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AN EXPLORATORY STUDY IN ALTERED CONSCIOUSNESS AND AUDITORY MEMORY IN CRITICALLY ILL PATIENTS

by

Marlene Spencer

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of Doctor of Philosophy

Educational Psychology

Edmonton, Alberta
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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled *An Exploratory Study in Altered Consciousness and Auditory Memory in Critically Ill Persons* submitted by Marlene Spencer in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

Dr. R. Sobsey

Dr. R. Short

Dr. T. Noseworthy

Dr. N. Nocente

Dr. L. Stewin

Dr. C. Pert

Light. . . Not looking at it. . . *Being* it. . . Ultimately and essentially there was only a luminous bliss, only a knowledgeless understanding, only union with unity in a limitless, undifferentiated awareness. This, self-evidently, was the mind's natural state.

Aldous Huxlely
(1962, *Island*, page 303, London: Flamingo)

ABSTRACT

Most critically ill patients exhibit amnesia for events as an expected consequence of medications or anesthesia. Even if they cannot explicitly recall events, they may respond to stimuli given when in an unconscious state. This study was the empirical portion of a larger exploratory study, loosely following the Glasser & Strauss (1962) method of grounded theory. In an effort to develop a credible reference indicating reliable, replicable responses, two questions were initially addressed: Do critically ill patients hear conversation when they are judged to have low levels of consciousness, and, if they do, do they understand the content of the messages? Biophysical measures displayed on monitors (blood oxygen levels, heart rate, and blood pressures) of five ICU patients, were recorded on time stamped videotape. The study employed a single-subject (ABAC[D]A) design, each patient acting as his or her own control. During several 35 minute recording sessions, the researcher approached the patient's bed and sat quietly in a chair for a five minute 'baseline' period. Two or three interventions were then implemented, with baseline periods between. The interventions consisted of: a) giving oral instructions for relaxation and healing

(using standard scripts adapted for the patients to specify name, condition and healing needs); b) instructions to do a mental problem solving task (e.g., "add 3 and 5; subtract 2 . . ."); and c) to engage in an active mental task without researcher verbalization beyond the beginning instructions, (e.g., "subtract from 100 by 3's until told to stop"). This procedure was repeated several days until the patient either regained better health or succumbed. Responses were portrayed by accentuation in variability of biophysical measures when the clinician was speaking to a patient, as opposed to baseline.. This was more pronounced with lower consciousness levels and tended to disappear as the patient improved. Further, some observations suggested that the patient appreciated the content of interventions with a difference in variability of response between interventions. The greatest response (deviation from baseline) occurred when a patient was asked to perform an active mental task without accompanying verbal input from the researcher. It is felt that this is a preliminary indication that the patient appreciated the nature of the verbal message itself.

DEDICATION

Dr. Bruce C. Bain
IN MEMORIUM

One unseasonably mild and sunny Saturday near the beginning of the last year of the millennium, Bruce felt spring first nudge winter. He proceeded to clear snow from the ice-dams building on the roof of his home so the snow-melt could nourish the ensuing summer garden below. His meticulous gardens were always fine and famous expressions of his creative urges. Alas, his unwitnessed descent from the roof was rapid, unexpectedly altering the lives of those whom he knew and ending his own.

This volume and all between student and teacher that predated it were part of the daily work of my instructor, confidant, antagonist, initial supervisor, mentor, fellow patient, and age peer. I met Dr. Bain as a student in one of his graduate classes. I had just been released from hospital, and attended class one evening a week after driving in three hours from Saskatchewan, dragging a canister of oxygen behind me. Bruce confided later that he had been frightened by my presence in his classroom, as I appeared pale and breathless and might momentarily expire. He hid his anxiety well, and after reading a short paper I had written, proposed that I consider using my illness experience and the questions it raised as the basis of my dissertation.

Dr. Bain wrote, "Your brief essay has the makings of an original thesis, and this is very exciting." He offered to support me in this quest. With such encouragement, I began a long journey on this academic path. It is my sincerest hope that the trek has been completed with some semblance of Dr. Bain's original vision.

ACKNOWLEDGMENTS

Dr. Richard Sobsey, the most compassionate of passionate scholars. Thank you for having given freely your advice, opinion, and support these past couple of decades. Thank you also for completing the dangerous work of Drs. Bain and Schmidt as my third supervisor in this doctoral endeavor.

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Dr. Bruce Bain, a scholar of Bilingualism, who could read, write, and speak fluent Existential Phenomenology. Thank you for listening to my 'authentic' voice, and teaching me to listen to it as well.

To the three heroic ICU Physicians:

Dr. Tom Noseworthy, who saved my life, then encouraged me to live it. Thank you for your steadfast support as a member of my supervisory committee this past decade. You have been a 'participant-observer' from the beginning, and have demonstrated that exploring boundaries can well serve the highest moral purpose.

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Dr. Richard Johnston, who, in addition, helped me to understand my ICU experience and the meaning of it.

Thank you each in a very special way-for humanizing the patient/ doctor relationship.

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Dr. George Fitzsimmons, as my professor, introduced me to biofeedback and relaxation techniques; then reminded me of them when they were needed to keep me alive. Thank you for 'being there'.

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Karen Weis Bridges, my daughter, and her husband, David, for giving me encouragement and grandparenthood. Thank you for the joys that are Spencer Albert and Evan Donald Bridges.

Andra Weis, my first-born child; a woman now. Thank you for the joy that was parenthood, and for the cherub, Tiffany Zoe Weis.

Helen Josephine Schiller, my mother. Thank you for being considerate and patient as I wrote, and wrote, rewrote, and wrote again, the words found here.

My research assistant, who can makeup my unmade mind, decipher my dysfluent thoughts, and speak for me with the fidelity of the Liberty Bell. You have my deepest affection and admiration.

PREFACE: WHAT HAPPENED?

> *This was a time of feeling great physical and intellectual liberation, and intense emotion. Love and sorrow were equally beautiful. Cognition and consciousness were united in awesome altruism, free of the constraints of time and location. I felt elation as a disinhibited spirit. I spent little time in my hospital body. Hovering between life and death was to float, effortlessly, in a dark expanse, becalmed in space that was warm and comforting, a space that was loving. I can't explain that loving feeling, but I was greatly drawn to it. This attraction is still with me. Thus, I look forward to my demise with affectionate anticipation.*

The passage above is a portion of a narrative taped by the author in 1991 describing aspects of an experience while critically ill in a hospital's Intensive Care Unit (ICU) during the preceding ten weeks. Far from being an inert and passive patient, when critically ill, one may exist in a creative and stimulating alternate state of being, albeit literally and tenaciously connected to *common (consensual)* reality. In this sense, *common* refers to a communal experience of reality. *Consensual* reality implies that we all agree on the general occurrence and characteristics of an event. These descriptors are used interchangeably in the literature. The terms *common or consensual reality* is used in this dissertation to distinguish 'real time' events from those experienced by persons whose consciousness is altered for whatever reason, and whose experience of reality and associated events is *idiosyncratic*,

experienced from the perspective of the individual, internal Self, and not necessarily validated by the experience of others.

The dying event, which we shall all experience, creates its own reality, a reality that is not normally a part of our everyday world; therefore, it is removed from common reality. Nevertheless, it demands that we admit the possibility that death can be a peak experience; one for which we might, with help of healthcare-givers, plan, prepare, enhance, even enjoy. We have to decide how we view death and the individual experience of it as a basis for making law regarding death with dignity; aided death, suicide, euthanasia, and refusal or provision of heroic medical treatment.

My personal view of death changed radically nine years ago. I became ill, and, as the illness swiftly overtook me, I knew I was dying. That remarkable experience lengthened into several weeks, while I existed in another dimension. Occasionally, some bits of information, some voices or fragments of conversation from this common/consensual reality called me back. Later, I learned that I understood much that happened around me. Consensual reality was used in the creation of an altered, idiosyncratic reality. This volume is the result of that peak experience, which left me with a great hunger for knowledge about what had happened, the nature of that other world, and indeed, the universe in which all realities reside.

This study documents one aspect of the exploratory work that followed the realization that there are few methodological traditions, and fewer theoretical constructs, to guide the academician in the study of dying experiences. The challenge of this study was the development of an empirical protocol to learn if

unresponsive patients might actually be aware of the hospital environment. Until now, the plethora of first person reports asserting that patients are aware were categorized by the scientifically minded as *anecdotal* reports. The proof needed to fulfill scientific rigor was the controlled collection of data. Control is needed to provide a benchmark for replication. A credible reference, indicating the possible presence of cognition in unconscious patients needed to be generated, but, first, some theoretical hypotheses needed to be generated, and a research method developed.

This inquiry became a true voyage of discovery. There was much more to the task than satisfying my own curiosity or cathartic needs. Great synchronous tides and currents of least resistance carried me along. This study is the result of the efforts of my medical heroes, the prayers of my formerly agnostic family, the encouragement of my academic mentors, and an almost universal curiosity about near-death phenomena. It was thus, that I found myself with the training and the mentors, the encouragement and enthusiasm, to begin to learn about that human life-experience, the approach of The Big Event, DEATH!

Edmonton, August, 2000

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CHAPTER 1: INTRODUCTION

Sorting Realities

We are unaware of a vast spectrum of probable or possible realities by nature of our corporeal limitation and our science. Does life continue after death? Perhaps our current definitions of life and of death preclude that. There may be separate realities in cosmic chaos, but we can not, by our definition of life, range the universe. Perhaps those who are dying, that is, between the states of living and not living, catch a glimpse of chaos, even of separate realities, which might abound in the creative vicinity of life.

For those readers who envision only one "objective" reality, other "subjective" or phenomenological views are alternate perceptions of the one 'constant' reality. Some readers may think of reality as being purely a construct of the mind, fed in part by sensory perceptions from an external world, interpreted internally, and incorporating any data to which the 'mindbody' has access and desires. An astrophysical view entertains the notion that there may be many 'objective' realities existing simultaneously in time in the universe, but inaccessible to us, as we are creatures of this part of the universe. This author requests the reader to suspend judgement as to preconceived notions of reality and be open to reformulation of ideas to accommodate an understanding of the patient's experience of near-death phenomena and of the dying process.

This study found evidence that the hospital experience is very different for the patient than for the healthcare provider. Communication with the 'real world' is largely through sound. There

is a tendency to give a literal interpretation to the things one hears, although there is evidence that more subtle nuances can be comprehended. Things heard either determine the content of fantasy or the affect associated with it. In the context of the extraordinary experience of critical illness, there is an ongoing need to reconstruct some form of reality in order to sustain the Self and maintain the life of the mind.

The question is not, "*How many* unconscious individuals hear and understand what is happening in consensual reality?" The question is, "Does *anyone*?" If no one does, we might postulate that unconsciousness is characterized by absence of awareness, arousal, or sentient activity in the patient. Yet, according to many first person reports, patients may be aware and even affected by the environment and events going on around them. Idiosyncratic reality can produce odd events, even weave bizarre phantasms around the illness experience. These usually occur without reference to time. The only way to examine the patient's experience of events is to observe and document events in common reality, then find traces of patient response or later report of features specific to the event. These concordances between consensual and idiosyncratic realities could prove to be extremely important demonstrations of the presence of an active inner-life of the patient during periods of observable physical non-participation. If correspondence between two different ways of being-in-the-world can be demonstrated, if one can exist in two realities simultaneously, events in common reality might affect that idiosyncratic reality experienced by the unconscious patient, either positively or negatively.

