

## The impact of home based ventilator dependence on family life

C A Glass BSc MClinPsych PhD AFBPsS CClinPsychol

*Consultant Clinical Psychologist, Mersey Regional Spinal Injuries Centre, District General Hospital, Town Lane, Southport, Merseyside PR8 6NJ, England.*

Those who experience spinal trauma above the level of C4 require continued ventilation to keep them alive. Over the past 15 years considerable expertise has been developed in not only successfully treating these patients, but also returning them to their home environment with full ventilator support.

Little objective evidence is available concerning the views of those who receive permanent ventilation and whether they or their relatives consider it would have been better to allow them to die. The present investigation examined the perceived value of returning home whilst still requiring ventilation, from the point of view of both the injured persons themselves and their nearest relatives.

Objective analyses were made using the Family Environment Scale (Moos 1986)<sup>1</sup> and a measure of affective state<sup>2</sup> of the interaction patterns within each of the families. Although there was some alteration in affective state experienced in most families, the most important factors associated with adaptation appear to be the level of communication within the family and the degree of commitment between all family members.

*Keywords:* spinal injury; ventilator dependence; psychological effects; family life.

### Introduction

Tetraplegia (paralysis below the neck) is a devastating experience producing sudden loss of control of life. Rehabilitation after such a catastrophic injury is emotionally overwhelming, extremely expensive, and requires a considerable length of time. Hospital treatment alone, without considering the expenses of social support, special appliances and community care, costs approximately £16,000,000 a year to the UK exchequer. For a number of patients who experience injury above the level of C4, there is frequently the added complication of ventilator dependence, due to the neurological inability to control the diaphragm. Recent medical advances have meant that a number of such individuals have received

phrenic nerve stimulator implantation<sup>3</sup> which has enabled them to regain some breathing control, although this is not a universally applicable procedure in all cases. The vast majority of such patients currently require continued ventilation and this often results in their lives being restricted to institutional care.

The 35 bed Mersey Regional Spinal Injuries Centre in Southport has an integral 6 bed intensive care unit in order that new injuries may be accepted as soon as possible after injury. Over the past 15 years the centre has developed an expertise in treating high level tetraplegics who require continued ventilation, and developing support services in the community to such a degree that it is the norm rather than the exception for the majority of our patients to return home rather than require institutional care.

The cornerstone of this venture is the willingness of the individual and the family to adapt to the alteration in circumstances.

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

In a recent study<sup>4</sup> the ethics of providing ventilation for patients who experience spinal trauma resulting in tetraplegia were discussed. The views of 21 patients and families, who between 1968 and 1984 had received ventilatory support for varying periods of time, were canvassed and 18 reported that they would wish to be temporarily ventilated again in the future should the need arise, with only one patient stating a desire to be allowed to die. Little objective evidence is currently available concerning the views of those who receive permanent ventilation and whether they or

The implications of spinal cord injury on family life has received little attention; Christopherson<sup>5</sup> commented on the high frequency of role reversal where a male partner experiences a spinal cord injury. It had been suggested<sup>6</sup> that the family of severely disabled individuals pass through some stages of adjustment which parallel those of the individual themselves, although more recent research has argued that such stage theory concepts of adjustment are not supported by empirical evidence.<sup>7</sup> Hoard *et al*<sup>8</sup> have produced a retrospective examination of the views of SCI relatives who had passed through Stoke Mandeville Spinal Injuries Centre and concluded that they have traditionally been expected to cope with little comprehensive support. Current research undertaken by the present authors<sup>9</sup> has shown that provision of comprehensive information and support to individuals and families results in a significant improvement in understanding the goals of the rehabilitation programme. Since 1986, 11 high traumatic tetraplegic patients who require continued ventilation have been discharged home from the Mersey Regional Spinal Injuries Centre. In each case, prior to discharge, the implications for the individual and on family life were discussed, and the decision to return home arrived at following comprehensive liaison with all concerned, including the patient, family, spinal unit and community/local hospital support services. The economics and practical aspects of returning a patient requiring continued ventilation to their home are the

subject of a further investigation by the staff at the spinal unit.

The purpose of the present investigation is to examine the perceived value of returning home whilst still requiring continual ventilation from the point of view of both the injured person themselves and their immediate relatives.

