

Music Therapy  
and Neurological Rehabilitation  
Performing Health

*Edited by David Aldridge*



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# Encounter with the Conscious Being of People in Persistent Vegetative State

*Ansgar Herkenrath*

[sono ergo sum – *I sound, therefore I am*]

This chapter is based on qualitative research of music therapy with patients suffering from traumatic, ischaemic or hypoxic brain damage whose condition is described by the medical terms *apallic syndrome*, *coma vigilé* or (*persistent*) *vegetative state* (in German: *Wachkoma*). These patients are seen as unable to perceive, and communicate with, their environment. Participants in this study were between 20 and 50 years of age and had been in the described state for between 18 months and seven years. All therapy possibilities were considered as exhausted. The patients were living in a long-term nursing institution for adult residents with severe neurological handicaps in Haus Königsborn, Lebenszentrum Königsborn, Unna, Germany, where I have been working as a music therapist for the past six years.

From the beginning of my music therapy activities, my work with these patients confronted me with their condition, its definition, diagnosis, progress and prognosis. My personal impressions in music therapy sessions, where I experienced changes in patients not only as reflexes but as re-actions, and thereby expressions of their awareness, were in direct contrast to the opinion common among physicians that patients of this type are unable to perceive and react. I found them to be resounding personalities who met me with their entire being. This impression finally led me to the motto of *sono ergo sum*.

This motto comprises more than considerations on the sounding of a human being in the musical sense. *I sound* – man also *sounds* in his innermost body, in his state of being, in his inner harmony or his dissonance. Man *sounds* in his mood and

his self in relation to himself and others. The words *I sound* are therefore an image of our inner self in our relation to ourselves and others.

The words *I am* raise the questions *Who am I?*, *Where am I?* – and most of all *What am I?* Observing myself in a mirror, I can see my body in its various forms of expression. But I would vehemently reject a description of me, my being, my self or my soul based exclusively on my body. My personality comprises more than a mere organic structure. Observing patients with apallic syndrome in my work, and perceiving not only their body but also an expression of their personality, their self, and seeing how many different brain regions can be affected without a loss of the self, the personality, then I must wonder where this self of a human being is located in the body. Is it an element of the brain? Where does this part come from that is conscious of itself and says *I am*, what is it, and where does it go when this body dies?

The word *ergo* (therefore) implies a conclusion in the sense of 'because'. I am because I sound, and as long as I am able to sound, I will be. But what about those people who are impaired, ailing, seriously ill, and what about patients in persistent vegetative state who are considered unable to show intentional reactions? Are they able to sound at all, if they cannot show any directed reactions? Or would it be true to say in their case *I do not sound therefore I am no longer (myself)?*

Persistent vegetative state and awareness are mutually exclusive according to the medical tradition. The general term *Wachkoma* in German is an attempt to describe summarily the acute state and also the rehabilitation phases of the condition specified by the medical terms 'apallic syndrome', 'vegetative state' and '(persistent) vegetative state' that are often used synonymously; the inherent dilemma is that the above medical diagnoses exclude the existence of a consciousness in itself in the afflicted patients. The title *'Encounter with the conscious being of persons in persistent vegetative state' therefore appears contradictory at first and will have to be further verified.*

Consciousness generally implies a consciousness of the self that perceives the self and others, defining the self in contrast to the environment and inducing a communicative behaviour in dialogue with this environment; it is a core element of existence and human life. Persons who have no consciousness and are therefore considered unconscious are without this element of their human existence. But the defined loss of consciousness means not only loss of this core element of human life; according to the generally accepted prognosis of this illness it is impossible to recover it. This diagnosis and prognosis push a patient aside, to the verge of human existence.

The irreversible loss of consciousness is a sign of transition from life to death (Valarino 1995). A patient in the long-term phase of the vegetative state is therefore in danger of not being recognized as a 'living person' any longer. This

conclusion leads to discussions on the basic rights of such patients, on the economics of their long-term care, and on euthanasia. The objective of this study is to demonstrate that patients with apallic syndrome are by no means unable to perceive, or in the process of dying, but human beings who live in their own specific form of life and animation.

A necessary precondition for the music therapy approach described here with patients with apallic syndrome is the existence of an elementary form of consciousness in these patients and a potential that allows them to react intentionally to what they perceive in this consciousness; the approach is based on 'creative music therapy' as initiated by Paul Nordoff and Clive Robbins and involves joint improvisation and joint interpretation in the therapeutic encounter. The medical definition and prognosis for the condition apallic syndrome / persistent vegetative state either nullifies this therapeutic approach, which is based on the potential of every person to enter into mutual communication, or is a contradiction within itself. A consequence was that I saw the need to raise my personal observations and assumptions from the area of subjective experience and feelings, to objectify them and to explore a scientific basis for my interpretation and therapeutic approach.

This essay presents a basic introduction to the neurological condition and the terms 'brain' and 'mind', 'perception' and 'consciousness' from the perspectives of medicine, neurophysiology and neuropsychology, philosophy, theology and ethics, and describes a concept of a human being on this basis. I shall then relate the observed changes in patients with apallic syndrome to generic terms like 'reaction' and 'reflex', significance of respiration, speech and music, distance and nearness. This combination produces various findings that will be presented in a conclusion. Necessary preconditions will be described for an encounter with the consciousness of such patients, and I shall formulate detailed questions on medical and social consequences involved.