The Objective Body: Thematization, Schematization, and Body Image

The line of researchers flowing from the school of existential phenomonologists, particularly the students of Merleau-Ponty, write of 'being-in-the-world' by means of the individual's constructed *body schema.* Bain (1991/1992) discussed the thematization of experience as a process. Thematization creates identity by organizing experience, by symbolic form, into a schematic framework for knowledge of both external and internal reality. Bain cited Erikson (1964) as postulating that schematic self-knowledge is the basis of trust and autonomy. Illness robs the individual of autonomy and of trust of ones' self. Writing about the neurobiology of body schema, Cumming (1988) reminds us that each of us has a (perhaps) vague, but permanent, perception of one's own body. According to Wright:

> Psychoanalytic theory places a special importance on the physical self both in the differentiation of the person from other realities and in the continuing development of the ego . . . In the development of reality the conception of one's own body plays a very special role. At first, there is only the perception of tension, that is, of an "inside something." Later, with the awareness that an object exists to quiet this tension, we have an "outside something." One's own body is both at the same time (1960, p. 139).

The body schema is forever altered as body boundaries blur, as they do in critical illness and unconsciousness where the body becomes an object - sometimes experienced, sometimes not. Two

types of perception are utilized by humans: a)*participation* and b)*contemplation* (Bain, 1973). Participation requires interaction between the body of the individual and the world of objects and others. All of these notions presume a body functioning within normal limits. When the body is non-functional, only contemplative perception could operate. The ability to inspect, judge, and analyze may not be impaired. In fact, being released from executive control as the only operational mode of perception, there may be a disinhibition of contemplation resulting in the types of experiences reported in the near-death-experience. Bain further explains:

> . . . consciousness of the object is given to the perceiver not in terms of bits of isolated stimuli, but in terms of a body-schema . . . schematization establishes the polarization of the body and the experienced world. . . . the greater the gap between the poles of being, the greater the ability to look at oneself looking at something. *(e.g. distantiation)* (1973, p. 265)

In illness, the ability to *distantiate* may become disordered. Illness disturbs " . . . consciousness of the subjective and objective poles of being in relation to the phenomena of experience" (Bain, 1973, p.157). The subjective and objective poles were defined by Bain as 'body-as-subject' and 'body-as-object'. The OBE (Out-of-Body Experience) places the perspective of the individual to the extreme 'body-as-object' pole. How might this effect consciousness and the perception of reality? "Perhaps the chief difference between primitive and mature experience is in the relational structure of reality . . . the relation of subject and object . . ." (Church, 1961, p. 13).

Trauma

Both critical illness and admission to a hospital's Intensive Care Unit are traumatic events. As a situation becomes life threatening, the patient experiences the stress of ongoing trauma. The American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders*, the DSM IV (American Psychiatric Association, 1994, p. 424), describes pathological patterns of response to traumatic stress: Posttraumatic Stress Syndrome, [309.81], Acute Stress Disorder [308.3], Generalized Anxiety Disorder [300.02], etc.. Since most categories specify that the disturbance is not due to physiological conditions, Anxiety Disorder Due to a General Medical Condition [293.89] is included, as is Substance-Induced Anxiety Disorder. Finally, there is a catch-all category; Anxiety Disorder Not Otherwise Specified [300.00)] (American Psychiatric Association, 1994, pp. 429-444). Some reactions to stress (e.g., the near-death experience,) are adaptive, protecting the individual from intolerable stress. DSM IV does acknowledge that, "Dissociation should not be considered inherently pathological and often does not lead to significant distress, impairment, or help-seeking behavior" (p. 477). One assumes that the authors will eventually agree that this caveat applies to anxiety, stress, somatoform, and other types of responses as well.

ICU patients may exhibit all pathological and non-pathological characteristics of anxiety. In fact, they might well demonstrate any or all of the features characteristic of the somatoform disorders and the dissociative disorders as well. Most DSM IV categories are restrictive and multiple diagnoses are avoided by ranking of criteria by

differential diagnoses, duration of symptoms, severity, etc. Therefore, one would not be diagnosed as having every disorder described; the only appropriate disorder to use as a diagnostic label would be the most prominent or pathological disorder. Often diagnostic categories are limited by duration of symptoms or the presence of physical pathology. So, finding an appropriate DSM IV description of the experience or reactions to the experience of critical illness cannot be found. Alas, the psychological professions are forced to treat the patient's mental stress without an understanding of the experience that produces the stress.

It is this author's observation that virtually all ICU patients, rather than being 'distressed', are somewhat 'dissociated', existing in an outright or quasi-trance state. ICU workers have coined the parsimonious phrase, *ICU psychosis,* to describe common patient responses to ICU trauma (Fisher & Moxham, 1984). However, a psychosis is an abnormal response to normal stress; as critical illness and treatment in an ICU are not normal situations, *ICU psychosis* is a misnomer. It is suggested here that we must attempt to understand the nature and characteristics of the patient's ICU experience in order to understand the resultant response.

Memory

Terr, a researcher of childhood trauma, observed, "One terrible event in an otherwise non-terrible life stands out in a child's mind" (1994, p. 7). This truth is evident in adult experience as well. Who of us of sufficient age can forget what we were doing when we heard of the attack on Pearl Harbor, of the assassinations of

President Kennedy, Reverend King, or John Lennon, or the deaths of Elvis Presley, Glenn Gould or Jerry Garcia? Terr speaks of two types of trauma victims: Type I are those who have suffered a single traumatic event. They tend to recall events in great detail. Type II trauma victims are repeatedly traumatized. They tend to develop automatic repression. A 'ground' and a cue are needed for repressed memory to return (1994). "Anticipation encourages defensive memory loss . . . " (p. 40), but traumatic memories (or the opposite; extremely 'high' moments) do not deteriorate much at all. They stay more alive than other kinds of memories. "Clinical studies of traumatized adults [show] that the memory of a terrible episode, once buried and not discussed with anyone else, also tends to stay intact" (p.41). 'Not telling' apparently moves toward suppression of thought and eventually to repression.

> When people are extremely stressed, they do not necessarily see everything correctly . . .[People] may retain both the correct and incorrect perceptions in impressive detail. Their memory may be both "right" and "wrong" at the same time. Parts are correct, other parts incorrect (Terr, 1994, p. 27).

So, does trauma cause repression, or increased recall to the point of intrusive flashbacks and increased reliving of trauma through dreaming, as DSM-IV describes? Are patients avoiding reminders of their personal traumas, or is recall obstructed by repression, as Terr asserts? Perhaps, as many health-care workers report, amnesia is just a concomitant of *ICU psychosis.*

Time

The importance of understanding 'disorders' of time for the ICU patient can be grasped if we realize that primary existence in consensual reality ends and begins again as a function of the patient's sense of time.

> Time perception is another perception that frequently goes "off". . . A sense of time is a recent evolutionary acquisition, probably the most recent of all. Even though animals mate and migrate at certain times, their time sense relies on instinct, awareness of polarized light, day length, and so forth. In human beings, however, there is a well-developed linear sense of past and future-of sequencing, causality, and of time extending far beyond one's own existence. But this faculty, being new, is extraordinarily vulnerable. Alcohol or drugs damage it. Traumatic states damage it. The confusion increases even more after the trauma is over (Terr, 1994, p. 29).

Gorman and Wessman (1977, p. 218) discuss the difference between "human time" and "clock time." Does time have an external existence? The authors point out that for many years, scientists searched for an 'organ of time' in the brain. We now recognize that the inborn ebb and flow of biological processes, the biological clock, can be easily altered and therefore do not measure clock time.

> Perhaps, we might simply define time as 'what the clock measures'. But if we examine our fiat, we will see that our clock is no more the "essence" of time than rulers are the "essence" of space (p.220).

Patient time is 'mind time' or 'lived time'. It is an internal construct or *schema*, which, absent at birth, develops during childhood. "It arises from *my* relationship to things" (Merleau-Ponty, 1962, p. 48).

> Piaget [1966] views the [cognitive] development of temporal concepts as following a course similar to that found in the development of concepts of space, volume, and matter . . . the concepts of time are not *a priori* "givens" but are always derived by the child from relationships among more primitive concepts of effort, work, power, velocity, and distance (Gorman & Wessman, 1977, p. 232).

As with the body, time, for the adult, is a mental construct, a psychological schema upon which reality is constructed and maintained. While ill in the ICU, whether the patient is conscious or unconscious, he or she may be deprived of normal sensory input and the use of habitual schematization as the usual method of monitoring consensual reality. The patient may still attempt to build reality in which he or she may function and attempt to communicate with the external world. The patient lives in an idiosyncratic reality in which the body is objectified, memory decontextualized, and time disrupted by degraded or absent external relationships.

Organization of This Work

Chapter 1: The Introduction was organized to present issues in exploring this most elusive phenomenon of how the environment, consensual reality, and idiosyncratic reality operate under unusual circumstances. The nature of some of the pertinent psychological elements of conscious experience (body schema, trauma, memory, and time) are briefly discussed so that the author and reader may use a similar point of view of the praxis of life-threatening trauma while reading onward.

Chapter 2: Background. Justification for the study is extrapolated from the survey of related literature. The discussions begun in the first chapter are elaborated, and relevant research and methods are reviewed. Finally, the objectives and methods of this study are presented.

Chapter 3: The Study. This chapter describes the conditions and preparation for this study. Research questions, design, variables, equipment, and procedures are, according to tradition, included.

Five patients are introduced. Each participant uniquely contributed to this study and to the expanded awareness of related issues. The first patient was given the experimental protocol as a 'run-through' as part of the preparation of the protocol. He did not fit the criterion of being unconscious during the study, yet in retrospect, his amnesia for events in ICU rendered him "as good as" unconscious. From him we learned that the distinction would perhaps be more meaningful if not between 'consciousness/ unconsciousness' but between 'awareness/unawareness.' Another patient stands as an exemplar because the researcher was able to collect a relatively complete set of data, including follow-up interviews. Several participants succumbed to their illnesses, but one was able to provide much feedback regarding her experience and her concerns during recovery.

Chapter 4: Results. This section is composed of the biophysical information recorded at bedside as the researcher instructed the patient in relaxation, imagery, word and ideomotor

responses, and active mental tasks. Data is presented graphically for visual inspection, as is traditional in single subject designs.

Chapter 5: Discussion. This chapter provides possible theoretical explanations suggested by the study, relating the illness experience to logical physical possibilities based on current knowledge regarding audition, assessing 'goodness-of-fit' to existing anatomical structures, and the ontology of phylogenetic development. The discussion is extended to current notions regarding Chaos Theory and the Holomovement. Newer ideas encompassing the notion of a unified mind/body theory are explored. This author proposes that this study revealed some of the characteristics of the dying mind, and that a feasible explanation of these characteristics could be regarded as evidence of the dissolution of the construct of the Self.

Implications for future research are explored through comparison with another experiencer's verbal account, and her interpretation of the meanings of recalled events as she pieced together elements of concurrent consensual and idiosyncratic realities. These were supplemented with the objective record - ongoing hospital reporting by medical, nursing and laboratory reports. These reports provide excellent triangulation of single events, a goal highly valued in the methods and methodology of grounded theory generation.

