

## THE HIGH-LEVEL TETRAPLEGIC: PSYCHOLOGICAL SURVIVAL AND ADJUSTMENT

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*Abstract.* From the date of injury tetraplegics with spinal cord lesions of C4 and above are faced with unparalleled social and psychological adjustment. The individual will be involved in a process of re-establishing his identity by learning to develop and adapt his only remaining resources, his mind and his ability to communicate.

This patient population is absolutely dependent in all aspects of meeting basic needs during the initial stages of the injury. If we attempt to return the patient to an active role in society, the rehabilitation team must be aware of the dynamics by which the patient achieves control of both himself and his environment.

He will undergo a marked regression of his physical and emotional being and will face the turmoil of realigning ego parameters. The focal point of patient, family and staff interaction is the months of rehabilitation, where the team deals with the problem of social reintegration. Family involvement is essential from the beginning and reaches a high point at discharge and home planning.

The scope of the paper will be to trace the psycho-social development of the patient with cervical lesion of C4 and above through the initial, rehabilitation and discharge phases of the injury. Our aim is to develop sufficient insight to the problems facing our patient population that we may aid in their search for meaningful lives.

**Key words:** Tetraplegia; Psychological survival; Ventilator dependant.

### Theory

THE aim and intent of this paper is to develop insight into the problems facing the high-level tetraplegic so that we, as rehabilitation counsellors, can be an original and consistent reference in his search for a meaningful life. In this instance, insight is developed through an examination of the psychological processes which our patient must face as a result of his injury. The psychological condition of the patient is a statement as to why the individual is as he is and more importantly a description of the underlying process which brought him to that point. Interestingly enough, we have heard from staff and the community that the patient is psychologically ready for this and psychologically ready for that. When a request is made to describe that psychological condition, we hear a variety of statements about the same patient and all different according to who is speaking. The same people who ask about the psychological condition are often turned off when the theoretical explanation is delivered. Irving and Mariam Polster (1973), in their book, *Gestalt Theory Integrated*, state 'Theory and knowledge remain suspect . . . because of their historic isolation from action. Without theoretical orientation, however, action is vulnerable to oversimplified and glib imitativeness—even mimicry and to the use of the gimmick'. The explanation must include a strong theoretical base because no one can fully understand the totality of another's life experience.

Our inquiry makes the assumption that man's search for a meaningful existence is an inherent quality of human nature. Given this assumption, we can address ourselves to the problems which develop when the answer to the search yields a meaningless and futile existence. It is with ultimate concern that we direct our inquiry for tetraplegics with spinal cord lesions of C<sub>4</sub> and above, who invariably state, 'Now that I do not have the use of my arms and legs, life is meaningless and I want to die.'

As with most inquiries, the research must begin with what is known. A functional definition of the individual with cervical lesion at levels 1, 2, 3 and 4 covers a multiplicity of behaviours, all of which are basic to man's survival in a complex society.

1. The patient is usually on a respirator some or all the time.
2. He usually requires two wheelchairs; a manual one when he is being transported via car or when his electric breaks down. The manual chair needs troughs for the arms, a high back for trunk and head support and no rims. (The electric wheelchair is usually one with chin or breath control.)
3. Weight shifts must be done by chin or breath control while in the electric wheelchair and the person is dependent while in the manual wheelchair.
4. Dependent in moving his manual wheelchair but is able to propel the electric chair on level ground.
5. Dependent in feeding.
6. Dependent in bathing, hygiene, and the bowel programme is most easily done in bed.
7. Any communications in terms of typing, signature writing, using the telephone, tape recorder and game playing must be done with mouth-sticks.
8. Dependent in dressing.
9. Totally dependent in transfers and the person who is transferring him must keep the respirator in mind.
10. Dependent in driving.
11. Dependent in homemaking.
12. Usually standing on a tilt table.
13. Dependent in placing his pads for skin protection at night. Doesn't sleep prone due to respirator.\*

If a society has the technology to keep this patient alive, then it must consider the human being and adapt its technology to respect the dignity of the life it has saved.

The following chart is presented as a diagrammatic representation of individual theories which are relevant to the psychology of the high cervical lesion. (See Fig. 1.)

The complexity of the human organism demands that several theories be synthesised to insure a comprehensive coverage of high level cervical lesion psychology.

