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Experience with ventilator dependent patients[1]

R E Carter MD

Professor of Clinical Rehabilitation, Baylor College of Medicine and Director, Spinal Cord Injury Programme, The Institute for Rehabilitation and Research, 1333 Moursund Avenue, Houston, Texas, USA.

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Historically, in the early 1960s most patients who sustained a spinal cord injury with apnea died either at the accident scene or within the first few weeks in an acute trauma center. In the mid 1960s those that survived the initial traumatic episode to be admitted to a trauma center generally died within the first three months due to tracheal erosion with severe hemorrhage or other pulmonary complications. In the later 1960s a few patients began not only to survive the accident, but also to survive the initial hospitalization in a trauma center and subsequent transfer to a rehabilitation facility. Using the expertise learned during the polio epidemics of the 1950s, some of these patients were able to return home on ventilatory equipment. Their survival time continued to increase due to better public knowledge of cardiopulmonary resuscitation, improved respiratory equipment (particularly the corrugated plastic hoses), smoother thrusts of ventilatory machinery on inspiration and expiration, improvement in training and organization of emergency medical services, establishment of respiratory therapy departments in community hospitals, and improved knowledge of spinal cord injury among healthcare professionals. In the 1960s electrophrenic respiration (EPR) was developed by Dr W W L Glenn for patients with Ondine's curse and then in 1969, he performed the first application of phrenic nerve stimulators in a traumatic apneic spinal cord injury patient.[1] Since then EPR has become a very valuable addition in the rehabilitation of apneic quadriplegics when appropriately used. It appears to be more physiological, has greater portability, and the patient has better speech. Ultimately the tracheotomy tube can be plugged so that air is drawn through the mouth and nose for warmth and humidity as well as for the improvement of speech. The increasing number of surviving patients has created increasing medical, social, moral and economic problems. The cost of ventilator dependent or high quadriplegics was covered previously in a publication from a three center collaborative study on high quadraplegia in 1985.[2]

The utilization of EPR is not suitable for every high apneic spinal cord injury patient, but only for selected candidates. Guidelines for candidates for EPR were initially published in the 1985 second multicenter conference on the multidiscipline care of high quadriplegic patients C4 and up.[3] Subsequent updating of these guidelines is currently in press.[4]

The most difficult problems associated with utilizing electrophrenic respiration are in selecting appropriate candidates using the published guidelines and overcoming the diaphragm fatigue and deconditioning occurring between onset of trauma and electrophrenic implant. The major goals are to adequately utilize phrenic pacing both supine and in the wheelchair for a total of 24 hours with no other means of ventilation being necessary. The current study is a retrospective one from January 1, 1968 through January 1, 1992 of all spinal cord injury patients at the Institute for Rehabilitation and Research (TIRR) who received EPR implants plus those who required 24

[1]Paper read at the first European Conference on Domiciliary Ventilation and High Spinal Cord Lesion in Southport, England, in October 1991.

hours per day on mechanical ventilation at the time of initial discharge from TIRR. The EPR study contained a total of 13 males and 10 females, a total of 23 patients. The average age of the males was 18, ranging from 4 to 46 years of age. The average age of the females was 23 years, with a range of 7 to 54 years of age. This gives an overall figure of 20 years average age of the 23 patients with a range from 4 to 54 years of age.

As of January 1992, 8 males and 6 females (61%) were living. Five males and 4 females have died representing 39% (Table I). Of the 5 male deaths, 3 were due to cardiac problems, one due to pulmonary problems, and one secondary to renal problems. The females died of cardiac problems (one) and of pulmonary difficulties (three). Several of the problems classified as 'cardiac' were due to sudden death because the heart suddenly stopped. These were thought to be secondary to vagal arrest rather than intrinsic cardiac disease.

Over the same period of time (January 1, 1968 to January 1, 1992) a study was performed of patients initially discharged dependent 24 hours per day on mechanical ventilation. These ventilator dependent patients number a total of 19. Those living as of January 1992 include 7 males and no females, totalling 7 or 37%. The living patients have survived from 8 to 152 months with an average of 96 months. Those that died include 10 males and 2 females, a total of 12 or 63% of the total. Average survival time of the 8 spinal patients upon which accurate data is available was 28 months. Causes of death in the males include two from cardiac difficulties, two secondary to gastrointestinal bleeding, one from renal problems, one resulting from pulmonary problems, and four with an unknown cause (Table II). The female deaths include one due to cardiac problems and one from an unknown cause. Unfortunately, the entire study of the 19 patients includes 3 males and one female that are totally lost to follow up and thus have to be presumed dead. They are listed in Table II as the four deaths of unknown cause.