CHAPTER 2: BACKGROUND

There have been many anecdotal reports of the influence of overheard conversation affecting post-surgical recovery and the prognosis of patients at other times when they are assumed to be comatose or adequately sedated to have no recall of ambient conversation (Rossi & Cheek, 1988). Most patients exhibit amnesia for events as an expected consequence of medications. Yet, both positive effects, such as improved recovery and reduced postoperative stay (Evans & Richardson, 1988) and negative effects, such as slow healing, unexplained disability, and depression (Rossi, 1986) have been observed as consequences of patient's hearing conversation or comments made within earshot. Rossi and Cheek (1988) speculated that, although patients could not consciously recall events, they may respond to suggestions given directly to an attentive subconscious mind.

Implicit Memory and the Encoding-Decoding Process

In the hospital's Intensive Care Unit (ICU) patients lie in the midst of a noisy milieu. They are usually sedated or have medically determined low levels of consciousness, and, even if awake and interactive, often report that they remember little or nothing of the ICU experience (Johnston, R., personal communication, April 26, 1994; Compton, 1991). Yet, the patients may, in fact, carry memories of the experience as a function of altered (or other) states of being (Bain, 1973; Kolb, 1987; Bonebaker, et al., 1996). Further, the functionalist psychologist, Jacoby, stated that there is a memory for

the past in the subjective experience of the present, even if feelings of familiarity are not retrieved. While discussing procedural and autobiographic memory as examples of implicit memory (In Neisser & Winograd, 1988, p. 170), he hypothesized that the result of encoding-retrieval interactions was to actually change stimuli, which in turn changed perception. Even the act of asking patients what they recall of a prior experience, changes that experience.

Effects of context

When in an altered state, things learned and things remembered may not easily generalize or transfer to another state (Ludwig, 1988; Spear & Riccio, 1994). This author eschews the use of the term *altered state of consciousness*, arguing later that consciousness may not be a state, nor a process, but a point of view - the point of view of the Self. Acceptable alternative phrases might be 'altered state of being', 'altered state of Self', 'altered reality', or even 'altered state of reality'.

State dependent memory is seen under a variety of circumstances. Spear and Riccio (1994), in their *Memory: Phenomena and principles*, devoted much space to outlining the variables and research on the effects of context in state dependent retention and learning in animals and humans. They discussed drug induced, as well as endogenous and exogenous states such as mood, circadian rhythms, hormonal changes, temperature, light and other conditions, and the circumstances in which they occur. These are examples in which learning may be dissociated from memory when the contextual cues for retention are missing in the recall

environment, or the cues outweigh the original reinforcers. Their view was that retention is proportional to the similarity of the learning and testing contexts. The most frequently cited example is that of an alcoholic, who, when sober, forgets where he or she hid a bottle and must return to a state of inebriation to retrieve the bottle (Ludwig, 1988; Overton, 1972). More recently, we read of the adult who has no memory of prolonged, traumatic, early physical abuse until regression under hypnosis (Spiegel, Hunt, & Dondershine, 1988), or the war veteran who has no memory of traumatic events until he suffers an incapacitating flashback (Blank, 1985).

The belief that 'that which one cannot recall cannot hurt one' is wrong. That is the logic of the child abuser, who believes that his or her egocentric behavior hurts no one, as a child will have no memory of abuse. As we have learned, amnesia does not protect one from the effects of trauma (Pert, 1997; Putnam, 1989; Ross, 1989).

The special case of critical illness

Critical illness is a threat to life. Treatment of critical illness is often brutal, albeit for noble purpose. Critical illness is psychologically as well as physically traumatic. Trauma can destroy the individual's trust in life (Erikson, 1968; Maslow, 1968). Upon survival and recovery, the focus of impending death recedes and one falls into old ways of living, yet trust in life is not necessarily restored. The result may be an inability to establish an orientation toward the future. There may be a disinclination to set goals; a reluctance to 'promise' or 'commit' . Moreover, this mistrust of life may extend to family members and caregivers, those healthy

individuals whose lives become entwined in the drama of the ICU. When in an altered state the individual is particularly vulnerable to suggestion, which may be acted upon by psyche or body, then or later (Hilgard & Hilgard, 1965). Suggestion can be inadvertent, a byproduct of the environment; it can possibly be controlled, as in hypnotherapy, or even used to enhance healing. The study undertaken is especially motivated by concerns about inadvertent suggestions arising in the ICU environment.

Patient Response to Auditory Stimuli

Pertinent studies relating to patient response to auditory stimuli while under anesthesia include the work of Bennett, Davis and Giannini (1985). They devised an empirical protocol for investigating the memories of surgical patients who were under general anesthesia. They observed that studies had used electrophysiological recordings (auditory evoked response, or AER) to investigate the phenomenon and found evidence of cortical arousal when patients were exposed to messages that were important to them. Their subjects had impenetrable amnesia for content when interviewed postoperatively. Although they did not recall the messages, they did indeed touch their ears when given verbal cues, as suggested during anesthesia, indicating that the messages were received, processed, and retained at some level. The failure to remember was a failure to retrieve the information, not a failure to encode into memory. Of the 33 patients, 11 were randomly assigned to the suggestion group in a double blind design. The results supported the hypothesis of a dissociative reaction to

the suggestive messages. The authors cautioned later investigators not to consider the depression of ability to recall as a negative indicator of learning or failure to lay down a memory trace.

Schwender, Klasing, Faber-Züllig, Pöppel, and Peter (1991) used the example of the ability of surgical patients to postoperatively recall auditory information given when they were under anesthesia to explain the distinction between 'explicit' and 'implicit memory'. "Explicit memory is characterized by an active and conscious recall of space- and time-related events; i.e., episodes in a person's life" (p. 583). They found that explicit memory is regularly eliminated during anesthesia. Implicit memory, however, may often be preserved. "Implicit memory recalls passively and unconsciously without being related to space and time, i.e., language and general knowledge." They estimated that between 20% and 30% of their patients demonstrated, under subsequent hypnosis, that implicit memory was retained.

More recently, Ghoneim, et al. (2000) used AER measurements on 180 surgical patients during anesthesia to compare four anesthetics with explicit and implicit memory after anesthesia and the relationships of the memories to the AER data. Six participants were found to have explicit recall of a story heard intraoperatively. All had received an opioid bolus regimen. Significant associations were reported between AER, priming (a second association test), and awareness. When AER amplitudes were greater there was greater recall. Shorter AER latencies were associated with successful priming. The authors concluded that recording AER during

anesthesia may help to predict awareness and, to a lesser degree, implicit memory.

Effects of specific medication on patient recall

Since different anesthetics are used in various operations, it is unfortunate that no indication was given by Schwender, et al. (1991) as to which anesthetics suppress auditory perception the most or least. This question was addressed by Bethune, Ghosh, Gray, Kerr, Walker, Doolan, Harwood, and Sharples (1992), who also distinguished between explicit and implicit memory in their work on learning. Particularly relevant for our purposes is the fact that this was the only study found which used ICU patients in a study of recall. Bethune, et al. produced postoperative behavioral responses in surgical patients, ten of whom were anaesthetized by methohexitone, and ten by propofol. The twenty postoperative patients were exposed to the taped messages after being returned to the ICU. The propofol group demonstrated significant implicit memory recall. Neither group had explicit recall of hearing the tapes. No patient of either pharmacological group recalled events regarding the tapes. The authors concluded that the anesthetic method and depth of unconsciousness do, in their study, affect learning, and the specific agent is an important factor.

Another study investigated *low* doses of propofol on memory. This study used EEG recordings to monitor the reactions of *healthy* subjects (Veselis, Reinsel, Wronski, et al., 1992). Nine of the ten subjects who were measured, experienced memory impairment for auditory learning tasks, as well as tasks in other modalities. They

concluded that propofol produced significant memory impairment which had characteristics of true amnesia. The term 'true amnesia' was undefined by the authors. It has become an important issue in view of the holistic notion that no true amnesia ever exists because memory is stored in every cell (Pert, 1997). Memory is generalized rather than focalized. One may loose the ability to recall, but the mindbody has no way of ever erasing a memory once formed. This was independent of the drug's sedative effects. All subjects were able to operate in a manner requiring implicit memory: only the ability to recall stimuli was impaired.

Many researchers are reporting on "unconsciousness" and the effects of various anesthetic chemicals to induce amnesia (e.g., Reinsel, 2000; Alkire & Haier, 2000; Veselis, et al., 1997). Reinsel and her colleagues (Veselis, Reinsel, Feshchenko, & Wronski, 1997) have been earnest in their efforts to separate sedation from amnesia. Since dependent measures of memory are often used as measures of amnesia, they have been careful to attend to the problem of whether these drugs affect memory directly or whether the observed amnesic effects may reflect impairments in attention, arousal, or mood.

As to actions of specific pharmaceuticals, Veselis, et al. (1997), using EEG, found that propofol and midazolam provided similar, mild memory impairment, thiopental had mild memory effects and fentanyl had none. Propofol and midazolam, known to have amnesic effects, are active at the same receptor sites. Thiopental binds at the same receptor site, but has sedative and amnesic properties. Fentanyl, an opioid, does not have effects at

the receptor sites of the others, so it was used as a sedation level control. They developed a viable and useful method of separating effects of amnesia from sedation.

In anesthesiology, amnesia sometimes means the failure to experience; sometimes it means the failure to recall. Some clarification maybe forthcoming from the same research team, Veselis, et al. of Memorial Sloan-Kettering Cancer Center in New York. They proceeded to use several functional imaging techniques to look at the different neuroanatomical substrates activated by similar stimuli to different drugs. The benzodiazepine family (midazolam) and alkylphenol class (propofol) produced profound amnesia at low concentrations, while barbiturates (thiopental) and opioids (fentanyl) did not. Their results indicated that the left prefrontal cortex demonstrated a selective decrease in neural activity by certain sedative agents, resulting in reversible drug-induced amnesia.

Methods of retrieving unconscious memory

Most of the studies herein reported, except the Sloan-Kettering group, have used some form of hypnosis to retrieve implicit memory. Norse, Yakovleff, and Nenna (1989) used hypnosis to suggest to surgical patients that they be aware of "corporeal sensations during the operation in order to relate them" (p. 163). The brains of these patients were shown to be alert for auditory messages under anesthesia, and, very active! Again, the authors suggest that the subjects were in a dissociated state.

Electrophysiological methods (measuring brain waves) have been used to assess 'vigilance' after benzodiazepine sedation (Engelhardt, Freiss, Hartung, Sold, & Dierks, 1992), and nitrous oxide and isoflurane (Thornton, et al.,1992). Recorded as well were 'cognitive functions' after desflurane or isoflurane and nitrous oxide (Tsai, Lee, Kwan, & Chen, 1992), and 'awareness' with isoflurane (Newton, et al,.). We are to assume that 'awareness', 'vigilance', and 'cognitive functions' all refer to the same brain wave activity measured after administration of the target drugs.

It is clear that anesthetists are keen to discover if the patient is aware during anesthesia in the operating room. Apart from studies using healthy subjects to observe effects of particular chemicals, only Bethune, et al, (1992), followed patients from the OR to ICU. However, the emphasis in that study was on the patient's experience in the OR. It was not designed with the ICU environment in mind, and the usual "no recall" result was obtained.

Objectives

Nursing and medical staff members ask for direction in improving communications with patients. Families request information regarding patients' awareness and experience. For contact with the world, patients are often forced to rely on hearing as it is their only operational sensory modality. By investigating the experience of ICU survivors, perhaps not only the quality of the lives of the survivors can be improved, but the quality of the deaths of the others can also be improved.

> . . . clinical studies of people who have undergone traumatic events are the best way we currently have to understand how . . . events are perceived, stored, and recollected. One can plant 'wrong things' into each phase of memory-perception, storage, and retrieval (Terr, 1994, p. 51).