### **Apallic syndrome: a form of life in search of a name**

'*Wachkoma*' is no term to be found in the general medical terminology. In medicine, the terms (persistent or permanent) vegetative state, coma vigile and apallic syndrome are used synonymously to define this condition. In Germany, Kretschmer (1940) was the first to describe case studies of a disease with failure of all cerebral functions and a lowered level of cerebral functions to the midbrain level with disinhibition symptoms, in *Zeitschrift für die gesamte Neurologie und Psychiatrie*. Kretschmer called it a transitional syndrome that may disappear either completely or almost completely. He differentiates between a supposed state of alertness and the inability to enter into meaningful contact with the environment

or to react to it. Later Gerstenbrand (1967) described the condition in more detail in a monograph, from its onset, progress, fully developed state up to the remission phases. Jennett and Plum (1972) described an analogous condition and called it 'persistent vegetative state', and they added to the title 'a syndrome in search of a name'. Observations made by nursing staff, relatives, therapists and physicians led to the term *Wachkoma* (literally: 'awake-coma') in German, since this term summarizes the discrepancy of such observations between recognizable sleep-alert phases and seeming inability to enter into contact.

Coma vigilie is mostly caused by brain damage due to severe craniocerebral injury trauma, cerebral haemorrhage, or hypoxia. Advances in rehabilitative medicine and emergency care facilitate successful reanimation and treatment in a growing number of patients. They survive such acute events, and are even fully rehabilitated in most cases. Some, however, remain in a permanent state of coma vigilie. All descriptions of the state assume a functional failure of the cerebral cortex and complete loss of cognitive potentials while brainstem functions are maintained. There are various descriptions of a possible remission, and all assume that recovery cannot be expected after a period of more than 18 months in this condition (Andrews 1996; Mummenthaler and Mattle 2002; Poeck and Hacke 1998).

The title of this chapter may be held as provocative. It is based on an assumption about a phenomenon that is generally deemed to be non-existent – the consciousness of a patient in persistent vegetative state and the possibility of an encounter with this consciousness.

## **On brain and mind, perception and consciousness**

Consciousness – this term is used as a matter of course in medicine, but the question remains, 'What is consciousness?' Is it reducible to neurological processes, or does it go further? May we locate it within the brain or does it exist as a mental phenomenon only, and as such, can it be explained at all in neuroscientific terms? Is it of decisive significance for us, is it the essence of human individuality? Consciousness, and questions about its existence, significance, generation, localization and demonstrability, and a differentiation between brain and mind, provide such a wide range of issues that it is impossible to cover them exhaustively in this essay. But further deliberations on consciousness require a short survey of its various definitions and interpretations in medicine, philosophy and theology.

### *Brain and consciousness in medicine*

Medical theory relates consciousness directly to brain functions as a biological phenomenon generated by the cerebral cortex. Part of consciousness is the ability to perceive the self and the environment, and a disorder of this ability is defined as pathological, with a differentiation between qualitative disorders (content-related consciousness, awareness) and quantitative disorders (alert awareness, response). Examples of qualities of consciousness are alertness, orientation (time, space, personality), attention, thought processes and memory.

The medical literature provides no definition of consciousness in itself but defines it in the negative form as the absence of pathological disorders; that is, consciousness is defined through a description of its deficit, not in its existence, but as a lack of pathological disorder. A recognizable, expected and therefore adequate response to defined stimuli is seen as proof of its existence. This means that everybody who is neither somnolent, nor soporific, nor comatose, and responds adequately to all levels of stimulation is 'conscious', and those who do not correspond to the expected stimulus–response correlation are 'unconscious'.

Despite intensive discussions of the term 'consciousness', the general and uncontroversial view in medicine appears to be that brain function determines consciousness. Attempts at a medical definition of consciousness inevitably lead to questions of brain functions and their significance for the human mind. Neurophysiology as a field that covers among other functions those of the brain should therefore provide more information on consciousness.

For centuries, generations of brain researchers have tried to define consciousness and always been faced with the much-discussed problem of body and mind. The main problem today is not to demonstrate which neurobiological processes produce certain states of consciousness and perceptions in the brain. According to Searl (1997):

the second and more difficult problem consists in explaining how consciousness actually works in the brain. I believe indeed that a solution to this second problem would be the most important scientific discovery of our time. (p. 10)

Numerous brain researchers have explored brain physiology and the concept of consciousness and have chosen many different methods, from an analysis of various imaging and electrophysiological procedures to discussions on a 'stream of consciousness', the self-healing potential in the brain, the functions of the prefrontal cortex, and even quantum mechanics (Bayne 2001; Blackmore 2001; Calvin 1998; Goldberg 2002; Kotchoubey *et al.* 2002; Müllges and Stoll 2002; Pickenhain 1998; Rudolf 2000; Stein, Brailowsky and Will 2000; Sutherland 2001; Wilber 1997). They all can contribute significantly to an explanation of the

physiological preconditions for something to function that may be called consciousness. But all of them are unable to explain or localize this specific thing, consciousness in itself. Kotchoubey *et al.* (2002) conclude their study by saying that consciousness is a heterogeneous concept both philosophically and physiologically.

A cooperation between neurologists and psychologists has been demanded repeatedly. Neuropsychologists have started to explore correlations between psychic functions and anatomical, physiological and biochemical states. A literature research, however, revealed a significant deficit in that only a few articles by neuropsychologists or neuroscientists address the concept of consciousness with the intention to clarify the meaning of consciousness itself. Attempts to explain consciousness are often connected with hypotheses. This interplay between existing knowledge and assumptions, demonstrability and subjective interpretation, findings and questionable premises, characterizes the discussion and appears to be an effort to find a way out of this controversial situation (Edelmann and Tononi 1997).