The initial perspective can be seen *vis-à-vis* the functional definition and its relationship with the maturation process. Maturation is a process whereby an individual develops physically (moving from infancy to adulthood), and behaviourally. The movement takes place over time and has culturally determined limits. In America, for example, one is taught to be assertive but not aggressive or

\* J. Maggie Hawn (1977), unpublished material developed at Craig Hospital.

PARAPLEGIA

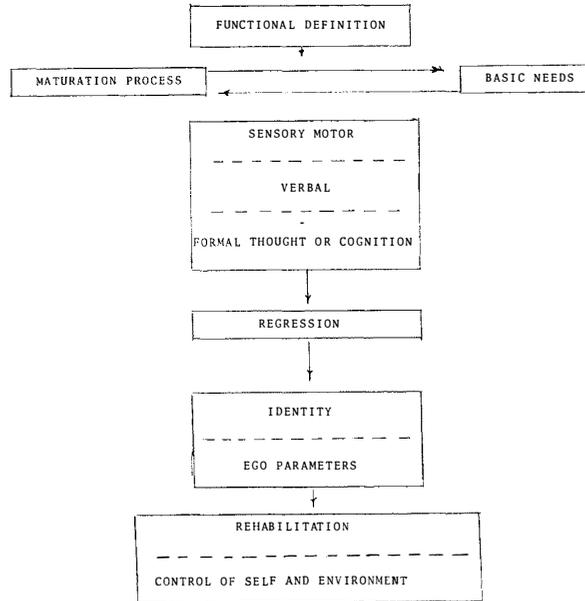


FIG. 1

passive. Chris Argyris has developed a scale of behaviours which describe the state of infancy and those behaviours of the mature adult:

Infancy (from)	Adult (to)
Passivity	Increasing activity
Dependence	Relative independence
Few behaviours	Many behaviours
Erratic and quickly dropped interests	Deeper interests
Short time perspective	Longer time perspectives
Subordinate position	Aspiring to or superordinate
Lack of awareness of self	Control of self*

\* As published in Flippo (1966, p. 2).

The high cervical lesion initially reduces the behaviour available to the adult to that which would parallel the behaviour of an infant.

In the able-bodied population, a simple gauge of an individual's maturity is how well he is able to fulfil his basic human needs. The basic need construct, as presented by A. H. Maslow, outlines five universal needs. Food, water, clothing, shelter and air are the basic physiological needs. Safety is second on the list and has the function of motivating man to secure the physiological needs for survival. Love, esteem and self-actualisation complete the list (Maslow, 1968).

The person who has an impairment in his ability to meet basic human needs is said to have a disability. Maslow also states that the individual cannot pursue the higher needs unless the basic survival is secured. The high-level tetraplegic

does not have means of meeting basic needs and is initially locked into a question of staying alive.

The basic needs construct and the from-to orientation of the maturation process have a logical growth quality but do not speak of what components the human being naturally possesses in order to effect the incorporation of culturally prescribed data. Inhelder and Piaget describe three phases of normal maturation: in infancy and early childhood on a sensory motor or perceptual level; in later childhood on a representational or verbal level; and, in adolescence, on a level of formal thought or cognition.

While in the able-bodied population the input from the sensory motor level of perception continues throughout the normal lifespan, and is the dominant mode of in-putting data, it is the sensory motor and most primitive level of perception which is eliminated in the body below the level of lesion. Irving and Mariam Polster elaborate this idea: 'Because of the permanence of contiguity in contact, it is tempting to give highest priority to touch itself, thereby devaluing that contact which can be made through space. Hitting, stroking, holding, patting, etc., are among the most obvious ways of reaching people quickly and powerfully. Nevertheless, the opportunities for reaching people through space, as by talking, seeing and hearing, are certainly more abundantly available than touching, even in ideal interpersonal situations. The discovery that a well-placed word can be as touching as a physical stroke expands the lustre of every-day communications. But these are subtle influences, requiring that the person tune in more attentively to his own sensations.'

Discussion of the initial effects of the injury on the remaining resources, *i.e.* the representational or verbal level, and formal thought or cognition, are as pertinent as the loss of the sensory motor level. We see, for example, the patient who is fortunate enough to have a tracheostomy which allows him to speak must learn to speak only during the inhalation cycle of the ventilator. The patient who has just suffered a traumatic physical and emotional injury is going to have tremendous difficulty with formal thought or cognition. There is some question in our minds that this inability to communicate may retard the expression of emotional factor inherent in the grieving process. Even after many of the emotions of grieving have been worked through, the formal thought will, if Mr Maslow is correct, be focused on securing basic needs.