Ultimately, a major objective of this study was the generation of suggestions for improving patient well being and recovery through improvements in the ICU environment. If some patients can demonstrate recall of verbal information, caregivers will be reminded that each patient, in illness, may be experiencing a profound life-event.

The present study was proposed to extend the work reported with the memories of surgical patients to the ICU population. Differences in medications, patho-physiology, length of period of clouded awareness, therapies, and expectations for outcome are a few prominent variables. But as ICU patients are totally dependent upon caregivers for a longer period, the need to understand possible mechanisms of communication and mentation is also greater. The best way to identify areas for improvement in patient care in an already medically, technically excellent unit, such as the ICU, is to begin to understand the patient's experience of his or her illness and treatment. This can only be achieved by beginning to learn of the patient's mental life while in critical care facilities.

The basis of the author's original interest in patients' experience of illness in the ICU was personal. Audition was the only sensory modality operational during most of the 53 days in the ICU. The realization that many patients are in similar circumstances and

may have experiences as bizarre as were those of this author, led to the pursuit of understanding the circumstances more fully. Two major research questions were initially formed:

- *Do critically ill patients hear conversation during periods when they are judged to have low levels of consciousness?*
- *If so, can the patient demonstrate differences in content of things heard with differences in immediate response or later recall?*

After asking these questions, it was necessary to ask what evidence would constitute proof. Since those learned persons who were consulted responded differently depending upon the research preference of each, an effort to find convincing evidence for all was attempted. The result was an accumulation of methods. The data from each, when focused upon a single question, are said by phenomenologist to 'triangulate'. In this case, triangulation included the results of both empiric and qualitative data. The focus of this work is on the empiric portion of the data.

Question 1 seemed straightforward. Can certain ICU patients learn and recall specific auditory information during their ICU stay? A live voice message was given to each participating patient on a daily basis. The message encouraged relaxation and positive imagery, which has been found to promote patient well being (Rossi & Cheek, 1988). Suggestions were made to recall certain parts of the tape later in the recovery period. Reference to the suggested images, or parts of the images, were noted if recalled later in the recovery period during documented interviews. The live-voice messages were recorded for later verification of content. The justification for using live versus

recorded voice messages was that some clinical judgment might be required as to pace, loudness, and personalization of the messages in response to the patient's level of arousal, medication levels, ambient noise levels and other idiosyncratic variables present at the time of delivery.

During the period of interaction with participating patients and families the questions became more esoteric:

- *What might one hear in an Adult Intensive Care Unit?*

Question 3 is seemingly easily answered by recording ambient sound in the vicinity of the patient. As a pilot study, those sounds were to be recorded automatically during pre-set periods over a sufficient span of time so that a representative sample could be evaluated for intensity, content, and intelligibility. The purpose of gathering a random sample of activity was to adjust sensitivity of instrumentation, judge feasibility of transcribing unstructured samples of recorded activity around the patient, and discover unanticipated problems or elements which might arise during a more controlled phase of the study. Later, the patient's memory of various incidents could be compared with the record.

All academics, advisors, consultants and ethicists who read the proposal approved. However, when the nursing staff were provided with information regarding the study, they were hesitant to participate. They were advised that only the patients or workplaces of nurses who volunteered would be recorded, and that individual informed consent would be sought. To that, a petition of protest was circulated by the nurses. That element of the study was immediately

deemed unessential and dropped. No recordings of ambient sound were recorded.

In discussion with the director of the unit, it was advised that the staff often participated in research as part of the job, and that they were unused to being asked for consent. Subsequently, this researcher notified each patient's nurse of the time and length of the next "visit." With the consent of the families, the study proceeded with audio and videotape recordings made of each contact between the researcher and the patient. Although the intention was to only capture a record of researcher intervention and patient reaction, excellent samples of ambient sound were recorded with no staff objections.

Knowledge can come from empathy so that we can understand another's lived-experience without having it ourselves (which is extremely important because we want to understand the alcoholic's experience without drinking to excess, the suicidal person's torment without being suicidal, etc.) The task was to find appropriate research methods; to produce evidence that could withstand, if not skeptical, at least rigorous scientific scrutiny.

Methods

This study explored the ICU auditory environment and the patient's experience of it using *biophysical monitoring* in addition to direct and participant observation. Regular changes in the unresponsive patient's heart rate in beats per minute, blood pressure in mmHg, and per cent of blood oxygen saturation were

monitored by videotape recording while the investigator was providing stimuli. This had the advantage of providing documentation of the exact auditory environment under which the stimuli were given and time-locking the patient's response to the message, or lack thereof.

Of particular interest were the interactions with or about the patient during rounds, contact with physicians, certain nursing routines, and family visitation. Care was taken to protect the identity of all recorded participants. Since a great deal of the activity surrounding each patient was recorded, documentation of specific events, if they were *both* recorded *and* remembered, would be fortuitous. Even one corroborated memory may give information, when analyzed, regarding the manner in which language is perceived. One corroborated memory could elucidate the manner in which the ill restructure reality, how medications might affect perception, memory, and recall, or any of the myriad of questions that lie in wait in the researcher's book of provocative questions regarding the nature of the ICU auditory environment.

> If the artist does not perfect a new vision in his process of doing, he acts mechanically and repeats some old model fixed like a blue print in his mind (Dewey, 1935, p. 50).

Fundamental considerations regarding methodology

The author conscientiously attempted operate in as objective a manner as required to collect accurate data. Empathy was not withheld from patients, nor their families, as would be expected in a strictly controlled study. I was a dutiful participant observer; but

one that would have, if I could, influenced the outcome that befell many of the patient participants. As one can never prove the null hypothesis (i.e., patients can *not* understand the information presented), it became clear that the task was not to confirm nor refute the initial research questions, but attempt to understand the dynamics of the patients' experience. This could be done by generating some hypotheses concerning the common and unique experiences when patients are nearing the end of life. Having begun to understand the differences from traditional research required by the circumstances of the study, phenomenological methodologies also were examined.

Grounded Theory

Grounded Theory is a philosophy about how to conduct field research. It is committed to the existentialist idea that human experience cannot be effectively studied 'out-of-context'. "Grounded theory, unlike phenomenology, assumes the existence of a process" (Field & Morse, 1985, p. 23). It assumes that common processes underlie experience. It involves both inductive and deductive approaches to theory construction and is most often used in areas where the knowledge base is so sparse that propositions and hypotheses must be based on observation and interview data.

Sociologists Glaser and Strauss (1967) are credited with the popularization of the method of analyzing qualitative data called *Grounded Theory.* The Grounded Theory researcher does not begin with a highly focused research problem; the problem itself emerges from the data. Data collection and analysis occur simultaneously. In

this way, the questions that arise can be answered and hypotheses tested during the study. Theorization is not the result of pre-conceived hypotheses, but is "discovered" by being grounded in the data. The essence of grounded theory is constant comparison - comparing all pieces of data with other pieces in an effort to identify *core categories.*

> The core variable is the process that (a) is central and is related to as many other categories as possible, (b) continuously occurs in the data, and (c) accounts for most of the variation (Glaser, 1978). (Morse & Johnson, 1991, p. 5)

Often data is narrative, or text. Many researchers look for core variables in linguistic analysis. To limit the analyses of phenomena related in this thesis by linguistic features would be to ignore the eidetic nature of many experiences, and the almost universal preface of patients about to relate information, "There are no words to describe the experience . . . ".

From the beginning of this project the writer was aware of Glaser and Strauss as 'qualitative' gurus. She was not aware, however, of the nature of the research, nor how similar the circumstances of their investigations were to the one being discussed here.

The original work of Glaser and Strauss was not based so much on text analysis, as upon their own field research as observers in hospital settings. Each had experienced the death of a family member. This led to an interest in answering some questions generated by the dying experience. In an effort to understand how hospitals and caregivers operated and the dynamics of various interactions, these experienced research sociologists developed the

methods they needed. They supplemented their observations (which they recorded in journal notes) with both structured and unstructured interviews, asking questions, listening to conversations, etc. They stressed that the purpose of grounded theory is to *generate*, not *test*, theory. Quantitative methods test and measure hypotheses, which may or may not be guided by theory. Glaser and Strauss accuse many universities of no longer fostering the researcher whose focus is the generation of substantive or formal theory. The rush to measure things with the precision now technologically possible has resulted in a serious shortage of theory to guide research.

CHAPTER 3: THE STUDY

There is a great need for caregivers to understand the patient's experience of being critically ill, and of being unable to appreciate or respond to the world of consensual reality. Periods of reduced consciousness can be a result of illness or treatment. Low levels of consciousness are often assessed medically by the individual's inability to perceive or respond to physical sensation in a somewhat "normal" manner (i.e., The Glasgow Coma Scale, Bastos, Sun, Wagner, Wu, & Knaus, 1993). Failure to visibly respond to various stimuli (e.g. light, pressure, or pain) is interpreted to mean that the patient is beyond conscious experience, is in a vegetative or 'sleep' state, or in some way, unable to form memory of the occasion. Further, many people, with whom an unresponsive patient has contact, believe that failure to recall events protects the individual from the psychological harm that might be produced by the trauma of the illness or its treatment.

Patients are often forced by their circumstances to rely on hearing as their only operational sensory modality for contact with the world. Vision is easily disrupted by illness, medications, the use of paralyzing agents, anoxia, or by any decrements in cortical functioning. Audition, however, is one of the most resilient senses as it is an ancient sensorium, fully functional at subcortical levels.

An Intensive Care Unit (ICU) patient lives in a noisy environment. The effect of conversations overheard by patients during surgery or other times when comatose or sedated may have beneficial (Evans & Richardson, 1988) or adverse effects on

recovery or feelings of well-being (Rossi, 1986). Although the patient often cannot consciously recall events, he or she may respond to suggestion given directly to an attentive subconscious mind (Rossi & Cheek, 1988). In an altered state caused by critical illness, the patient may be particularly vulnerable to suggestion, which is often an inadvertent by-product of the environment. Turned to therapeutic benefit, a controlled auditory environment could help improved patient outcome. In 1996, White investigated the hospitalized patient's perception of overheard staff laughter and found that each of her twelve participants remembered overheard staff laughter as a significant event. Moreover, she concluded, staff behaviors were *never* neutral events in the patient's perception!

The present study was mounted in an effort to give empirical credibility to, or discredit, the rising number of anecdotal experiential accounts by formerly ill, comatose, or anesthetized patients (e.g. those reported by Rossi & Cheek, 1988; Ring, 1980; Moody, 1975; etc.) Many of these patients report accurate accounts of the experience of consensual reality, or accounts of unique experiences during a time of 'absence' from consensual reality while ill.

Earlier researchers (e.g., Bennett, Davis & Giannini, 1985; Bethune, et al., 1992; Schwender, Klasing, Faber-Züllig, Pöppel & Peter, 1991) were interested in determining if sedated or comatose patients could demonstrate implicit learning or memory of things that happened during their period of unresponsiveness. This researcher first attempted to replicate the retrieval of suggested behaviors (without hypnosis) with little success; yet anecdotal

evidence of implicit learning *did* emerge (e.g. recalling researcher's name after denying having ever met her, or identifying words which were not given as stimuli during the patient's period of unconsciousness. See page 46).

Research Questions

Some patients cannot recall events from the period of their unresponsiveness. Do failures of recall indicate a more generalized inability to form memory or have conscious experience? "There is some evidence that changes in arousal may modulate retention, although the relationship between arousal and remembering is not straightforward" (Spear & Riccio, 1994, p. 42).