Today, neuroscientists are aware of the existence of a consciousness that permits us to perceive us as individuals and self; and many of them believe that consciousness cannot be associated with any definite brain region (Beckermann 1996; Deikman 1996; Dennett 1996; Eimer 1996; Ross 2003; Smythies 2003). We often find a mixture of neurological, neurophysiological and neuropsychological concepts. But no area of neuroscience is able to give a satisfying explanation of consciousness. Attempts are made to reinterpret consciousness phenomena as results of culturally conveyed interpretations or results of cognitive processes (Prinz 1996), or to discuss self-perception in a differentiation between 'I' and 'self' (Deikmann 1996); but such efforts seem mere tricks to bridge the gap between neuroscientific findings and the fact that every person perceives something he calls his consciousness, the perception of his ego or his innermost self.

The phenomenon of human consciousness is almost our last big secret. A secret is something that men are – still – unable to explain ... And as is the case with all previous secrets, there are many who hope it will never be de-mystified, who insist that this last taboo remain untouched. (Dennett 1994, pp.37ff)

If the question of consciousness is to be answered at all, it has to be extended to comprise philosophical, theological and ethical aspects as well.

## Aspects of philosophy, theology and ethics

In the discussion of human consciousness we come across terms like 'ego', 'self', 'human existence', or 'soul'. We cannot avoid such terms. We have to take them up and try to express what goes beyond the activities of neurons in the brain and permits us to experience our individuality. 'What is man?' is a question asked not only in consciousness research but also philosophy, theology and ethics.

From times of antiquity, consciousness has been seen as an integral part of mind and soul. Plato saw the body as a prison of the soul that is controlled by the mind. The middle ages differentiated between a body-soul and a mind-soul (*anima rationalis*) that was seen to comprise conscience as well. The mind-soul was superior, was associated with immortality, and remained free from physical illness. Against this background, the Cartesian theory of a separation between body and soul appears an almost logical consequence, a release of the biological body from the soul. 'Thought' for Descartes is 'consciousness'. Soul for him is an immaterial thinking substance.

Such considerations formed the basis of the body/spirit problem that was addressed by a wide range of philosophers, including Spinoza, Locke, Leibnitz and Berkeley. Kant saw the soul as transcendental, as an idea without substance, as something beyond the reach of human experience. According to his scientific empirism, any knowledge presumes sensory information. Sensory information requires interpretation and order. He believed thought to be the only source of cognition, on the basis of reason. In his opinion, reason can neither prove nor disprove the immortality of the soul. Kant accepted self-recognition as the objective of human efforts and advocated soul research on an empirical basis. Schopenhauer in his theory of the 'primacy of volition' sees the human mind as determined by urge, instinct and volition. In his phenomenological approach, the body is subject, an embodiment of the will. For him, the human mind is more unconscious will and less conscious reason (Hannich 2003; Hinterhuber 2001; Spering 2000).

Again and again, philosophers underlined the directedness of activities as a characteristic of the mind. Brentano called this intentionality a characteristic of the mind, Heidegger found an explanation of a person's being in that person's activity, and Sartre saw the intentional directedness of actions towards a world of objects as an expression of consciousness (Feinberg 2002). According to Searl, intentionality is not the same as consciousness; rather, the former is a phenomenon that depends on the latter (Searl 1997). Humanistic psychology according to Assagioli, Fromm, Jung, Maslow and others comments on human consciousness among other things: 'The human being is more than a sum of his parts... there is something in us, a power, a tendency... that wishes to grow and unfold, that wants to live and strive towards something' (Reiter 2003, pp.4f). Feinberg concludes:

The personal uniqueness of mind and existence of each individual organism is what we call 'soul'. The soul of each brain is indeed something unique and unrivalled. We can donate an organ or blood for transfusion, but the sense of myself has a reality for me that only one person may experience: myself. (Feinberg 2002, p.223)

The term 'soul' is deeply rooted in the theological history of the Christian churches. The bible contains differentiations between 'soul' and 'spirit'. For the Christian religions, the significance of the soul transcends human existence on earth and from the very beginning is enhanced by the idea of a life after death. The soul is considered immortal and goes on living in the hereafter. These are the concepts on which church doctrines are based. Mind or reason (*anima rationalis*) are located on the highest level of the mortal world according to St Augustine. The human mind forms a direct connection with the invisible, elusive world. The mind allows the soul to reach that world. It is located between the material world and God. The orthodox churches take up these concepts and state that man is an indivisible entity of mind, soul and body. Luther and Calvin retain the concept of the soul as an integral part of human beings. 'Consequently, man does not *possess* a soul, man *is* soul' (Hinterhuber 2001, p.103).

In contrast to this historical tradition, terms like 'soul', 'human existence' and 'consciousness' are almost insignificant in current theological concepts. Current discussions among neuroscientists on such ideas do not find any expression in current theology, although the latter should feel challenged to address these questions, as some neuroscientists have pointed out (Roth and Prinz 1996). The obvious conclusion is that, as God does no longer figure in modern psychology, philosophy or neurosciences, soul and human existence seem to be no issue in current theology.

Schweitzer maintained that true philosophy has to be based on the most immediate and comprehensive fact of consciousness. This means that I am life that wants to live, surrounded by life that wants life. It is good to maintain life and promote life and it is evil to destroy and suppress life (Quester, Schmitt and Lippert-Grüner 1999). Albert Schweitzer's words address the ethical issues involved in brain research, philosophy and theology that concern man's consciousness, brain and existence, self and soul. Philosophy and theology play an important part in the ethics of any society.

