Brief Report

Update on the long-term survival of persons who are ventilator dependent after spinal cord injury

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We previously reported[1] on the survival of 319 adults with spinal cord injury (SCI) who were ventilator dependent at discharge from the SCI Model Systems in the years 1973–2003, and who had survived at least one year after injury. The present short communication updates this study based on a more recent version of the same database. We first revise the prior results based on more complete mortality follow-up of the original cohort through the year 2003. We then use a larger cohort to obtain further results through 2019. In addition, we sought to determine if survival has improved in the interim.

During the expanded 1973–2019 study period there were 1,799 persons who were ventilator dependent at discharge, of whom 1,162 died. As our goal was to study the long-term survival of adults who are permanently ventilator dependent, we restricted attention to those aged 18 or older who had survived at least 1 year post injury. For the final analysis we excluded persons who were coded as being ventilator dependent only for short-term complications, required a phrenic nerve stimulator, or whose ventilator status was unknown. The resulting data set consisted of 459 persons, of whom 320 died prior to December 31, 2019. The methods used here are the same as in the prior study. Briefly, we constructed a logistic regression model based on person-years, then used this model to obtain mortality rates by age, and finally input those rates into life tables to compute life expectancies.

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The new study population was 82% male, 98% had cervical injuries, and 80% were of American Spinal Injury Association Impairment Scale (AIS) Grade A. In addition, as previously, we found no significant survival difference by sex (male HR = 1.03, $P = 0.83$), race (white HR = 0.96, $P = 0.80$), or etiology (violence HR = 0.82, $P = 0.31$).

The final survival model contained terms for age (HR = 1.047 per year of age older than 40, $P < 0.001$), level/grade (C1-C5A versus others: HR = 1.46, $P = 0.002$), and time since injury (1.0–3.0 years post injury versus later years: HR = 1.95; $P < 0.001$). In the main group of interest here, C1-C5A (361 persons, 259 deaths), we found that survival has not improved since 1980 (HR = 1.003 per calendar year, $P = 0.71$). The absence of a trend towards improved survival was also found previously in a study of those not ventilator dependent.[2] Small changes compared with the prior study are likely due to the enhanced precision here based on a larger sample size and longer follow-up.

We computed life expectancies by age and injury level/AIS grade for persons who survived at least 3 years post injury. The results are given in the Table below. The first column of the Table is the patient's current age, not their age at injury. The second column reproduces the life expectancy figures given in the original study.[1] The third shows the result of using updated mortality information for the original cohort of 319 persons through 2003 (the changes here are solely due to late reporting of deaths). The fourth provides results from the expanded cohort.

In the Table we also compare with results from the UK study by Savic *et al.*,[3] that (a) included a relatively small number (n = 77) of ventilator-dependent patients,

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and (b) may have had some retrospective bias in the identification of ventilator dependent patients because, as the authors stated, "some of the information may have been biased by selective memory of longer surviving ventilator-dependent patients." The newer results given here for our U.S. data do not have those two limitations. Also, the Savic results are for all ventilator dependent persons, without restriction by level/grade or type of dependence. Finally, we note that the Savic model assumed that the effect of ventilator dependence was the same (an odds ratio of 7.5) regardless of age, sex, level, and grade. Such a simplifying assumption was necessary because of the small sample size. A separate analysis of our U.S. SCI data, including patients not ventilator dependent, and using the same methods and variables of Savic *et al.*, indicated that the effect of ventilator dependence *did* vary with age. Specifically it decreased by 2% for each year of age ($P<0.0001$). Use of a single term in Savic *et al.* thus led to underestimates of mortality at younger ages and overestimates at older ages, and thus explains the differences between their results and those given here. Finally, we note that life expectancy in the U.S. general population[4] has increased rather modestly since our prior study (for example, at age 20, from 56 to 58), whilst we have seen no such increase in the SCI population.

Not shown in the Table are updated life expectancies for persons with incomplete or C6 or lower level injuries. These values were modestly lower than those of the prior study, reflecting that mortality increased in this group in the interim. We note that ventilator-dependence outside the C1-C5 levels is uncommon (only 4% amongst those studied here), as the diaphragm is innervated by the phrenic nerve, which originates mainly from the 4th cervical nerve.

We also examined the causes of death for those in the C1-C5A group who died at least 1 year post injury. Briefly, these were respiratory (27%), infective and parasitic (14%), heart disease (6%), and other/missing (53%). We hope to report on this in more detail shortly.

Table 1 Life expectancies for persons in the C1-C5 A group.

	Prior Study (1)		Present	Savic *et al.*(3)	
Age	As Published	Updated	Study	Male / Female	GP (4)
20	22	18	17	25 / 30	58
30	19	16	15	20 / 23	49
40	14	13	12	14 / 16	39
50	9	9	9	9 / 11	31
60	6	6	6	5 / 6	22
70	4	4	4	4 / 3	15
80	2	3	3	2 / 2	9

GP = General population values, computed based on a weighted average of the 2016 United States male (80%) and female (20%) mortality rates.

The figures in the Table below are based on persons who were ventilator dependent at discharge from inpatient rehabilitation. Follow-up data indicate that approximately 10% of persons who are coded as being long-term ventilator-dependent at discharge are subsequently weaned over the next few years and thus have a better prognosis for long term survival once that occurs. The present life expectancies are therefore slight overestimates for persons known to be permanently ventilator dependent (Table 1).

Disclosure statement

No potential conflict of interest was reported by the author(s).

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