If one fails to respond to or recall events, can the presence of consciousness be demonstrated in other ways?

The two major research questions remained to be addressed:

1.) *Can a critically ill patient hear conversation when he or she is medically judged to have low levels of consciousness?*

2.) *If a patient can hear conversation while he or she is unconscious, can differences in content between messages be distinguished?*

Research Design

Due to its exploratory nature, the study's design evolved, adapting to questions as they arose, in the manner expected when the generation of data-grounded theory is the ultimate objective. The exploration began with narrative material, carried further with field observation in the hospital setting, with patient, family, and

care-giver interviews, and with attempts to apply traditional qualitative analyses. As we explored 'ways of knowing', the inclusion of the empirical measure that underlies this report was developed. Although most scientists abhor the melding of methods and any *ad hoc* application of them to collected data, one suspends preferences and the *status quo* when exploring "uncharted waters". Similar results from multiple methods strengthen the validity of hypotheses generated when using grounded theory.

The circumstances of the research environment required that a single-subject design, wherein each participant acted as his or her own control, be used. We could not control for many participant variables; such as mortality in both the literal and research sense, illness, treatment, or personal history variables, and more. In addition, groups could not be formed. The number of subjects would be quite small over the six month period allotted to the study. This problem did allow each participant to receive a slightly different protocol, with each intervention protocol tailored to each participant. A repeated measures, within-subject-comparison-withdrawal design was expected to answer the question, *Can a critically ill patient hear conversation when he or she is medically judged to have low levels of consciousness?*

The intent of the study was to describe the unconscious patient's ongoing responses to stimuli, as well as discriminate between different types of interventions. To answer the second question, several experienced researchers from various disciplines were queried as to what evidence they would accept as proof that a patient actually understood that someone was speaking to him or

her, and not reacting simply to the presence of another human being. What evidence would be accepted as indicating that a patient understood the content of an intervention; the 'gist' of the messages? If a patient could produce replicable differences in response on any valid dependent variable to interventions containing different semantic content, one might assert that the participant 'understood' the message. In practice, it was found that, although the patient did respond to conditions differentially, merely presenting an additional intervention would not distinguish between 'understanding' semantic content (meaning) from the prosody of language (non-verbal or 'musical' elements). Nor were other variables associated with what might be regarded as a primitive (subcortical or brainstem) and general response to a human voice distinguishable.

Later, a 'D' intervention was added in which the patient was requested (at the end of Phase C) to perform an active mental task while the clinician sat quietly at the bedside as during baseline conditions. The intervention proceeded without the stimulation of a human voice. In general, Condition D evoked the greatest response from subjects who received that phase.

An $A_1BA_2C[D]A_3$ protocol was generated. A_1=Baseline (no intervention) condition; B=Intervention condition; A_2=Second Baseline condition; A_3=Third Baseline. Condition C instructed the patient to execute an active mental task, then instructed the patient to perform a task while the voice stimulus was absent. During Phase D, the researcher sat quietly at bedside, as she had for the baseline intervals. Because of the flexibility of the experimental design, we were free to balance the order of presentation and to introduce

additional conditions as the need arose. Clear returns to baselines would strengthen the conclusion that observed changes resulted from interventions.

Independent Variables

Baseline; conditions A_1,A_2, and A_3: All variables were held as constant as possible. The clinician sat quietly in a chair beside the patient's bed during all baselines. Ambient room noise was uncontrolled; however, usually no nursing procedures were administered during sessions. The nurse would quietly check monitors, and with a few exceptions, quietly observe or withdraw.

Intervention B: Using live voice conversation without amplification, alteration, or artificial intonation, the clinician read prepared relaxation or imagery scripts following introductions.

Intervention C: Using live voice, the clinician instructed the patient to perform mentally active tasks, with suggestion to later recall words from one of two comparable lists of word pairs and to respond later with certain motor movements when cued. Instructions were also given to compute "in your mind" a simple problem in arithmetic (see Appendix B for sample protocols).

Equipment

Each session with each participant was recorded using a Panasonic home video tape recorder. Mounted on a tripod, the tape recorder was positioned to record the displays visible on monitors already in use. These monitors reflected the patient's ongoing

physiological activity: blood oxygen saturation level, heart rate, and blood pressure.

Oximetry

A Nelcor pulse oximeter (Malinckrodt Canada, Inc.) was in use to measure the patient's blood oxygen saturation levels. This instrument contains two components: a signal averager and the optical unit (the monitor) producing an ongoing display of the average of five to seven prior pulse beats. Accuracy of actual saturation levels is given in the technical manual as 70 - 100% (±2digits). Latency of response is thought to be negligible, and in the order of a few milliseconds (J. Alberta, respiratory therapist, personal communication, October 10, 2000).

Cardiac function

The display of a Fukuda Denshi cardiac monitor provided on-going display of changes in systolic and diastolic blood-pressure in mml/hg and real-time pulse rate, among other readings (e.g., pulmonary capillary wedge pressure, pulse pressure, etc.) selected for individual patients by staff.

Videotape recording

In addition to the visual recording, the tape was time-stamped so that, upon replay, it could be paused at one-minute intervals to hand-record the values displayed on the monitors. An additional advantage of using video tape recordings was that the audio pickup was time-stamped and correlated with the physiological responses

displayed on the monitors. It was very easy to verify the synchronicity of the voice stimuli, the content of the stimuli and the patient's response, if there were one. One could also view and judge *ex post facto* the effects of ambient noise, interruptions, etc..

Following recorded sessions, the videotape was re-recorded from 8mm video tape onto a VHS videocassette tape. It was then viewed on a home tape player and television set. Tape was stopped at one-minute intervals, according to the time counter on the VCR, and data recorded by hand from the screen to a tally sheet (see page 48). The data for one participant was recorded at each 30-second interval to see if there were significant advantages or disadvantages to recording shorter or longer intervals. One-minute intervals were thought to provide sufficient data for statistical analysis of results; a procedure that was contemplated at the time and later rejected as unhelpful in understanding the data.

The values on the tally-sheets were entered into a computer file using Microsoft Excel software. Charts and graphs were created using the Excel software on either a Macintosh PowerBook G3 or a 6300 computer.

Dependent Variables

The numbers that were read from the videotape at one minute (or 30-second) intervals formed the data measuring the patient's blood oxygen level, heart rate per minute, and blood pressure; the available dependent variables. Each trial or session lasted about 25 minutes, with about five minutes for each of the ABACA phases.

The nature of running speech makes it difficult to end a verbal intervention at an exact time. On several occasions, the length of phases would extend to the next minute or shorten to finish in the previous minute. It was easy to extend baseline phases a minute or two to be sure that they were long enough. The possibility of a significant latency of response induced the clinician to lengthen baselines before and after sessions. Therefore, the data points were not always paired across phases, and any statistical treatment that required truncating phases would have the tendency to obscure latency trends.

Subjects

Medical regimens in the intensive care unit varied considerably among subjects. Presence of neurotoxins, medications, changing levels of consciousness, and many similar factors were uncontrolled. Due to the infinite number of possible confounding variables, control was a major problem. In an effort to 'cast the net' wide enough, but not too wide, exclusionary criteria were established.

Inclusion criteria

Consent to participate in the study was sought from families of patient's who were:

- At or past the age of consent: 18 years old. Patients would be included if, after recovery, they extended that consent to participate themselves by signing a new release form (Appendix B).

- Unconscious or unresponsive to stimulation to a maximum level of 9 on the Glasgow Coma Scale (GSC) upon entry into the study.
- English speaking. Fluency in English would be a pre-requisite for successful completion of the auditory recall task. All stimuli were given in English.

Exclusion criteria

Patients in the following categories were excluded from this study:

- ICU admission shorter than 72 hours. This excluded those who were admitted only for dialysis, who were immediately terminal, whose medical condition had not yet been stabilized, or whose family had not yet been contacted.
- Documented premorbid disorders of mentation. This excluded those with diminished mental capacity due to developmental disorders, advanced degenerative diseases, stroke, or other processes that would interfere greatly with orientation, memory, following directions, or receptive/expressive language disorders.
- Head injuries preventing participation. Those who are so severely injured that participation would interfere with stabilization of body parts, equipment or treatment in any way were not asked to participate, nor were patients whose admitting diagnosis indicated brain injury or dysfunction.
- Mental health disorders as admitting diagnosis. Patients who had attempted suicide, for example, often require psychiatric or continuing psychological treatment. The researcher could not

initiate a research relationship that could be in conflict with ethics of professional therapeutics.

- Documented premorbid hearing loss or failure to demonstrate normal middle ear function when pre-screened. There was little sense in administering auditory stimulation to one who, in all likelihood, could not hear.
- Consent not secured. Ethical considerations require informed consent of the participant, or the informed consent of a guardian or person designated with signing authority on behalf of the patient, who, while critically ill, is considered to be incompetent. Several patients were bereft of family.

Participant characteristics

Over a period of nine months, the families of sixteen ICU patients gave consent to have their relatives participate. Of sixteen subjects, only four survived. Although few remained to interview following release from ICU, each participant contributed uniquely to this researcher's understanding of the experience or to expanded awareness of related issues. Those issues included end-of-life and consent ethics, bias and discrimination within the healthcare system, the impact of critical illness on family and friends, and many others. Three patients were able to provide extensive follow-up interviews.

Five of the sixteen patients were given some form of the protocol described in this paper (See Table 1). Of the five patients given this single-subject protocol, two of the three women survived to be released from the hospital; both men succumbed after transfer to a regular medical unit. Only the young mother expired in the ICU

during the study. Table 1. identifies the participants in chronological order of recruitment. The objective protocol was developed just prior to the time the tenth participant was hospitalized. During the development time, Participant 1 returned to hospital for surgery, after which he was again admitted to the ICU. He was enthusiastic to be included in the study again to "try the new protocol." Participant 1 did not meet the criterion of unconscious-ness, but the protocol needed to have a pilot run; therefore, the data for Participant 1 is presented with the caveat that he was judged to be quite conscious during sessions, although he failed to recall them at a later interview. Information (data) regarding other elements of the study is also presented so the reader might have a more complete picture of the entire study during which the physiological measurements were collected.

Table 1. Summary of Participant Characteristics

Number	Sex	Age	Occupation	Diagnosis	Outcome
01	M	74	Aviator (retired)	Pancreatitis	Deceased
10	Fe	74	Housewife (widow)	Ileostomy	Discharge
11	Fe	22	Housewife/mother	Hepatitis C	Deceased
12	M	77	Trucker (retired)	Gastric lesion	Deceased
13	Fe	37	Business owner	Ulcerative colitis	Discharge

Families were generally very enthusiastic about having another person to look in on the patient. They would ask the clinician to visit and speak to their relative even if no stimuli were given. Although they were assured that the experimental elements of the study were not therapies, and that the clinician was not a medical practitioner,

they often persisted in attributing metaphysical benefits to the interventions. The idea that a relative might in some way contribute to general knowledge was a strong motivator for those who were preparing for the death of a family member.

Patient history was noted. Many pre-existing factors affecting memory and cognition, health, life-style, education, gender, age, etc. had the potential to affect results. Level of consciousness was assessed several times a day by hospital staff, and the patient's chart provided information regarding medications and therapies. Basic medications were surprisingly similar in all patients observed. Regardless of initial diagnosis, the ICU routine of controlling all biological functions results in a similarity of treatment.