Ethical principles in medicine are demanded and postulated even today. The draft proposal of an ethics charter that was set up on the occasion of the European Council's 'Human Rights Agreement in Biomedicine' says, among other things, that the right of life has to be protected in any phase of its existence, that decisions on the value of human life by third parties are excluded, and that the unique nature

of human life forbids deliberate termination. Nobody may decide on the value of the life of another (Bavastro *et al.* 1998).

There is a highly controversial ethical debate worldwide on people in persistent vegetative state. The consciousness of patients concerned and its definition is addressed again and again with a view to ethical consequences of divergent opinions and even a discussion on their right to live.

Some countries provide the option to allow patients in coma vigile to die by food deprivation. Cases like those of Helga Wanglie, Karen Ann Quinlan, Nancy Cruzan and Tony Bland are under continuous discussion (Wade and Johnston 1999). There is a clash of diverging attitudes. On the one hand, coma vigile patients are prevented from dying through forced alimentation on intensive wards, and thereby forced to lead an inhuman existence; on the other hand, such patients are neither brain-dead nor dying but human beings with a right to live and be supported by society.

These discussions reveal the essential problem; that is, a right to live for patients in coma vigile may be postulated only by those who assume the possibility of an existing consciousness in these patients. However, the medical standpoint is that they have no consciousness and no cognitive potentials, which inevitably leads to a discussion of an 'end of life'. The concept of human existence that everybody involved in the care of these patients has is, therefore, of decisive importance.

## **Coma vigile and the concept of human existence**

There is no satisfactory answer to the question 'What is man?', and certainly not to 'What is man in coma vigile?' The basic statements of my study on the condition of persistent vegetative state and on human existence presented above in abbreviated form lead to the following general assumptions that form the basis of my concept of human existence.

The term 'coma vigile' describes a complex pathological condition concerning the human body. The nature of man, however, is more than the mere sum of his deficits or his pathologies. Neurophysiologists may be able to demonstrate a relation between consciousness and neuronal processes in the brain but cannot give a comprehensive explanation for consciousness. Similarly, neuropsychologists consider consciousness as one of the secrets of mankind. The inevitable conclusion is that each human being constitutes a physical, emotional and social entity that is basically preserved even in case of illness. Even persons in permanent vegetative state are therefore unique human beings with individual needs and potentials. The depth of consciousness is inviolable and must not be narrowed down.

The most essential characteristic in each person is consciousness. I discover a person's consciousness only in his or her reactions. The persistent vegetative state is a form of life that in the first instance offers no access. A lack of access, however, does not imply its non-existence. It is still impossible to find medical proof of consciousness in such patients. The challenge is to find and offer new ways of access.

Everybody is directed towards development and lives and acts intentionally and purposefully. There are no validated medical data on whether, when and to which degree changes occur, or may occur, in the brain of patients in the long-term phase of coma vigile, even years after the traumatic event.

I part from the assumption that a patient in coma vigile is a living person in possession of his most essential characteristic, consciousness, and who lives a form of life that for him is normal although I am unable to perceive or understand it. He has not lost the basic potential for development and is able to choose and decide whether to accept or refuse offers of an encounter and accompaniment in his life.

Man needs a you to become an I. The you comes and goes, relational events take shape and dissolve again, and it is during this change that the consciousness of the unchanging partner grows, the consciousness of self. (Buber 1962, p.32<sup>1</sup>)

This quotation from Buber expresses the essential concept of access that Hannich and Ziegler have demanded repeatedly as interpersonal dialogue (Hannich 1999; Zieger 1999). This approach describes a path I embark upon as a therapist, the objective of which is dialogue with the self of the other person.

I go in search of this self. I see the path as a continuous togetherness, and not as a one-way road with myself as the starting point. When Buber postulates that real life is always about encounter, then this encounter cannot be reduced to a therapist's directed activities (Buber 1962, p.15). What is required according to the hermeneutic theory is '*Zwischenleiblichkeit*' or 'intercorporeality', the relatedness to each other (Hannich 2003).

This demand is a challenge, not only for my professional knowledge, but my whole self: 'The basic word I-you can only be expressed with the entire being' (Buber 1962, p.7).<sup>2</sup> This approach implies a tremendous challenge for me. It involves a willingness to be open that I cannot and will not accept without reser-

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1 'Der Mensch wird am Du zum Ich. Gegenüber kommt und entschwindet, Beziehungsereignisse verdichten sich und zerstreuen, und im Wechsel klärt sich, von Mal zu Mal wachsend, das Bewusstsein des gleichbleibenden Partners, das Ichbewusstsein.'

2 'Das Grundwort Ich-Du kann nur mit dem ganzen Wesen gesprochen werden.'

vations, and that requires that I set personal limits. I cannot evade the offered encounter in the sense of a duality in the therapeutic relationship. I get involved – according to my abilities – with the patient in coma vigile, with what we do together, with myself. The issues addressed in this chapter obviously include a reflection of my own consciousness, my way of thinking, my emotions.

## **Basic aspects of work with patients in coma vigile and their significance as parameters for consciousness**

### *Reaction and significance*

In my music therapy practice, I experience situations where patients in persistent vegetative state mainly show changes in parameters of respiration, shifts in head and eyes towards the source of sounds and/or a variety of movements. I perceive most of these changes as *reactions*.

In this context I use the term ‘reaction’ in a sense derived from its Latin origin, as an activity that is performed as an answer (re) to another action. It may be a reflex, or may be performed intentionally and therefore have a rational origin. Situative and temporal references determine the difference between reflex and reaction. If a reaction has a rational origin, then it is intended and is an expression of a cognitive potential. In medicine, neurophysiology and neuropsychology, cognitive potential is seen as the basic requirement for consciousness.

