



EMOTIONAL PROCESSES OF COPING WITH DISEASE IN THE EARLY STAGES OF ACQUIRED CEREBRAL LESIONS†

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General Aspects of Achieving Adjustment to Neurological Disease

Neurological diseases—whether with or without cerebral lesions—have, in many cases, a traumatic character because of their often abrupt beginning. The physical and/or mental handicaps that appear suddenly with the onset of the disease, and remain forever, are often perceived as a deeply insulting humiliation. Very grave injuries, like cerebrocranial traumata after traffic accidents, can mean complete breakdown of all functions of the self. Therefore, in many cases, a whole new identity has to be constructed (Sacks, 1984). In most cases of illness with chronic disablement, the task is to learn to live with them, a task that requires a complete re-orientation of lifestyle, including a new concept of life (Beutel, 1988). To prevent later phases of depression and apathy (Kast, 1986), it seems necessary to accompany the patient as early as possible during this process of coming to terms with the disease.

In my experience, patients, during the acute phase, are most intent on regaining all of their physical and/or mental faculties, denying the existence of limits to their recuperation. (“If I train as much as possible, everything will be as it was before. . . .”) Or they are so deeply shocked by the traumatic event that they

remain caught in this paralysis, freezing into hopelessness. (“Why train at all—everything is lost anyway!”) Both reactions mean negation or repression of reality: whatever has happened is neither a bad dream from which one only has to awaken to live on as before, nor is it totally impossible to achieve an improvement of physical and/or mental functions. If, during the acute phase, patients keep denying their problems or have a fixation about their complete physical and mental recuperation, that is, if the chasm between perception of reality and wishful thinking becomes too wide, the danger of a depressive breakdown appears at the moment when the limits of medical possibilities become visible. The trauma would be repeated. If, however, patients drown in apathetic resignation, they will, under certain circumstances, block the functional training to a great degree and, by doing so, will hinder or even prevent an improvement of motor and cognitive faculties. In both cases, energies that are badly needed to adapt to the disease’s consequences are tied up in a battle against the fact of the disease itself. The patients will only be able to use the functional-cognitive training effectively if they succeed in finding the golden mean between a protective attitude of defense and a future-oriented attitude of achievement (Steffens & Kächele, 1988).

Only by balancing both aspects, with an integrating achievement of adaptation in mind, will patients

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be able to make full use of the functional-cognitive training program (Parekh, Manz & Schepank, 1988; Zihl, 1988). Assuming that there is a correlation between the level of emotional coping and successful functional rehabilitation, and aware of the importance of the first 6 months after the trauma for the ultimate development of the potential for rehabilitation (Cramon, 1988), it seems to me that there is need for early support of the patients by accompanying them during the process of mourning.

Programs for rehabilitation, especially during the acute phase, are mostly based on functional and cognitive training. Body and mind receive all the attention. Psychological support, however, for the insulted self remains mostly in the background. The neurologist, Oliver Sacks, who personally has lived through the trauma of neurological dysfunction, has written ". . . we have also noticed that the objective and empirical character of neurology excludes every consideration of the subject, of the self. If this contradiction, this dead-end road is to be avoided, something very basic has to happen. What we need now as well as in the future is a neurology of the self, of the identity" (Sacks, 1984).

The daily feedback that these patients receive during their training conveys: "You cannot . . . , you are not able to . . . , you have a deficiency of . . . , you have a dysfunction of . . ." Subliminally, this message means, and it coincides with the predominant way of thinking of an achievement-oriented society: "You are of no use the way you are now." The feeling of inferiority, which originated in the trauma itself, can thus be increased. The fact that the neurological patient in the majority of cases is confronted, without any time for inner preparation, with the regression from the autonomous life of a grown-up to the helplessness of a child, which also entails dependence and heteronomy, this fact alone means a deep insult to and humiliation of the self. The atmosphere of training, dwelling mostly on what the patients are *not* able to do, may even accelerate the progressive loss of their self-esteem. Working at deficiencies is, of course, a prerequisite for the improvement of function. Thus, training is absolutely necessary. But would it not be worth thinking about giving support to the wounded self-esteem to face the crisis of identity? From my experience, it seems most helpful for the full development of rehabilitation potential to transmit the feeling of acceptance in the sense of "You are important, and you are worth as much as any healthy person," especially during the early phase.

The breakdown of the self, including self-esteem, can manifest itself as a resigned retreat into isolation (mutism), as a severe lack of drive, or even in outbreaks of destructive impulses following severe narcissistic insults (Jochims, 1991). The most frequent disturbance is supposed to be the depressive disruption of coping (Prosiegel, 1988). Many authors see a connection between the outbreak of a depression and repressed mourning (or un-dealt-with loss) (Kast, 1986).

Adapting to Disease With Cerebral Lesion During the Process of Music Therapy

Acquired cerebral lesions are often accompanied by psychological problems: without knowing why, these patients perceive the difference between their former way of being (i.e., having been "normal") and their present state (i.e., according to their feeling, being "retarded" or "stupid"). From the reactions of their surroundings they receive the impression that something is wrong with them, but they cannot find the link between the disease and their cognitive deficiencies. In this light, one has to evaluate autistic tendencies and/or aggressive/explosive behavior as expressions of deep insecurity and humiliation. Difficulties of relating, culminating in total rejection of any communication, are not a rare occurrence after cerebral lesions. This is why a therapy is needed that works at social interaction (i.e., at a growing ability to build stable relationships). After a long time in a coma, the basic modes of behavior, such as imitating, initiating and reciprocal action, have been lost by the severe damage that has occurred. Only with a newly-gained ability of encoding and decoding can the phase of real coping with disease in the sense of a mourning process become possible.

With music or sounds, one reaches the part of the brain that is still intact (Alvin, 1976; Bang, 1980; Nordorff/Robbins, 1975, 1977; Rett & Wesetzky, 1975). Through music therapy one can give patients with cerebral lesions the experience of a relation based on partnership, where therapist and client are communicating in a medium to which both have equal access. For the deficiencies of finding and understanding of words, which usually exclude patients with cerebral lesion from society, are not relevant in this medium. Through the process of entering into a relationship and of shaping it by means of the medium of sound, patients are given the opportunity to ac-

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