Procedure

Preparation for this project included the planning, writing proposals, and securing ethics approvals that, in this case, included both faculty of education and hospital review committees (Appendix A). The proposal that was approved indicated that this would be an exploratory study, but it did not specifically describe the research design presented in this paper. The interventions used with this protocol did, however, receive prior approval. The hospital ethics committee chairman was contacted for permission to implement the revised protocol, it was developed, and approval extended.

Through small group in-services at the workplace, the ICU staff was familiarized over a period of a month with the procedures to be used. Questions were answered and cooperation solicited.

Selection of patients was initiated by observation of daily medical rounds. After introduction to a family by the unit physician, the researcher became acquainted with members, explained the study, and secured biographical information regarding the participant from them.

Scheduling was initially difficult. Nurses were asked which times would be least disruptive to their schedules as the clinician needed an uninterrupted half-hour with each patient. Consultation with a supervisor revealed that nursing staff was not accustomed to being consulted, and that simply giving them the experimental schedule would probably suffice. Shortly, they were working efficiently around the needs of the experimenter. (Copies of all forms can be found Appendix B.)

Phase Protocols

Biophysical measures displayed on monitors (blood oxygen levels, heart rate, blood pressure, and sometimes central venous or pulmonary capillary wedge pressure) of five ICU patients, each acting as his or her own control using within-subject or single-subject designs, were recorded on time stamped videotape. Figure 2. is a tabulation of individual protocols. Treatments were given on approximately successive ICU days until the patient became conscious or expired.

Recording sessions lasted approximately 35 minutes during which the researcher approached the patient's bed and sat quietly in a chair for a five-minute 'baseline' period. Two or three five-minute interventions were then given, with baseline periods

between. Participant number 01, Table 2, was administered the first two phases, but the tripod had been kicked so the equipment had not recorded the data from those phases.

Table 2. Phases Administered to Each Participant.

Number	Phases					
	A_1	B	A_2	C	D	A_3
01			X	X	X	X
10	X	X	X	X		X
11	X	X	X	X		X
12	X	X	X	X	X	X
13	X	X	X	X		X

Following each baseline phase (A), was Intervention (B): giving oral instructions for relaxation and healing using standard scripts adapted for each patient to specify name, condition and healing needs (see Appendix C); Intervention (C): Instructions to do a mental problem solving task (e.g., "add 3 and 5; subtract 2 . . ."): Intervention (D) Engage in an active mental task without researcher verbalization beyond the beginning instructions (e.g., "subtract from 100 by 3's until told to stop"). Daily visits were made to attend rounds and/or read of each patient's medical progress from the chart, and to maintain family and patient rapport. Interviews were held with surviving patients when recovery was sufficient to secure direct informed consent to continue.

CHAPTER 4: RESULTS

The results of analyses of the data from each of the five patients are reported here. Across subjects, it appeared that each patient had a unique pattern of responding. When using biofeedback with patients, we speak of "bracing patterns." Each individual expresses anxiety or tension differently physiologically (Peper & Williams, 1981). The physiological responses of our subjects were more pronounced in one measured modality than another, and the dominant modality seemed to vary across subjects.

Analyses revealed many differences in the biophysical responses between baseline conditions and interventions of patients who survived ICU. Further, on several trials they demonstrated an appreciation of the content of the verbal messages during trials with responses of different magnitudes between interventions. The greatest response (deviation from baseline) occurred when patients were asked to perform an active mental task without on-going accompanying verbal input from the researcher. This is offered as suggestive evidence that sometimes the patient appreciated the nature of the verbal message itself, and attempted to comply with instructions.

Participant 10

Participant 10 functions as an exemplar who illustrates methodological techniques and results typical of those found with the other four subjects. Her data were complete (although no PhaseD

was administered). We had the advantage of being able to compare notes with the patient well after her recovery and discharge from ICU.

History

Participant 10, 74 years old, was a bright, healthy, middle-class, widowed housewife who enjoyed golf and providing for her grandchildren. She was close to her two daughters and son who lived within driving distance of their mother. Participant 10's close family provided strong physical and emotional support for its members. She was attended while in the hospital by her daughters during the day and evening. One daughter was a registered nurse.

Participant 10 had been fond of travel, but found that wearing a colostomy bag to collect body-waste interfered with travel and with her golf game, in which she had excelled at an amateur level. Participant 10 had been injured in a motor vehicle accident the year before her return to hospital to have repairs done to the ileostomy that was performed at the time of the accident. She greatly desired the chance that reconstruction would give her of not having to wear the bag in the future. Her return to ICU occurred when infection developed following reconstructive surgery. She was mechanically intubated, hemodynamically monitored, and sedated on her 3rd ICU day when the study began.

Procedure

Biophysical information was recorded at Participant 10's bedside as the researcher instructed her in relaxation, imagery, word association and ideomotor tasks, and active mental puzzles as

discussed in the prior chapter. Six trials extending from Participant 10's ICU day 3 through day 11 were conducted. After that period, the clinician visited Participant 10 daily, but did not administer the protocol. The protocol was limited to the period of unconsciousness, although Participant 10 was not transferred to a regular surgical ward until her 62nd ICU day. A formal follow-up interview was conducted with Participant 10 on her 46th ICU day, at which time she was sitting, visiting, and breathing well on room air, with no pychotropic drugs having been administered for several days.

Another formal interview was recorded on Participant 10's 99th day of hospitalization - the day before her discharge home. Although Participant 10 denied any memory of the clinician or her earlier visits, of being asked to recall words from a list, or any of the other activities of ICU days 3 through 11, she did exhibit knowledge of these activities. On ICU day 62, a word from which she was to free-associate was presented. "You didn't say that word," she exclaimed! And indeed, that word had not been on the list to be recalled.

The condition of the patient during each of the six trials, as documented daily in Participant 10's chart, is contained in Table 3. Given in Table 3 are: trial number, Glasgow Coma Scale (GCS) score, the hour of data collection, days since admission to the ICU, psychotropic medications administered, dose, time of administration of psychotropics (or time covered by nursing report), and comments regarding the patient's observable behavior during data collection.

The protocol used in the final trial remained consistent, but the item content was changed (different words), as Participant 10 was considered to be no longer unconscious. It was felt that if she had

later recall of intervention content, it would be impossible to determine if she were recalling the words from the unconscious or conscious experience. She did recall that a certain distracter word had *not* been given with the other words for which she denied recall. The list being assessed was one given between Trials 1 to 3 (Appendix C). Thus, we knew that Participant 10's comment was not generated from exposure to the words on that final 6th trial.

Table 3: Participant 10 - Other Variables

#	GCS	Hour	Day	Medication	Dose	Time	Comments
1	09	2130	03	Valium	2.5mg	1510	No observable response
2	11	2200	04	Valium Morphine	2.5mg 2.5mg	1600 1600	Slight random motor movement
3	09	1140	05	Valium Morphine	2.5mg 2.5mg	1135 1135	Very agitated, but unresponsive
4	10	2400	08	(none)	-	(12h)	Shakes head in appropriate response
5	11	1840	09	(none)	-	(12h)	Nods yes/no in appropriate response
6	15	2100	11	Morphine	5.0mg	1800 2000	Awake and responsive (new intervention given)

Results

Assembling figures that made up the dependent variables, the results of each trial were charted then graphed from days 3 through 11. Table 4 shows the values transcribed from the taped monitors at one minute intervals for each of the four dependent variables: oxymetry, heart rate, systolic blood pressure, and diastolic blood pressure. The conditions are labeled according to sequence of presentation across the top of the *X* axis: Phases A_1 (first baseline), B (relaxation and imagery), A_2 (second baseline), C (active mental task), and A_3 (third baseline) for three sessions during week 1 and three sessions during week 2.

Table 4. Participant 10 - Raw Data

Conditions	WEEK ONE (Six sessions over two weeks)															WEEK TWO											
	A.1	B	A.2	C	A.3	A.1	B*	A.2	C*	A.3	A.1	B	A.2	C	A.3	A.1	B	A.2	C	A.3	A.1	B	A.2	C	A.3	A.1	B	A.2	C	A.3
Oximetry	97	97	97	93	97	92	91	92	91	92	97	97	97	97	97	95	95	95	96	96	98	97	96	97	96	100	100	100	99	100
	97	96	97	90	97	92	90	92	93	91	97	97	97	98	96	95	95	95	96	96	98	95	96	95	96	100	100	100	100	100
	97	97	97	95	97	91	92	91	93	91	97	97	97	97	96	95	96	95	96	96	98	94	96	94	96	100	100	100	100	100
	97	95	97	96	97	91	92	91	92	92	97	97	96	97	96	95	96	95	96	96	96	95	97	95	96	100	97	100	100	99
			97	93		91	91		93	92		97		97	96	95	96		98		96	93		93		100				
							92							97	96											100				
Heart Rate	109	107	110	95	107	121	180	113	113	118	118	119	115	182	117	99	99	100	99	102	115	108	104	107	112	102	111	104	107	104
	110	108	108	95	105	123	115	114	110	112	120	120	121	206	116	98	99	100	98	101	104	112	112	109	110	101	106	105	112	103
	108	109	108	106	107	114	121	113	109	110	153	122	152	155	115	99	100	100	99	102	117	111	110	112	111	104	102	103	107	102
	110	106	108	108	106	111	116	124	110	112	117	117	61	119	151	99	101	99	99	101	118	106	110	111	112	102	112	103	104	101
	109		109	101		125	113		113	110		114		117	187	100	101		99		117	111		114		102				
							148							158	118											101				
Systolic BP	116	112	121	112	118	125	136	130	122	134	128	131	130	133	123	128	132	125	132	139	135	140	142	141	137	114	129	128	122	116
	115	123	113	118	113	141	136	129	132	128	131	143	124	118	119	127	127	134	126	126	134	145	140	138	127	115	129	125	129	119
	113	116	113	102	114	138	140	130	134	118	129	145	119	145	126	127	131	122	128	142	136	147	138	136	127	125	126	121	133	114
	111	118	115	116	115	128	124	130	136	121	122	136	126	140	129	130	133	128	129	140	137	146	139	138	125	118	148	122	127	110
	113		113	113		136	139		132	120		132		137	128	131	133		129		137	142		128		121				
							136							131	127											110				
Diastolic BP	50	50	51	49	50	64	69	60	66	63	64	64	65	65	57	59	60	61	60	62	59	62	62	62	64	41	47	45	58	41
	50	56	49	53	49	71	64	60	70	57	67	69	58	66	53	58	58	60	57	61	61	64	60	62	58	42	47	50	53	42
	51	51	49	49	49	68	67	59	73	57	66	61	57	63	62	58	60	59	59	64	61	65	61	61	59	47	47	42	49	41
	49	52	49	51	50	60	62	62	64	57	60	67	56	71	63	60	61	59	59	62	61	62	61	62	59	44	56	44	45	39
	48		49	53		66	66		66	55		65		85	64	59	61		59		62	65		64		46				
							64							65	63											40				