Recognizable reactions should therefore not turn out to be mere reflexes but examples of an intentional activity in response to a stimulus situation. If this is the case then they have a rational origin and as such are an expression of a basically existing cognitive potential in coma vigile patients. The existence of basal potentials of perception and recognition – therefore of consciousness – could be observed in such reactions. In order to distinguish between reactions and reflexes, the observed types of reaction must contain an at least basic element of intention.

Respiration is among the activities we perform unconsciously and as a rule without interruption from birth to death. Respiration is controlled centrally in the medulla oblongata. Only rarely are we acutely aware of, or deliberately influence, our respiration. Sudden changes occur as a sign of a reaction, in the form of a startle response or acute anoxaemia, and may therefore be described as reflex-like. Regular interruptions in breathing or changes in intensity may also be part of a pathological respiratory pattern.

Apart from its physiological significance, respiration is highly individual and specific to each person. It is part of each human being’s personality and intimate in nature. Respiration may express the mental condition, may be used intentionally (e.g. in the form of sighs) and thus become an element of non-verbal communica-

tion. Respiration has therefore not only physiological but also qualitative significance (Aldridge 2002).

Many movements may be either reflex-like, unconscious or intentional. The same applies to movements that basically belong to reflexes. Eyeblink as a protective reflex is a reflexive and unconscious process. Nevertheless we can stimulate and employ it deliberately.

Examples of pathological movements in coma *vigile* are primitive reflexes, mastication and mass reflexes, or extensor reflexes. Basically, such movement patterns may be the only movements a patient can use as intentional movement as well. The external appearance of such movements alone is therefore no indication of their quality. Any assessment requires the situative and temporal context in which such movements occur.

An orientation of head and eyes towards the source of a sound implies a situative connection. It must not be confused with the source of sound that is placed in the line of vision. Different and changing orientation as well as turning towards and away from such a source are examples of situative body movements.

An orientation towards the location of the stimulus that calls for attention is innate behaviour. It not only permits visual contact and control but also facilitates optimum auditory directedness. This means that not only eye contact is decisive. The same movement that at first seems an unsatisfactory attempt at establishing eye contact may also be intended to align one's hearing. In cases where visual potentials of a patient cannot be reliably defined, such movements may have a quality comparable to the orientation of a blind person. An orientation without eye contact must not necessarily signify avoidance behaviour or imperfection.

The definition of the term 'reaction' already implied its temporal reference as a response to an action. A reaction therefore presupposes a previous perception, and this is why perceptiveness may be derived from a reaction. It suggests a quality beyond mere reflex – a deliberate performance. Reactions must reveal a situative and a temporal reference in order to be distinguishable from reflexes. A situative reference means that a reaction occurs only in the specific situation, or in an intensive form only in this situation.

Music may help to discover a temporal reference. Music itself has a temporal structure. Time in this context is significant for the basic beat but also as a temporal frame for the beginning and end of a melody. The internal logical structure of music influences the time factor, a structure that is determined by the *logos* of music. This involves the periodic generation of melodies and specific elements of accentuation that have developed in the musical history of the Occident and influence our musical perception even today.

Every human being has an innate musicality. This is why we perceive a departure from such musical structures, irrespective of the specific quality or

further education of our musicality, as unsatisfactory or wrong. This innate musicality also corresponds to our ability to convert music into movements. We have the natural skills to accompany a basic beat with a clapping of hands or otherwise joining in, and to follow musical accentuations.

Another element that is common to respiration and movement is rhythm. Rhythm provides a temporal structure for both. Improvisation on respiration or movement may direct the attention of patients in coma vigile to these elements and in addition to their temporal structure. Reactions to be observed in a temporal connection with the abovementioned musical structures may therefore indicate a basic ability for temporal orientation. Reactions occurring after a stimulus in the sense of a reflex-oriented stimulus–response pattern can be excluded here.

A movement occurring with a certain accentuation – perhaps the end accentuation of a melody in the final cadence, or a main accentuation within a melody phrase – comprises not only a simple temporal reference. If it occurs only in this instance, it indicates an expectant attitude, a temporal orientation towards the future, a knowledge of something that will happen immediately, and an awareness of the imminent start or end of a melody, of the importance of an accent. It also reflects an ability to remember: to remember something that has already been heard or experienced.

It is not the exactness, the simultaneous movement, as a chronology of events that is important; what is crucial is the *obvious decision* to move at this moment, in the sense of a distinction between chronos and kairos postulated by Aldridge (1997, 2001a, 2002) – that chronos is the time we measure, and kairos is the right moment for an appropriate and intentional action in response.

Repeatedly, we have situations in music therapy when a certain element of physical expression, such as respiratory movement, eyewink or another movement, is taken up in an improvisation by the therapist and we see an alteration in this original element. Although reference to the physical event is obvious, there must also be a perception that this is not recorded music but a live improvisation specifically for this situation; a situative orientation is required.

In addition, an awareness is necessary as to which body part or physical expression the music refers to. This also reveals the basic potential of a physical orientation. The patient in coma vigile must be able to perceive that the music directly relates to his breathing, his eyewink, or this movement he makes. This perception goes beyond the mere recognition of any physical element. This reaction implies not only the recognition of one element, but a recognition of *my* individual breathing, *my* individual eyewink, *my* individual movement. Re-action thus becomes a response to the other person. It reveals a recognition of the self, and therefore self-consciousness!

### *Distance and nearness*

My personal way of working with coma vigile patients as a music therapist is based on the Nordoff/Robbins approach. It presupposes an active participation of clients in joint musical improvisation. Persons in coma vigile are therefore included in the music and, just like the therapist, become part of this music. A distance in the sense of musical neutrality, music randomly available from previous recordings without any reference to the client, is therefore a contradiction to this therapy approach.