A quick review of Fig. 1 will show how the theories covered relate to the functional definition.

In addition to grieving, there is a larger emotional adjustment process which corresponds to and is interrelated with the physiological component.

Dealing with a high-level tetraplegic on an emotional level involves the theories of regression and identity. Regression is a turning back or return to a former state; regression, in psychology, is an abnormal return to an earlier reaction, characterised by a mental state and behaviour inappropriate to the situation.

In most instances we find a normal individual violently thrown into an abnormal situation as a result of the high cervical lesion. The dichotomy of the normal to abnormal produces some interesting conclusions. For example, functionally and behaviourally the high-level cervical lesion demands a return to a former state, but there is nothing normal about a high cervical lesion. The behaviour is certainly not inappropriate to the situation, but being totally dependent and an adult within the normal population is a contradiction in terms. This conflict is a dominant factor in the production of stress and subsequent ego regression. The conscious realisation of permanent and total dependence may be-

haviourally result in: an appearance of premorbid strengths or old fears and conflicts; difficulty delaying gratification and frustration; difficulty in substituting thought for action; thinking dominated by fantasy; and mobilisation of aggression by feeling of frustration and helplessness.

Identity or the concept of self is formulated over an individual's lifetime. Identity continues to develop and includes levels of maturity and how well the individual meets basic needs. Among the multiplicity of behaviours available to accomplish a task, some prove to be successful, while others are ineffective. Ego parameters, which serve to establish individual identity, are the guidelines by which the individual seeks to accomplish life's tasks. Because the premorbid behaviour patterns are, for the most part, ineffective and the identity and ego parameters of the high level tetraplegic must make a dramatic shift. For example, the athlete and the industrial worker who suffer high cervical lesions are obvious examples of sources of identity which would require totally new means of securing basic needs.

The direction which realigning of ego parameters will take is dependent on social and physiological factors and has potentially devastating psychological implications. Through the normal stages of growth and development the human being establishes a concept of self and learns to differentiate between self and environment. Prior to the differentiation a symbiotic relationship exists with the environment. Again, we might emphasise that much of this differentiation takes place on a sensory motor level. The individual who grows physically but fails to make the differentiation between himself, and, say a machine, is in danger of being diagnosed a schizophrenic. Consider then the inner turmoil of the individual who must remain on a ventilator to sustain the life process and/or the person who must rely on a sip-and-puff electric wheelchair, as an extension of himself, for basic mobility. The new identity must embrace as normal, some aspect of the symbiotic relationship. Theoretically infantile symbiosis begins to break up with the weaning process. Consider the symbolism if not the actual meaning of this term when it is used to describe the attempt of taking the high-level tetraplegic off ventilator assistance. Another aspect is the culturally prescribed dependence of the patient on an attendant.

The premorbid personality is the key to determining if the process of realigning ego parameters is to be successful. Personality differences will dictate differences in the varying degrees of emotionality felt by the patient.

Regression is the process that returns the patient emotionally to the beginning of the maturation process. He will learn to meet basic needs with his remaining resources and thereby establish his identity and ego parameters. Through this process the patient will regain both control of himself and his environment.

A programme must be developed, using the team approach, which deals with the sequential development of the regressed patient. Rehabilitation of our patients by attending to the physical aspects is only half an effort. To complete the rehabilitation process, the emotional aspects must be allowed facilitation and expression.

### **Application**

Rehabilitation can be defined as maximising all of the patient's abilities; it means seeking the upper limits of usefulness of all enervated muscles and it means assisting the patient to develop his mind and ability to communicate. All of the patients discussed in this paper are at least initially dependent on a ventilator. For them, rehabilitation also means decreasing the use of the ventilator if possible. This process of weaning from the ventilator is extremely taxing to the patient

from a psychological and a physical point of view. Psychologically we see a patient already thrown into a stage of infant-like total dependency, already aware at some stage of the grief process of terrible physical losses, and already extremely apprehensive, being asked to trust someone to remove the tubing which delivers his life breath while he tries to breathe on his own. If the patient is successful, and is able to gradually increase the number of minutes he can breathe unassisted, he experiences some of the first positive moments of his rehabilitation process. However, the pattern of ventilator weaning is generally far from a steady progress. The patient sees frequent set-backs as personal failures and thereby loses even more of his old identity.

From a physical point of view, the weaning process is exhausting. The energy spent on concentrating on each breath is tremendous. The patient is not as able to enter other facets of his rehabilitation programme.