### Method

All patients and families were visited at home and their involvement in the study sought. The exact nature of the investigation was explained and each family member was shown the test materials to be completed. Of the 11 patients and relatives at home, 8 were approached (2 were young children and unable to provide data, and the third was hospitalised at the time of the investigation). Six agreed to take part in the investigation. All these patients and relatives agreed to provide information on a structured interview scale concerning their views about the decisions taken when deciding on initial ventilation, ethical issues concerning the desirability of ventilation, and current quality of life. A complete list of the questions asked of both patients and relatives is contained in Table I. Each family member also completed two standardised questionnaires; the Snaith IDA scale,<sup>2</sup> and the Moos Family Environment Scale.<sup>1</sup>

### *Snaith Irritability Depression and Anxiety (IDA) Scale*

This 18-item scale is designed to elicit information concerning current affective state. It has been shown to be both valid and reliable with normal and acute hospital populations and yields 4 scores: anxiety (5 items), depression (5 items), outwardly directed hostility (4 items) and inwardly directed irritability (4 items). The respondents are requested to choose one alternative from 4 possible responses to a statement, eg 'I feel cheerful': (a) Yes, definitely, (b) Yes, sometimes, (c) No, not much, (d) No, not at all. The score for each item ranges from 0-3; the larger score reflects increasing psychopathology.

**Table I** List of questions contained in the standard interview format.

All the questions were asked of each patient and closest relative in a standard interview format, changed grammatically for person only

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Are you glad that you are still alive?

If the need arose for further continual ventilation would you prefer to be allowed to die?

Are there any circumstances where a patient should be allowed to die?

Should the doctor alone make the decision concerning ventilation?

Is there an appropriate time for the patient to make a decision regarding ventilation?

If complications in the future resulted in brain injury, would you wish ventilation to continue?

If personality or intellectual changes had occurred as a result of your injury, would you have preferred to have been allowed to die?

What makes life worth living for you?

What are your feelings about the time when your family may no longer be able to look after you?

Did your feelings about ventilation change between the time of your first admission after your accident and later in your period in hospital?

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#### *Moos Family Environment Scale (FES) (Form R)*

This 100-item scale comprises 10 subscales that measure, in this form, individual family member's perceptions of the social/environmental characteristics of their family. The 10 subscales assess 3 underlying domains, or sets of dimensions: relationships, personal growth, and system maintenance (see Table II). The relationship dimensions are measured by the cohesion, expressiveness and conflict subscales. These assess the degree of commitment, help and support family members provide for one another; the extent to which family members are encouraged to act openly and to express their feelings directly; and the amount they openly expressed anger, aggression, and conflict amongst family members.

Personal growth, or goal orientation, is measured by the independence, achievement orientation, intellectual-cultural orientation, active-recreational orientation, and moral-religious emphasis subscales. They assess the extent to which family members are seen as assertive, self sufficient, and make their own decisions; the extent to which activities such as school and work are cast into an achievement oriented or competitive framework; the degree of interest in political, social, intellectual and cultural

activities; the extent of participation in social and recreational activities; and the degree of emphasis on ethical and religious issues and values.

System maintenance is measured by the organisation and control subscales, and assesses the degree of importance of clear organisation and structure in planning family activities and responsibilities, and the extent to which set rules and procedures are used to run family life.

#### **Results**

##### *Interview schedule*

It is a measure of the dedication of the individuals and families concerned, and their desire to help others in similar situations, that they were prepared to answer a series of very personal and searching questions. In order that the confidentiality of individual views may be maintained, the responses to each of the questions outlined below contain interpretations of the patient and relative responses as general themes. Abbreviated questions and these responses are outlined below.

*Are you glad to be still alive?* All patients and relatives reported positively to this question.

*If you need a ventilator in the future would*

**Table II** FES subscales and dimension description

Relationship dimensions	
1 Cohesion	the degree of commitment, help and support family members provide for one another
2 Expressiveness	the extent to which the family members are encouraged to act openly and to express their feelings directly
3 Conflict	the amount of openly expressed anger, aggression, and conflict among family members
Personal growth dimensions	
4 Independence	the extent to which the family members are assertive, are self sufficient, and make their own decisions
5 Achievement orientation	the extent to which activities (such as school and work) are cast into an achievement oriented or competitive framework
6 Intellectual/cultural orientation	the degree of interest in political, social, intellectual, and cultural activities
7 Active/recreational orientation	the extent of participation in social and recreational activities
8 Moral/religious emphasis	the degree of emphasis on ethical and religious issues and values
System maintenance dimensions	
9 Organisation	the degree of importance of clear organisation and structure in planning family activities and responsibilities
10 Control	the extent to which set rules and procedures are used to run family life

*you prefer to die?* Two of the patients commented that if the future ventilation were permanent, or was related to severe loss of cognitive functioning, then they would rather die, whilst all relatives would rather the person should continue to live.