Involving patients in persistent vegetative state into joint activities may have a variety of qualities for distance and nearness. The sound produced by the therapist in improvisation is related directly to one physical element in the patient that is reflected in that sound. The sound becomes a signal; an offer for nearness, an offer of an intimate, personal encounter.

Despite this general offer, the music may imply different degrees of distance and nearness. The improvisation of a melody may be oriented to the client only in very general terms. The temporal distance from one event to the next (the distance from one eyewink to the next) would be filled with several notes of one beat or even with several beats. Improvisation may, however, also involve a very close physical reference, where each event itself (e.g. each eyewink) would correspond exactly to one musical event, one single note of the melody.

Although most music therapy sessions are characterized by physical distance and auditive means, where therapist and coma vigile patient do not touch each other, the translation of one body element in a 1:1 ratio to elements in the music may create a very intensive nearness. This intensity is not a consequence of the simultaneity of sound and movement but emerges through the experience of the situation. The emotional experience of this special nearness may convey an intimate character to the therapy session. Nearness in music therapy therefore does not depend on physical nearness, body contact or touch. Where physical nearness is used in exceptional cases, it is used more to provide technical support to movement and is not an expression or stimulus of this emerging nearness.

My study revealed that nearness did not depend on the choice of instrument nor music. In almost all significant examples, I was involved with my own voice and thereby immediately and personally. The sound of the voice is an intimate expression of personality. With the offer of nearness I offer myself through my voice – and not in my professional capacity – as a person with whom a client may enter into contact.

In music therapy with coma vigile patients, the terms ‘distance’ and ‘nearness’ describe not only a musical–technical method as part of an improvisation. Distance and nearness show themselves as qualitative elements. They add the relational aspect to the approach of a music therapy offer.

## Therapy and relationship

Perception is not an isolated capacity but leads to emotional experience and corresponding reactions in the sense that a situation takes shape. Listening to music means not only to perceive it, but also to experience it. Active music-making permits one to take an active part in this music and to give expression to one's own emotional experience.

Reaction is a response to action that has been perceived. Distance and nearness are qualitative elements of music therapy with coma vigile patients. If they perceive music and react to it in some way, then we may assume that they also experience the music emotionally for the above reasons. Such an emotional experience of music and nearness in improvisation creates a relationship between the coma vigile patient and his or her therapist. There are several requirements for such a relational situation that lead to further conclusions. Both may be described as follows.

A person in permanent vegetative state should be able to perceive and be aware of the physical reference of improvised music, and differentiate between a perception of his environment and himself. Only then would he be able to react with the corresponding body element. Such a reaction would express his willingness to open himself to the situation and turn towards his perceived environment. A reaction in a coma vigile patient would therefore imply that he recognizes that there is someone else who acts, that the music is actively produced by someone. This reaction to another person would illustrate the ability to differentiate between the self and the other and therefore to recognize the own self, an awareness of the self, a self-consciousness.

Healthy persons do not continuously reflect upon their self-awareness, although it is always there, and others have no way to assess it. Similarly, the depth of self-awareness in coma vigile patients in such situation cannot be described, but it exists without doubt.

The therapist must be willing to enter into a relationship with the coma vigile client. This means that his or her music cannot remain an isolated, technically skilful activity, and what he or she does in therapy cannot be reduced to professional activity alone. The focus must be directed to more than the client's pathology.

In addition, a therapist must see himself or herself as part of a social relationship, according to the definition of a relationship as a degree of connectedness or distance between individuals united by a social entity. The therapist must focus on the person, the personality of the coma vigile patient, and accept the patient as a partner with equal rights in this relationship. This implies that the therapist enters into the relationship not only as a professional but as an individual, with his or her own personality.

Both therapist and coma vigile patient must therefore be aware of their individual self in the therapy situation, as a necessary requirement for an encounter between the consciousness of the coma vigile patient and that of the therapist.

The parameters described here are confirmed in the single case studies of my thesis (Herkenrath 2004). They illustrate an encounter between the consciousness of coma vigile patients and that of their therapists. An encounter between two human beings depends on many factors and cannot be repeated in an identical fashion; despite various similarities and parallelisms, each encounter is a singular event and to be assessed as such. The sessions cannot be duplicated nor quantitatively evaluated. Each individual situation of an encounter is significant, and to be judged according to the described principles.

In general, it is problematic to examine each situation with a view to its significance. A therapy situation receives significance only from a comprehensive perspective. Basically, there is no situation without significance. With the idea in mind that normality should be an objective for the life for coma vigile patients, the everyday encounter with them without any exceptional events is already important for the emergence of a relationship.

## **Coma vigile: an art of living**

There are widely differing views on the situation and form of consciousness of persons in coma vigile. Assessments of this situation range from a state without consciousness and without perceptions to an interpretation as an active withdrawal from the outside world. Such differences are mainly due to the problem that it is difficult to recognize and interpret movements observable in coma vigile patients as reactions to the environment. The recognition of such movements is, however, essential for an assessment of a patient's state of consciousness. The dilemma for coma vigile patients is therefore that, if their form of life is an active withdrawal or reduction of previously performed activities, they must themselves demonstrate the existence of their consciousness, although their perceptive and communicative potentials are massively impaired.

Persons with serious neurological impairments lose their orientation with regard not only to their environment but also to their body and therefore to themselves (Sacks 1990; Zieger 1998). A frequently voiced opinion in this context is that these impairments may prevent such patients from an encounter with the environment and also with themselves, so that the impairment also prevents contacts that the outside world may want to establish with the patient. This might serve to isolate and exclude coma vigile patients.