Weaning from the ventilator has a very high personal priority among this group of patients. In spite of his anxiety, the patient has a strong desire to be independent of help in satisfaction of one basic physical need. We often hear the statement, 'I want to be rid of that damn machine!'

Staff and family play an important part in the weaning process. Early on, the rehabilitation team must do all in their power to insure that the intermediate steps in the weaning are controlled so that the patient has an optimum chance of physical success. In other words, the staff must not push too hard and must be reasonably sure that they are not asking the patient to do the impossible, thus avoiding failure which is devastating to the patient. Trust and confidence are significant aspects in the rehabilitation programme. The staff needs to have developed the patient's trust since they are dealing with life support mechanisms. The patient is often understandably apprehensive about starting the weaning process. Each step of the process should be explained in as much detail as possible prior to being undertaken. This information and the events which bear it out help nurture the patient's feeling that the process is predictable. This knowledge gives him a feeling of assurance and thus his safety needs come closer to being met.

Staff need to be understanding and supportive of the patient. They need to show confidence and warmth, much as a parent who helps reassure a child in a frightening experience. All patients report feelings of near panic at their first weaning attempts. This is not a time for berating and exhorting if the patient is reluctant to try to breathe on his own, but rather a time to listen to the patient's fears, calm him, and support him in his attempt to prepare himself.

The patient's family, too, needs to have a thorough understanding of the weaning process. They need to be assured that they have open lines of communication with the rehabilitation team. The family is probably experiencing some of the same fears as the patient, and must understand their own feelings in order to be effectively supportive of him.

Near total dependency is another important consideration in the adjustment of the high-level tetraplegic. When he realises the extent and permanence of his physical losses, he becomes extremely depressed. He sees himself as a burden upon his family, thinks of himself as useless, and speaks of suicide. His physical therapist and occupational therapist are especially important to him during this time. They work with him to strengthen all available muscles to maximise their usefulness. The therapists prepare him to guide his power chair with a chin control. They may help him develop the neck strength and mobility to use a mouthstick for typing. However, looking at fundamental tasks such as feeding, dressing, and taking care of bowel and bladder needs, we see a patient who cannot take care of himself. He is

again a young child in the realm of his dependency. He cannot alter his situation. How can he be helped to cope with his feelings of helplessness and inadequacy?

First of all, the rehabilitation team members must be comfortable enough with their own feelings regarding the patient's traumatic loss that they are able to let him grieve. Anger and grief are difficult emotions to tolerate, yet these emotions of the patient are the very ones that staff must be able to allow at this time. Then, the staff members who are assisting the patient must treat his needs in a cheerful matter-of-fact way and not contribute to his self-depreciating feelings by expressions that are negative about providing his care. Positive staff attitude helps the patient regain his feeling of self-acceptance and self-worth. Family attitudes at this time are also of prime importance. The family, too, must become comfortable with the patient's needs and must come to terms with their feelings regarding his dependency.

Up to this point we have been discussing the patient's views of his fundamental needs for basic survival and safety. We have looked at how he can be helped to incorporate his altered way of fulfilling these needs into a realistic view of himself. When these needs are fulfilled, the patient can, according to Maslow, move toward satisfying higher levels of need. These higher needs are related to the individual's meeting his own expectations in terms of his role in society and as a human being. As Maslow says, 'to become everything that one is capable of becoming'. It is a supreme challenge for the totally dependent quadriplegic to meet these higher needs and continue his maturation process. The rehabilitation team has a great responsibility for facilitating the start of this process. The staff needs to educate the patient to the greatest possible extent about his condition and his needs and must then encourage the patient to use this knowledge and to take increasing responsibility for seeing that his needs are met. This means encouraging him to take the initiative and to monitor his own fluid intake, skin care, and daily routine. Thus, the patient is taking care of his own body as much as he is capable. When he is showing this much responsibility for himself he is ready to begin to assume greater responsibility for things outside himself. He can start looking to the future. He can start fulfilling his role as a husband or a father or a son. He can think and plan and start making some decisions.

How can this be accomplished? Often the wife has assumed responsibility for making business and financial decisions. It is important for her to include the patient in the decision-making as soon as he is able. Generally, some long-range planning is necessary. For instance, it is often necessary to make modifications to the home environment to enable the patient to return to surroundings where he can use his mobility skills and to achieve as much normalcy as possible in family routine. Again it is essential that the patient participate in the decision-making process. He must hold the reins as much as possible. By exerting more control over his environment, he has moved to regain some lost self-esteem.