In the EPR group, the average number of months from onset to surgical implantation was 14.4 months in the 12 patients who are still alive and 14.8 months in the 9 patients that have subsequently died. The time from surgical implantation of EPR to the present time is 93.9 months. The average time from surgical implantation to death in the 9 patients who have died was 47.7 months. This gives an average of months of total ventilator dependency from the onset to the present time of 108.3 for the living, and from onset to death of 62.5 for those who died (Table III). Our first EPR patient was injured in the spring of 1968 and had bilateral EPRs implanted in January 1970 (285 months onset to present and 252 months EPR to present). In the 8 patients who died and on whom we had data in the ventilator dependent study, the average number of months from onset to death was 28. As noted previously, this includes 4 patients lost to follow up and presumed dead. They are not included in the survival statistics since the dates of death as well as reasons could not be obtained. Of those patients in the ventilator dependent study

Table I EPR survival status as of January 1992

	Living	Dead	Cause
Males	8	5	3 cardiac 1 renal 1 pulmonary
Females	6	4	1 cardiac 3 pulmonary
Total	14 (61%)	9 (39%)	

Table II Ventilator survival status as of January 1992

	Living	Dead*	Cause
Males	7	10	2 cardiac 2 GI bleed 1 renal 1 pulmonary 4 unknown
Females	0	2	1 cardiac 1 unknown
Total	7 (37%)	12 (63%)	

*Includes 3 males and 1 female, lost and presumed dead.

Table III EPR longevity as of January 1992

	Living (n = 12) average no of mos	Dead (n = 9) average no of mos
Onset to surgery	14.4	14.8
Post surgery		
to present	93.9	
to death		47.7
Ventilatory dependent	108.3	62.5

Table IV EPR usage in 14 patients with EPR implants as of January 1992

No of patients	EPR hrs/day	Ventilator hrs/day
8	24	0
1	16	8
2	12	12
1	5	19
1	2	22
1	0	24

who are currently alive, there are 7 males who have been living for an average number of 96 months, with a range from 8 to 144 months.

Eight of the 14 patients who have survived on EPR are on EPR 100% of the time (Table IV). One patient is on a respirator 66% of the time while remaining on a ventilator at night. Two patients split their time equally between mechanical ventilation and EPR with their local physicians believing that there might be 'burn out' of the phrenic nerves if they were to pace 24 hours a day. These 2 patients are not allowed to use their phrenic pacing unless they are up in the wheelchair. I know of no recorded cases of phrenic nerve 'burn out'. Our initial patient, after 22 years of full time pacing by EPR, has the same electrical sensitivity this year as when she was initially tested in late 1969. One patient is pacing 21% of the time, one 8% of the time, and one lives in a nursing home and only uses EPR when he gets up in a wheelchair approximately every other day. The final patient is no longer using the EPR. We had tremendous communication difficulties with this patient and mother during his hospitalization. When the patient went home, his mother ran into a number of frustrations in working with the phrenic stimulators and subsequently gave up and refused to use the EPR any further.

The discharge plan in the EPR patients showed that 11 patients returned to their home and have remained there. One has returned to school with an attendant, one is in a nursing home, and one returned to a local hospital waiting to go to a nearby nursing home. This, however, is potentially misleading since with the small number of beds in our rehabilitation hospital a viable discharge plan must be developed before admission so that the patient does not become domiciliary. It is too difficult in our locale to discharge a patient to a nursing facility when they are on either EPR or tracheotomy with full time mechanical ventilation.

Numbers comparing mechanical ventilation with electrophrenic respiration in apneic spinal cord injured patients are extremely small and certainly need to be enlarged upon and perhaps collected by a collaborative multicentre study to become statistically significant. It appears that the survival status of patients on EPR (61%) compared to the patients on mechanical ventilation (37%) at home supports the hypothesis that physiological ventilation by EPR might be safer in the long run. Comparison of the survival time of 107.6 months for the living patients of EPR with 96 months for living patients on mechanical ventilators seems to be approximately the same. It could be that the patients surviving the first year or two at home on mechanical ventilation will have a greater degree of longevity since major complications tend to occur early. In conclusion, we can note that while the total series is not large enough to permit an accurate interpretation EPR is an extremely valuable tool when appropriate guidelines are followed and may result in increased longevity over full time mechanical ventilatory maintenance.

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