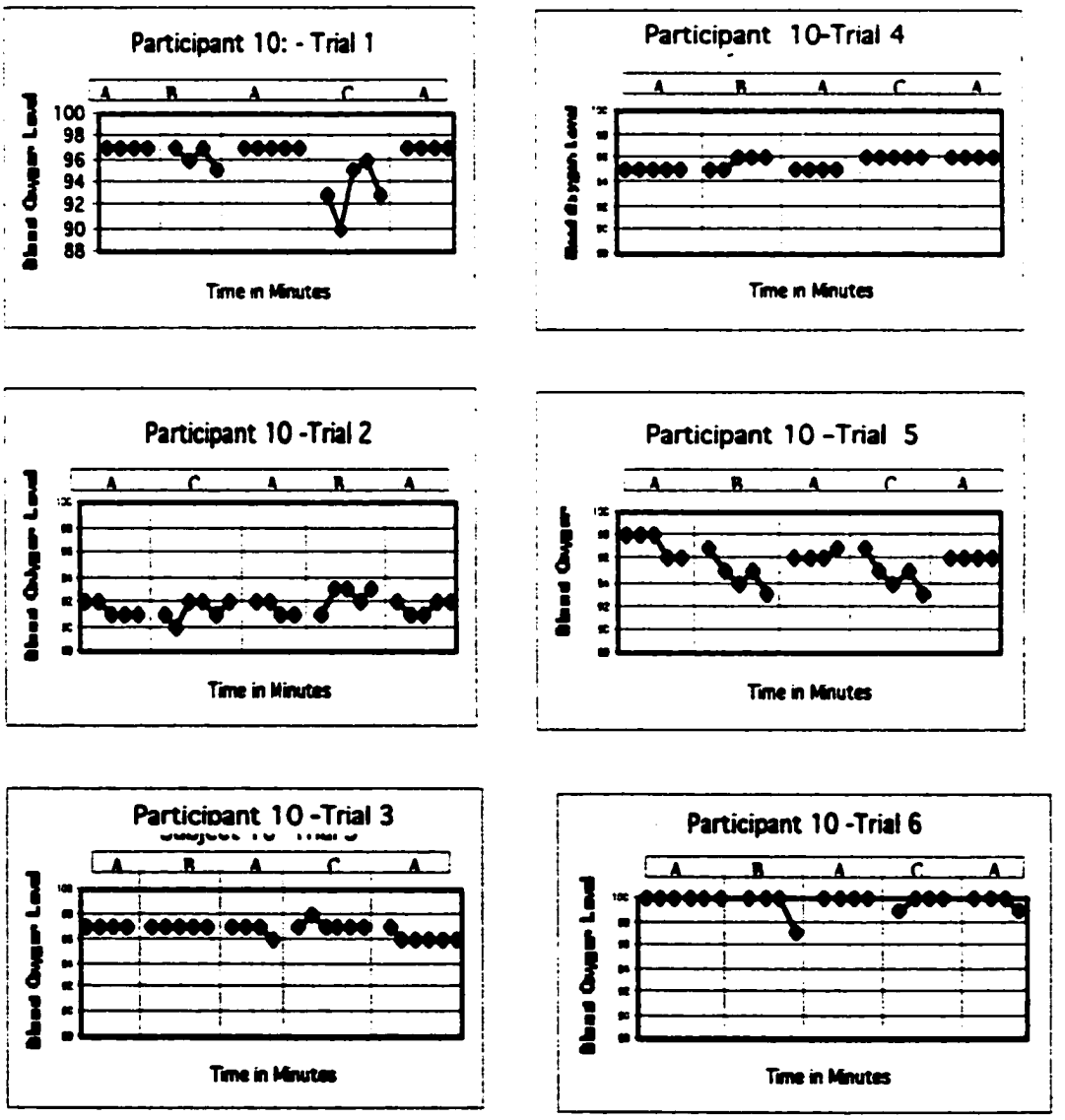
Minutes

Note: Phases B and C, Week 1 were reversed in order of presentation.

(Table 4 does not reflect the order of presentation of Phases B and C of Week 1, Day 2, which were, in actuality, reversed in an effort to see if there might exist an "order effect".)

Charts are generally more easily understood than tables of numbers, and the visual inspection of graphs illustrating participant responses, such as Figure 1, is the traditional method of analysis in single case studies (Richards, Taylor, Ramasamy, & Richards, 1999; Kazdin, 1982; Kratochwill, 1978).

Figure 1: Participant 10 - Oxymetry



Visual inspection of Trial 1 - Oxymetry results with Participant 10, indicates a stable baseline (Phase A) at the 97% blood oxygen saturation level. Since the participant's breathing was maintained by a respirator, wherein each breath was delivered at a specified rate, pressure, and gas mixture, stable levels might be expected. A slight, but distinct deviation from baseline during Phase B (the relaxation and imagery intervention) is seen. The second Phase A shows a return to original baseline levels. Phase C shows a strong negative deviation during the time the researcher was instructing the patient to perform an active mental task. Again, the third Phase A demonstrates a clear return to baseline. In the case of the first trial, visual inspection of Figure 1 clearly implies a time-locked response to the interventions.

As we progress to the second trial, responses are not as easily seen. Baselines are much lower, 91 to 92% (the equipment only reads whole per cent intervals). The most notable feature of the second trial is that Phase C appears to deviate negatively, while Phase B revealed variation in a positive direction. Note that the presentation of interventions in Trial 2 was reversed (ACABA). As mentioned earlier, this was an effort to counterbalance, to identify any possible 'order effects' when looking at the magnitude of response between interventions. Trial 5 shows considerable variability during the two intervention phases. We might have confidence in declaring this variability significant if it is replicable and remains time-locked to the intervention phases. The pattern is repeated in Trial 6.

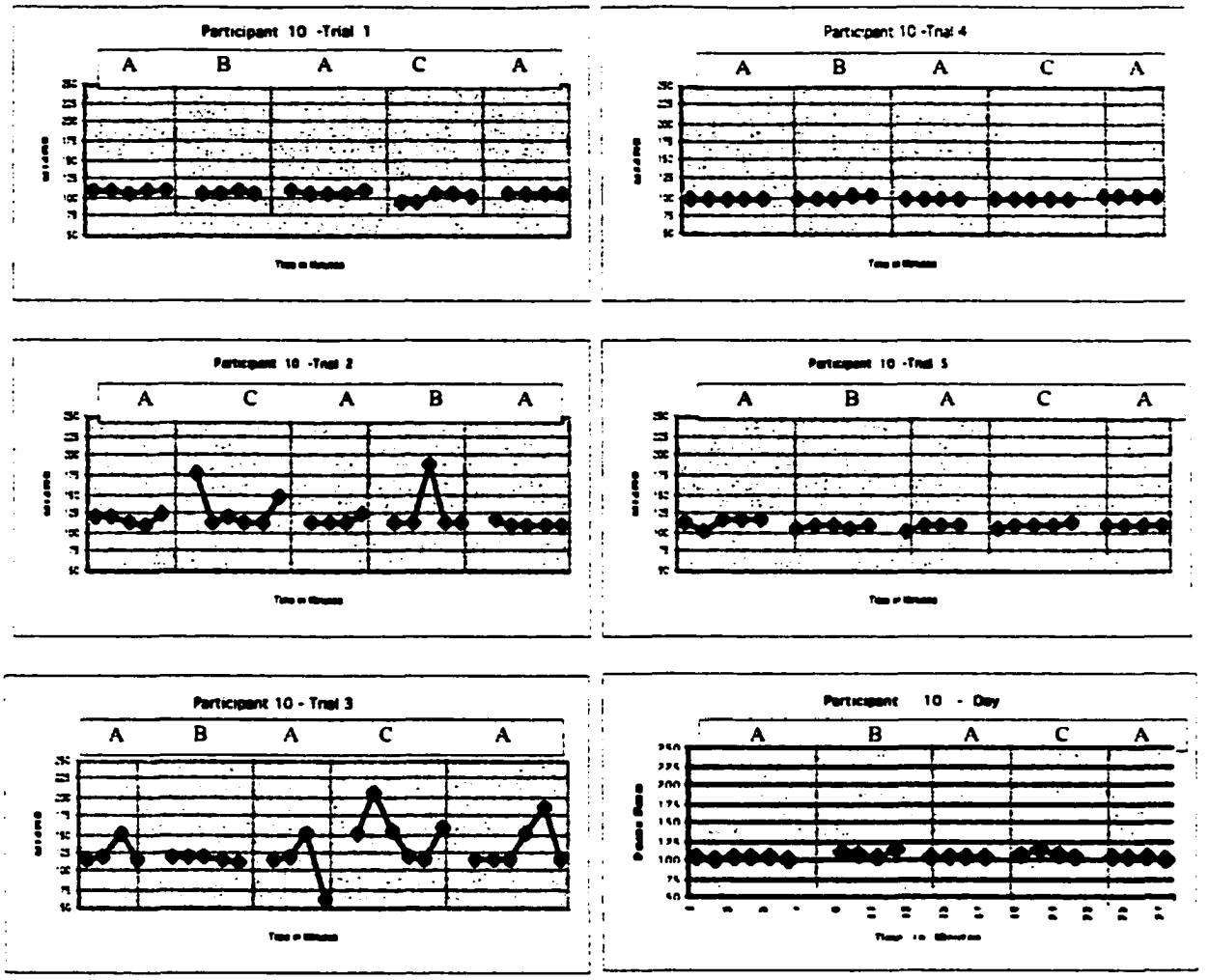
In trials 4 to 6, there was a trend in the data toward normal values as Participant 10's condition improved. By the fifth trial she

was beginning to regain consciousness, her oxygen saturation levels approached normalcy and reached 100% during much of the last trial. Obviously, the trend toward normalcy could *obliterate* the unconscious response, as the healthy person can easily tolerate a barrage of environmental stimuli without much observable physiological reaction. The trend possibly indicated that the more ill our participant, the more pronounced the response. This trend was more pronounced in other recovering patients, and was notably reversed in those who were deteriorating.

Figure 2 illustrates heart rate responses generated by the same interventions and at the same time as the oximeter readings represented in Figure 1. Again, baseline conditions (A) can be identified by great stability, except during Trial 3. Interventions (B and C) are generally identified by greater variation from baseline. And again, the variability of response tends to disappear as the subjects' physiological functions begin to normalize.

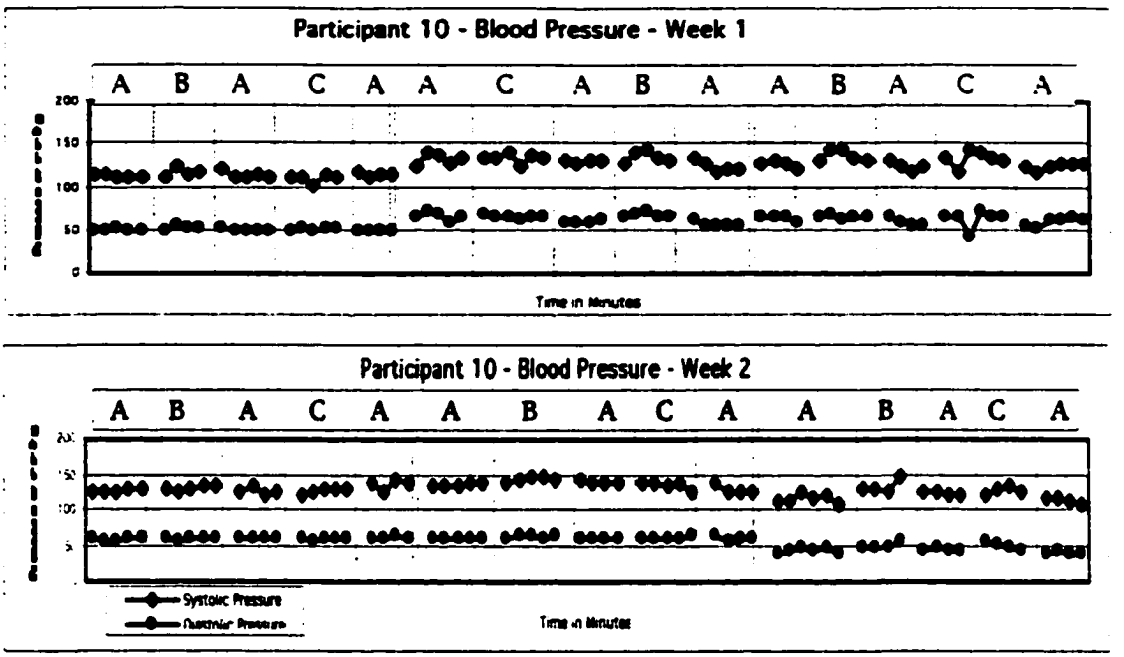
Figure 3 reports data from both systolic and diastolic measures on two strips of three sessions or trials each. Again, these data were collected at the same time and results from the same interventions as shown in Figure 1. Although there was no significant trend toward 'recovery', an increase in variability of response is observable, particularly during the third trial (Week 1, third panel). This is consistent with results observed in Figure 2 - Heart Rate. When diastolic pressure varied, it tended to be during the Phase C conditions. Systolic pressure replicated diastolic with greater variation.