The patient must also be encouraged to look at the future and to consider vocational or avocational possibilities since these are traditional ways of expressing creativity and defining ego parameters. Discussion with patients many months or years following their injuries reveals a strong desire to feel useful. These former patients are seeking outlets for their energy. Many of them see work as an avenue of self-expression and a way to give increased meaning to their lives. The same technology which saved the life of the high-level tetraplegic yesterday should develop vocational opportunities for the survivor today and tomorrow.

At low moments the high-level tetraplegic sees himself as a burden and sees little positive in his existence. But the low moments do not seem to be the over-

riding experience of these individuals. They are not overwhelmed with hopelessness. They continue to maintain a will to live, much as the prisoners of World War II concentration camps. Some feel great responsibility for raising their children; some feel useful to those whose condition they see as worse; some feel that God spared them to be an inspiration to others. These private definitions of personal purpose reflect a driving force much stronger than the search for physical sustenance. They point to some fulfilment of needs more toward the top of Maslow's hierarchy.

#### SUMMARY

We have examined the physical losses sustained by the high-level tetraplegic as determinants of his psychological processes and looked at ways that the rehabilitation team can apply this knowledge to help the patient achieve a psychological adjustment to his disability. We have seen that a patient with an injury at C4 or higher is physically as dependent as an infant and has suffered such drastic sensory motor losses that his ability to deal with his environment is greatly impaired and he must in a sense begin the maturation process again. With an understanding of these dynamics the rehabilitation team needs to treat the patient with warmth and understanding and design tasks at which the patient can be successful. We have also looked at this patient in the light of A. H. Maslow's hierarchy of needs and found a patient suddenly floundering at the bottom rung for his basic survival. We looked at ways in which the high-level tetraplegic can be assisted to meet his basic needs and thus be free to find meaning in his life—to become all that he can become.

#### RÉSUMÉ

Nous avons examiné les pertes physiques du malade tétraplégique à degré avancé comme déterminants de ses développements psychologiques et nous avons considéré les moyens, lesquels l'équipe de réhabilitation puisse utiliser pour aider le malade à réaliser un ajustement psychologique à son invalidité. Nous avons vu qu'un malade avec un dommage à C-4 ou de plus a la dépendance physique d'enfant à bas âge. Il a souffert telles pertes drastiques moteur sensorial, que sa capacité de s'accomoder à son environnement a fortement diminué et, dans un certain sens, il doit recommencer le processus de développement. En se rendant compte de cette dynamique l'équipe de réhabilitation est obligée de traiter le malade avec cordialité et sympathie et de préparer des besognes, auxquelles le malade puisse réussir. Nous avons considéré ce malade du point de vue de la hiérarchie de besoins A. H. Maslow et nous avons constaté que le malade se débats à bas échelon pour sa survivance fondamentale. Nous avons considéré des moyens pour aider le malade tétraplégique à degré avancé à pourvoir à ses besoins fondamentaux, le libérant ainsi à devenir tout ce qu'il peut se faire.

#### ZUSAMMENFASSUNG

Wir untersuchten die erlittenen Schäden des hochgradigen tetraplegischen Patienten als Determinanten seiner psychologischen Prozesse und betrachteten Methoden, durch die das Rehabilitierungsteam dieses Wissen anwenden kann, um dem Patienten zu helfen, sich seiner Körperbehinderung psychologisch anzupassen. Wir fanden, dass ein Patient mit einer Verletzung Stufe C-4 oder höher körperlich genau so abhängig ist wie ein Kleinkind und solche drastischen Empfindungs- und motorische Nervenverluste erlitten hat, dass seine Fähigkeit, sich in seiner Umwelt zurecht zu finden, stark beeinträchtigt ist. Er muss daher den Prozess des Reifens erneut beginnen. Mit einem klaren Verständnis dieser Dynamik muss das Rehabilitierungsteam den Patienten mit Sympathie und Verstehen behandeln und Aufgaben für ihn entwerfen, die ihm Erfolg bringen. Wir untersuchten diese Patienten auch in Bezug auf A. H. Maslows Bedürfnis-Rangordnung und erkannten,

dass ein solcher Patient sich plötzlich auf der untersten Stufe mit der Grundlage des Überlebens abquält. Wir untersuchten Möglichkeiten, dem hochgradigen tetraplegischen Patienten in der Erfüllung seiner Grundbedürfnisse zu helfen, so dass er frei wird, den Sinn seines Lebens zu finden und alles das zu werden, was er werden kann.

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