In music therapy with coma vigile patients, we have situations where changes or movements may be observed and may even be identified as reactions and

therefore define orientation potentials. The occurrence of such reactions suggests that the described isolation and exclusion are broken down and a form of relationship has been established between the coma *vigile* patient and his or her surroundings. We must ask ourselves what makes this possible and which conclusions may be drawn for persons in coma *vigile*.

Respiration, eyewink or other movements are taken up in the musical improvisation and reflected as elements of physical expression. Reactions demonstrate that patients perceive and reflect this coupling with an auditive level, and thereby the physical element itself. We may conclude that persons in coma *vigile* are able to direct their attention to their own body, at least upon a corresponding stimulus.

All described elements of physical expression, including respiration, are movements. Movement comprises rhythm, requires time and space and receives structure through these elements. Music, too, is movement with a temporal structure. When movement is taken up and reflected in improvisation, the structures of music and movement melt into each other. Movement becomes music, and music becomes resounding movement. Reactions show that persons in vegetative state are able to recognize such temporal structures and the rhythm of their own movements and thus actively relate. Reaction in response to action is an essential part of any encounter. An individual reacts to a perceived offer in order to influence the offer and his or her own situation. Communication and dialogue result from a sequence of reactions and counter-reactions. Communication is not limited to one person but constitutes a relational phenomenon.

As a rule communication is understood as verbal communication. Persons in coma *vigile* have no way to express themselves verbally or through a yes/no code. In their non-verbal reaction to the therapist's action, who on his or her part shows a counter-reaction and thus produces a change in the reaction of the patient, persons in coma *vigile* are a link in the chain of action, reaction and counter-reaction and in this way become partners in a non-verbal communication.

In music therapy sessions, coma *vigile* patients frequently exhibit reactions in the form of changes in the intensity of respiration, eyewinks or movements. Intensity of physical expression not only has physiological causes but is also connected to emotions. Changes in intensity also lead to changes in the experienced emotions or are caused by them. Such patients are therefore able to have emotional perceptions in encounters with another person and are able to give expression to their emotion.

The above suggests that a person in persistent vegetative state is not only affected by a serious impairment of his perception and has lost his orientation towards the environment and himself, but also that he possesses the potential for a re-orientation in time, body and self, in space and situation. The results of this

study on the form of life of coma vigile patients may therefore be summarized as follows.

Despite his withdrawal and reduction to the physical self, a coma vigile patient also lives in a correlation with his environment that allows him to respond to offers in the sense of a re-action. Like any healthy individual, he is able to live this correlation and also to participate actively in this environment. The life form of coma vigile is his normality.

Consequently, coma vigile patients are living individuals with consciousness, with emotional perceptions despite massive physical impairment, and the ability to enter into social contact. As a physical, mental and social entity, they have individual needs and potentials like any other human being.

Persons in coma vigile are able to perceive and experience themselves as part of an encounter. The degree and way of entering into contact is something they decide according to their personal competence and individual potential.

Personal competence in a coma vigile patient means that he can either accept or refuse offers of contact. Developments or changes in his situation are not to be expected in a chronological sense (*chronos*) and do not occur as a consequence of the offer alone. They rather depend – in the sense of *kairos* – on a patient's decision to tolerate them.

The above considerations lead to the conclusion that coma vigile patients live in a process where they are in need of support in order to cope with their situation and to develop new perspectives, and where as living individuals they have a right to be protected. The specific life form of a coma vigile patient is his or her way of life and art of life at the same time.

## **The therapist: professionalism and humanity**

The encounter with coma vigile patients challenges a therapist's professionalism, but also his or her humanity. The therapeutic focus from the very beginning is on those elements that need to be treated; but in each encounter the therapist will first perceive a patient's physical appearance in its expression and recognizable impairments. Subsequent activities will inevitably be determined by the therapist's perceptions and pertinent emotions. On the basis of these combined perceptions and emotions the therapist enters into a relationship with the patient that has to be filled with life.

The way this relationship develops depends on the therapist's attitude. If he or she believes coma vigile patients are unable to perceive and therefore unable to react immediately to perceptions, activities will be directed to the patients' physical phenomena alone, denying a patient's existence as a person. This would prevent an encounter with the personality of the patient. But the basic precondi-

tion for encounter and relation is a mutual level of I and you. 'The other person encounters me. But I enter into the immediate relation with him. The relation therefore comprises being chosen and choosing, passivity and action' (Buber 1962, p.15).<sup>3</sup>

We see that a therapeutic relationship depends not only on the personality of the coma vigil patient but also on that of the therapist. A therapist's objective observations are connected with his or her personal experience of the situation. The therapist's subjectivity, his or her subjective experience, is therefore part of the therapeutic activity. Objectivity and subjectivity cannot exclude each other; but the acceptance of their existence and the willingness to admit them is a basic precondition for an encounter.

Among the most profound experiences in my work with coma vigil patients are situations where my personal attitude towards the patient prevented an encounter in music therapy. Only my willingness to open myself for a patient, to accept him despite his possible resistance against me, to offer him my nearness and not to see the responsibility for the situation on his side but to assume it myself – only this helps to create a background for encounters.