*Would it have been better for your family if you had died?* The general view of patients was that if they had died at the time of their accident their families would have grieved but gradually adapted. The majority also considered that their families would have had a better quality of life if they had died but when questioned further found it difficult to give examples. Relatives were somewhat pragmatic, stating that they would have been better off in terms of freedom to engage in other activities. There was some difficulty resolving the issue of allowing others to care for the patient against their own needs to take some respite. They often reported feeling guilty that they could not cope without assistance, although when

assistance was offered within the home they became anxious that the person would not be properly cared for. Respite within the hospital was viewed favourably as it overcame these worries.

*Are there any circumstances where a patient should be allowed to die?* Most respondents felt that at the time of the injury, the patient and relative have no option but to allow life to continue as it is taken out of their hands by the hospital services. They felt that the patient should at least have the opportunity to discuss the issue whilst in hospital. All felt that it must always be an individual decision and therefore legislation would be difficult to impose, although in cases where there was no family support, or if there was severe associated brain trauma, there should be an option for the person to be allowed to die.

*Should the doctor decide to ventilate?*

All patients and relatives felt that the relatives should be involved to some degree in making the original decision to ventilate

wherever possible, although they accepted that in emergency procedures this was not often feasible. However, if the doctor had all the available information concerning the likely future for the individual then most patients would be happy for them to make the decision without family consultation.

*Is there an appropriate time for the patient to decide on ventilation?* All patients felt that there are times when they wanted their ventilators switched off. These times tended to coincide with periods of physical complications, when they felt emotionally low, and when they had reached a particular plateau in their therapy. When questioned further it became clear that patients and relatives were more concerned about there being a forum within which to raise these essentially negative feelings; all commented that once they had talked the issue through they felt more settled to continuing ventilation.

*If there are future complications leading to brain injury should ventilation be continued?* All patients and relatives stated that if the brain injury was severe they would wish to have the ventilator turned off. The severity of the brain injury was an important factor with patients more than relatives tending to qualify their answers by saying that if they could not communicate or enjoy activities such as reading and watching things around them, then they would rather die. Only one patient felt a desire to continue regardless of their neurological state.

*If complications occurred at the time of injury would you rather have been allowed to die?* All views were comparable to those raised by the above question.

*What makes life worth living for you?* Patients and relatives stated unanimously that the major factor which kept each of them going was the quality of the relationship with their family and friends. Without this degree of communication and contact most felt there would be little reason to carry on. All respondents similarly raised the issue of activity levels continuing essentially as before their accident though with some slight compromise in some of the activities involved (most notably sporting activities).

*What about when the family is no longer able to look after you?* There appears to be a tacit

understanding within families that should the primary care providers become unable to continue providing care, then the younger generations of family members will take over. This is true both for those who are in older age groups where the partner provides care, and for the younger patients where the siblings will provide care in the event of parental incapacity. When questioned further, most patients stated that institutional care would be tolerated but that this would not be undertaken out of choice. All patients commented that they felt fortunate to have at least spent some of their postinjury lives with their families.

*What are your feelings about ventilation?* Approximately half the patients felt that they had not really noticed the ventilator during the early stages of rehabilitation, while the other half felt some relief that it allowed them to continue to breathe. As time continued a number developed some hostility to their continued need but then settled into a routine, and no longer worried about it.

#### *Snaith IDA Scale*

The individual patients and relatives scores on the Snaith IDA scale are shown in Table III. Patients and relatives scored significantly lower (2 way ANOVA  $p < .01$ , Duncan's Multiple Range Test  $p < .05$  to  $p < .01$ ) than the test norms on the inwardly directed irritability subscale. Depression and anxiety scores were high in 3 and 2 patients respectively. No patient scored significantly higher on both the depression and anxiety subscales. None of the relatives' scores were above the normal range on any of the scales.

