.4)	19 (0.5)	24.9
Male											
15	15 (1.1)	19 (1.0)	-	19 (1.3)	24 (0.9)	-	29 (1.6)	33 (0.9)	44 (0.8)	52 (0.7)	62.0
30	14 (0.7)	19 (0.8)	-	14 (0.7)	23 (0.8)	-	18 (1.5)	27 (0.8)	32 (0.5)	39 (0.4)	47.9
45	12 (0.9)	14 (0.7)	-	12 (0.9)	17 (0.9)	-	12 (1.0)	18 (0.6)	22 (0.3)	26 (0.4)	34.4
60	7 (0.8)	9 (1.0)	-	7 (0.8)	11 (0.6)	-	7 (0.8)	11 (0.6)	13 (0.4)	16 (0.4)	21.9

Abbreviations: FBO, fed orally by others; SF, self-feeds orally; TF, tube fed.

Note: Dashes indicate cases where the sample sizes were too small to permit reliable estimates.

[a]Survival in this group proved to be similar to the 'rolls/sits, fed by others' group.

[b]The results here assume that individuals in the group will not lose the ability to walk before age 60 years.

[c]We also examined the highest functioning subgroup that consisted of persons who walk well independently and feed themselves using utensils without spillage. As previously, life expectancy proved to be roughly 90% of normal. For young adults *not* in this subgroup, the figure was about 3 years lower.

Tables 1 and 2 here update and supercede those in our previous article.[2] The values are similar to before, and any slight differences reflect more accurate figures because of the additional data from the years 2011 to 2019. The 'General population' column has been updated using the 2019 US life tables.[5]

DATA AVAILABILITY STATEMENT

Participant data is not available from the authors.

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