How to initiate a dialogue with coma vigil patients has been described in various ways in this chapter. Hannich and Ziegler repeatedly point out in their publications that this dialogue requires, apart from professional competence, also interpersonal contact on the basis of a sympathetic, emphatic and supportive attitude towards the patient (e.g. Hannich 1994, 1999; Hannich and Dierkes 1996; Zieger 1996, 1999, 2003). The obvious requirement of appropriate professional competence on the part of the therapist is expanded here by an essential aspect that goes beyond the concept of relational medicine – the need for a therapist's personal competence in the sense of an involvement of his or her personality in the encounter with the coma vigil patient. The situation is influenced by the therapist's attitude, and his or her attitude towards the patient has a decisive influence on success or failure of the intervention; but the essential aspect – apart from rational and professional action – is a willingness to enter into contact with the patient. In this encounter, the therapist must offer his or her own self – the therapist as a self that meets the patient in his or her personal being and with his or her individual identity.

This willingness to open oneself is more than a mere technicality and must be demanded not only from the therapist but also from everybody who is involved

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3 'Das Du begegnet mir. Aber ich trete in die unmittelbare Beziehung zu ihm. So ist die Beziehung Erwähltwerden und Erwählen, Passion und Aktion in einem.'

with patients. Everybody involved in such a relationship should become a partner who not only observes the patient and tries to recognize him or her, but who also permits himself or herself to be observed and recognized. 'But in the perfect relationship, my you comprises my self without being it; my impaired recognition melts in a boundless feeling of being recognized' (Buber 1962, p.101).<sup>4</sup>

## Human existence as a counterpoint to human brain

As mentioned before, medical specialists are not in a position to localize nor define human consciousness, despite the general opinion that brain functionality is essential for consciousness. Many brain researchers call the phenomenon of consciousness the last big secret.

The abilities of perception of self and the environment and an adequate reaction to these on the basis of existing orientation potentials are seen as part of consciousness. If the term 'adequate reaction' may be understood as a directed reaction to outside stimuli, then patients in coma vigile have consciousness because of their re-actions described above.

But are statements on orientation potentials, cortical processing of perceptions and adequate reactions enough for a comprehensive description of human existence? The spirit, the self, the ego of man is more than a mere neuronal activity, and human consciousness is so manifold that it cannot be reduced to the functionality of brain nerves.

Coma vigile is not caused by damage to one particular, isolated brain area; coma vigile patients may be affected by a variety of different impairments to the brain. But despite the different degrees of brain damage, each single one of them has an individual personality and lives his or her individual existence, as described before. This realization, however, implies the question of what human existence really is if it cannot be reduced to brain activity. First of all, we may assume that each human existence is individual, unique and not transferable to another human being. It may not be duplicated in the sense of cloning. This uniqueness of being and of human spirit is often called 'the soul' (Feinberg 2002). It is not material in any way known to us. It cannot be reduced to brain nor body and therefore cannot be explored scientifically. This may be the reason why after years of studies many brain researchers realize that they are unable to solve this last secret and have to admit: *Ignorabimus!*

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4 'Aber in der vollkommenen Beziehung umfasst mein Du mein Selbst, ohne es zu sein; mein eingeschränktes Erkennen geht in einem schrankenlosen Erkenntwerden auf.'

The personal experience of being an individual living in his own body does not help anybody to find out when and how he became who he is and started to live in his self, his soul. The soul, the conscious-ness of man, constitutes a counterpoint to the brain in the musical sense, as an independent existence of equal importance. It is there, like the brain, but cannot be localized. It may be experienced but not be proved with scientific means. *Ich bin Leben, inmitten von Leben, das Leben will* – I am life, surrounded by life that wants life.

## Medical and social implications

Medical knowledge on long-term phases of coma vigile turns out to be full of gaps, and many prognoses are wrong. Prior to a discussion on definition and terminology of coma vigile, the phenomenon itself urgently requires new scientific research. Such research must focus not only on the acute situation of patients or the first months after the event, but foremost on the long-term phase in order to close the tremendous gaps in knowledge.

A first objective would be to update knowledge on the illness and its progress, diagnosis and treatment in order to gain new scientific findings. The perspective must then be expanded beyond the acute stage and the first few months, and data must be collected on long-term development and the condition of coma vigile patients. The subject of this study is not the abstract illness of a patient but the entire human being himself or herself. This is why in such a research project the search for biomedical findings and concepts of relational medicine must not be mutually exclusive, but must complement each other. Only a combination of both allows us to collect comprehensive data on the illness and the patients affected, and in addition on consciousness as the core of human existence.

Accordingly, an evaluation must focus equally on the search for high efficiency in therapy and care, and on the quality of life for coma vigile patients. Such an evaluation must be free from the pressure of expectations from medicine and society on cost reduction in treatment and care, and also free from economic interests. We may assume that the ideas presented in this chapter will be confirmed by such scientific research. Medicine would thus provide new descriptions of coma vigile patients, and thereby encourage society to recognize these patients as living persons with a consciousness the depth of which is hard to evaluate.

Opinions on coma vigile patients are divided. There are open discussions on the value of life in such patients, their right to live and be taken care of by society. This study tried to demonstrate that coma vigile patients are people with serious brain damage, but also with a consciousness who in their specific form of life have the capacity to meet others or be met in an encounter, and who have the same basic rights as everybody else.

Our society must address the legal and ethical implications. Society is challenged to ensure the rights of coma vigilie patients to a protected life and physical integrity. The right to physical integrity implies the right to medical and nursing care. The aspects involved here are more ethical than legal in nature. Patients in coma vigilie are not in confrontation with society, but one of its parts. As a consequence of their impairments, they are among the weakest elements and in need of support. Any discrimination, any debate on the value of their lives as a cost–benefit calculation, or possible euthanasia, are in sharp contrast to the findings of this study, ethically unjustifiable and thoroughly reprehensible.

In my workplace we follow the concept that every form of life in its specific way is valuable (Konzept Haus Königsborn 2002, p.6) and this applies to coma vigilie patients as well.