#### *Family Environment Scale results*

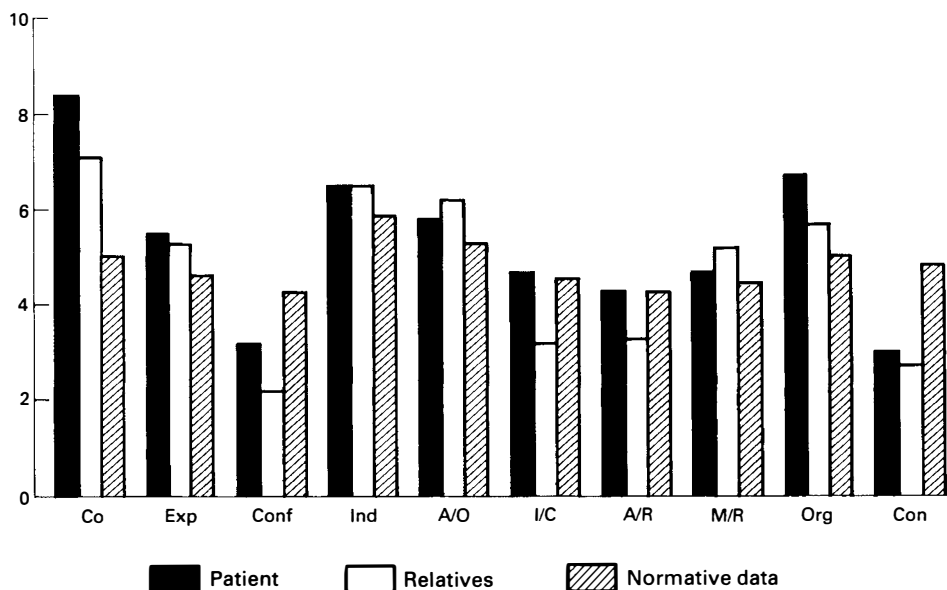
The results of the FES for mean patient and family grouping are shown in Figure 1. These results are expanded in each of the sections below.

#### *Patient responses*

Patients' scores were significantly different from the normative ranges on a number of subscales (2 way ANOVA,  $p < .01$ ). Scores

**Table III** Individual patient scores on each of the 4 subscales of the Snaith Irritability Depression and Anxiety Scale. Relatives' scores in parentheses

	Depression	Anxiety	Outward irritability	Inward irritability
Patient 1	7 (5)	7 (7)	3 (4)	0 (3)
Patient 2	6 (3)	9 (8)	6 (3)	3 (0)
Patient 3	1 (2)	9 (6)	6 (3)	0 (2)
Patient 4	7 (3)	8 (5)	9 (4)	1 (2)
Patient 5	7 (5)	6 (2)	8 (3)	3 (2)
Patient 6	7 (0)	6 (3)	8 (5)	3 (0)
Patient 6	4 (6)	2 (4)	1 (3)	0 (2)
Normal ranges	0-6 (4)	0-8 (2)	0-7 (1)	0-6 (0)



**Figure 1** Mean patient and relative FES scores.

were significantly higher than normal (Duncan's Multiple Range;  $p < .01$ ) on the following subscales; cohesion, organisation, and expressiveness. Patients score was significantly lower on the conflict subscale.

#### *Relatives' responses*

Relatives' scores were significantly higher than normal on the following subscales: cohesion, expressiveness, independence, achievement orientation, moral/religious

beliefs, and organisation; and lower on conflict.

### Discussion

The limitations of interview procedures, and the bias attributable to 'known' investigator involvement are accepted by the present authors. However, the responses of this group as a whole tend to reflect earlier findings in the USA<sup>10</sup> that the majority of individuals report that they are 'glad to be alive since injury' and rate their quality of life as average or above. Such individuals intermittently express a wish to die, and in the present study it is notable that this group would only wish to consider death if their cognitive abilities deteriorated considerably. It is a tribute to the fortitude of the individuals concerned and the dedication of close family members that the wish to die does not occur with greater frequency. It is interesting to note the comments of one patient, who felt that at the point at which the decision to ventilate is taken, the absence of close family should be a considered factor.

The ethical decisions concerning continuation of ventilation are difficult to resolve,<sup>11</sup> though the individual's competency and informed decision to decline medical involvement must be taken into account. In accepting any individual for rehabilitation the primary goal must be achieving the highest level of quality of life. Implicit in such a statement is the involvement of the individual in deciding the parameters of quality, which may alter as the implications of the disability alter. As Maynard and Muth<sup>12</sup> conclude: 'The ability to support a responsible choice to end life is thus consistent with, if not central to, humanistic rehabilitation.'

The individual's relationship with the ventilator tends to reflect the views of other trauma groups who require attachment to machinery for continued existence; haemodialysis patients often report a 'honeymoon period' when the machine is seen in an extremely positive light, followed by some swing towards rejection and than gradual acceptance.<sup>13</sup> The current trauma group,

however, tended not to remember or experience the early acceptance of the ventilator due to the severity of their medical condition at this time. The anxieties experienced by relatives concerning the role of others in care reflects the need for centres who offer ventilation programmes to ensure the availability of 24 hour support and regular respite. The involvement of the family at all stages of rehabilitation, and individually tailored training programmes go some way to alleviate such anxieties, although the need for ongoing dialogue cannot be stressed too highly.

It would be wrong to extrapolate the views and experiences of this group to others requiring ventilation as they are undoubtedly a highly select population, with clear lines of communication and stable family interaction patterns. The decision to return an individual to the community must take place following comprehensive assessment of all the relevant individual medical and psychosocial factors.

In examining the affective state it might be expected that the pressures of coping, on both patients and relatives, would lead to severe difficulties. This was not shown to be the case. In only 3 cases were patients' depression scores above those of the normal population; similar elevated anxiety scores were only shown in 2 cases. There is some evidence to indicate that those who have been at home the shortest period of time experience elevated anxiety scores, whilst those who had been at home longer produced higher depression scores. It is possible that patients who have been at home short periods of time remain anxious because they are still unsure about their daily protocol and insecure concerning the long term feasibility of the arrangements, whilst patients who have been at home longer develop higher levels of depression because of some worries over the repetitive nature of their existence. There is certainly evidence in other areas of loss<sup>14</sup> for similar trends in response to long term illness though the numbers involved in this study do not allow firm conclusions to be drawn. However, such responses are compatible with behavioural correlates of anxiety as a form of conditioned suppression,<sup>15</sup> being incompa-

tible with depression as a sudden loss of a major source of reinforcement.<sup>16</sup>

Patients' perceptions of their families, assessed with the FES, indicate a high level of interaction, clarity of communication, expressiveness, high levels of organisation and significantly lower levels of conflict. These responses correspond closely to the patients' perceptions of their family members' attached importance to the relationship and system maintenance dimensions of the scale. These scores support the view of staff members that high quality of family interaction is imperative for successful community management. Similarly, the importance attached to a high level of organisation is understandable given the need for family members' involvement in a number of medical and caring procedures to maintain, for example, the ventilator and the management of the physical conditions associated with the spinal trauma.

Families' views of the patient similarly reflect their high level of cohesion as an important factor in maintaining the family structure. Significantly higher than average scores on the independence, achievement orientation and moral/religious subscales emphasise the families' views of the individual's need to maintain a high level of personal growth which reflects positively on all family members' desires to maintain as normal a family life as possible. As with the patients' responses, the organisation subscale reflects the need for clarity and organisation in maintaining the ventilator dependent person at home.

Given the essential interdependence and intensity of the relationship between the patient and family it is reassuring to see that

the fundamental factor which underlines all the responses noted above is the perceived importance of a high quality of communication. The significantly lower scores by both patients and relatives on the inwardly directed irritability measure of the Snaith IDA scale would also seem to support this notion; the availability of good lines of communication increases the possibility for resolution of internalised concerns or distress. The availability of such open lines of communication helps militate against some of the commonly held misconceptions concerning the effects of spinal injury. It has been hypothesised that the higher the level of spinal injury, the lower the degree of emotional expression.<sup>17</sup> The current data do not support this view. Similarly, levels of motivation and achievement orientation may be expected to decline in those with severely disabling conditions, as the physical constraints reduce the range of available activities and interests. This is definitely not the case with those in the present investigation, and has implications for ensuring access to comprehensive vocational retraining support, similar to a scheme organised in conjunction with the Technical College in Southport.<sup>18</sup> Patients and relatives who elect to return home are a highly selective group. There will always be the fear of complications and concerns over each individual's ability to cope. However, it is our experience in Southport that with comprehensive family, hospital and community based support, the quality of life for those requiring continued ventilation can be optimised and community reintegration should be the norm rather than the exception.

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