Figure 2: Participant 10 – Heart Rate



Baseline values for each trial were analyzed according to one of the four dependent variables. The mean and standard deviation of each Phase A for each trial was examined and no significant differences were found. The data was collapsed and analyzed by days, weeks, and finally across subjects. Homogeneity was prominent and a single value for all A phases was generated and used in subsequent analyses.

Figure 3: Participant 10 - Blood Pressure



The variability of responses was compared without resorting to compressing the data with measures of central tendency, as would be required in an analysis of variance (ANOVA). For instance, visual inspection revealed that some responses vary as both negative and positive deflections from baseline; thus, a mean value for each condition could be zero despite labile responses. We therefore avoided measures of central tendency as they tended to *obscure* the variability that, upon visual inspection, was the response we wanted to describe!

After establishing that the differences between the three baselines (A phases) for each trial were insignificant, as reported earlier, all phase A data was compressed and a common value of A used thereafter.

It was somewhat puzzling that there was so little variation during A conditions, as occasionally there were interruptions, talking, the banging of equipment in the background, etc.. We must recall, however, the widely accepted principle in experimental psychology of the phenomena of *habituation*. One might expect that the patient *accommodate* ambient noise and that *habituation* would be responsible for the decrease or cessation of responses to stimuli that are not significant to the patient. Habituation may have been responsible for many of the trials that, during stimulation, failed to evoke a clear response from the patient. The use of Condition D was designed to distinguish between a response to the novelty of voice and the meaning of the message. Conversely, *attention* facilitates learning, and would likely be necessary to produce a differential response between experimental conditions. Were there no difference between Conditions B, C, or D, learning could still be present and a response could be evoked through subliminal or unconscious processes.

An interesting (and potentially significant) finding was reported in an article published by Luckas, Woodman & Vogel (November 2000). The authors reviewed some of the recent ERP (evoked response potential) studies of attention, focusing on studies that isolate the operation of attention in specific cognitive subsystems such as perception, working memory, and response selection. One conclusion drawn was that attention does not modulate sensory activity unless sensory systems are overloaded. When sensory systems are not taxed, attention may instead operate to influence memory or response processes. That is, attention

operates to mitigate information overload in whichever cognitive subsystems are overloaded by a particular combination of stimuli and task.

Oxymetry proved to be a difficult modality to analyze for Participant 10's data. Her response pattern was most apparent in her heart rate measures: both B and C interventions were different from one another and from the baselines. In all modalities, the Phase B intervention evoked a reliable, but less dramatic response than the Phase C intervention.

Thus, Participant 10's responses to the interventions were reliable and replicable over six trials in nine days. On visual inspection of the data, responses B and C were easily identified, and returns to the baseline conditions were present. The variance which represented "the response" exceeded levels in heart rate between Baselines A - B intervention (relaxation and imagery suggestions) and the A - C intervention (active mental tasks). The differences in responses to interventions B and C imply that Participant 10 appreciated the difference in content of the messages she heard while unconscious, since both varied only in linguistic content and perhaps prosody. Finally, that result was confirmed anecdotally, as the patient recalled that some words given during post-test were not given during the C intervention.

Participant 11

When considering results from all five subjects, there is some indication that a reliable response to voice while the patient is unconscious may indicate conditions necessary for recovery. Participant 11 was a 22 year old housewife and mother of two young children. Participant 11 was admitted to hospital for elective surgery (cholelithiasis) on September 30th. Complications arose due to diabetes, which she had developed at 10 months of age. She also had developed advanced cirrhosis of the liver secondary to hepatitis C contracted as an infant.

Participant 11 was transferred to the ICU on October 7th and was first seen by the researcher on her fifth ICU day. She had five sessions; two in Week 1, followed with three sessions in Week 2, after which she expired. Her medication log is found in Table 5 below.

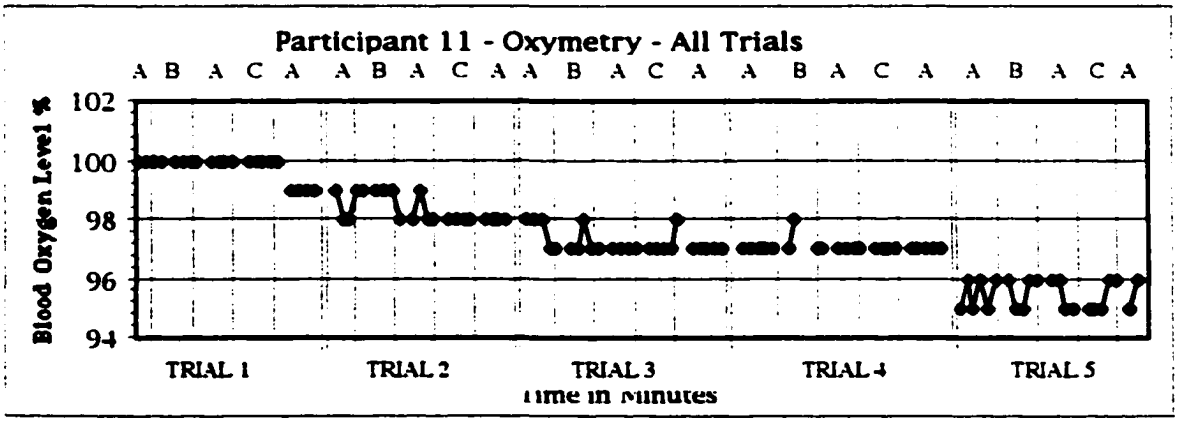
Table 5: Participant 11 - Other Variables

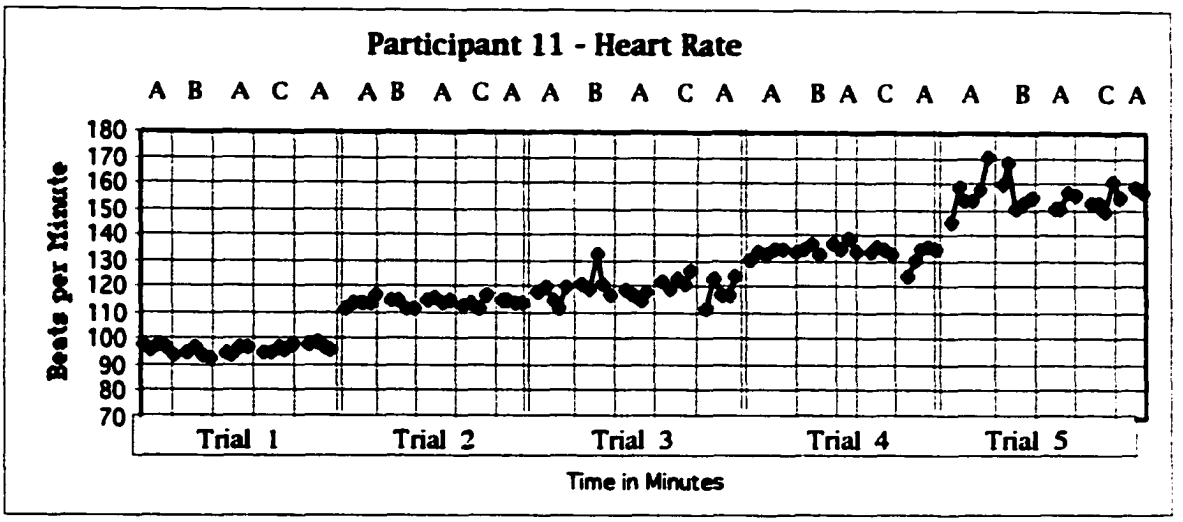
#	GCS	Hour	Day	Medication	Dose	Time	Comments
1	10	1500	05	Morphine Haldol IV Pavulon	2.5mg 15mg	650h 24h	No observable response
2	10	2200	06	Morphine	2.5mg	2000	No observable response
3	11	2200	07	Morphine	2.5mg	(last 24h)	Eyes open to speech. Tube Irritates-coughing.
4	11	2400	09	Morphine Haldol IV	(?) (?)	(?) (?)	Eyes open weakly to speech
5	?	1400	10	(?)	(?)	(?)	No motor response (No chart - no nurse)

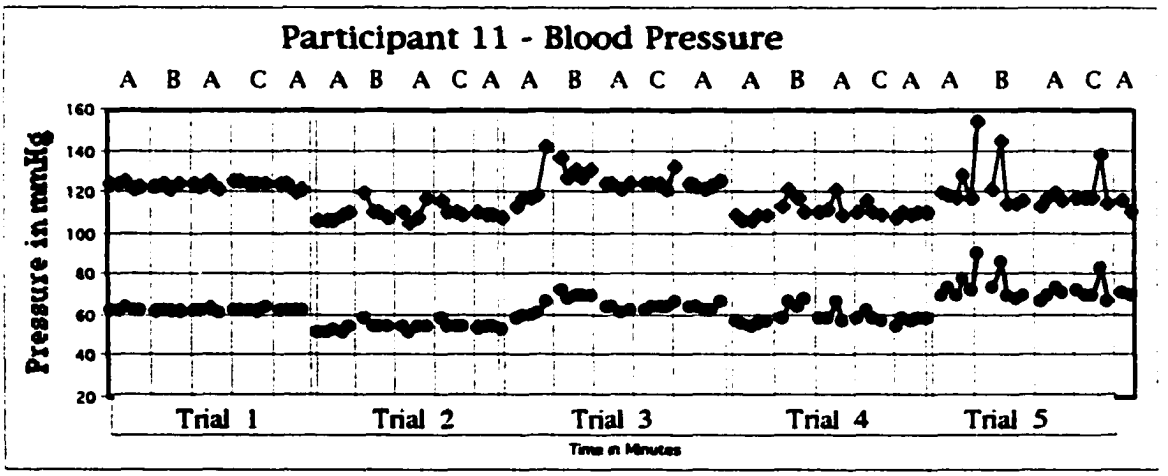
Participant 11 began the project with healthy dependent measures, but quickly deteriorated (see Figure 4). When she became unconscious she yielded responses much like those produced by Participant 10. As her condition further deteriorated, the responses became chaotic and we were unable to identify patterns or return to baseline. (At autopsy it was demonstrated that there had been considerable swelling of the brain.) The trend in data was essentially opposite to Participant 10's profile, and of course, so was Participant 11's outcome. In addition to the four basic dependent measures, values for central venous pressure were also recorded.

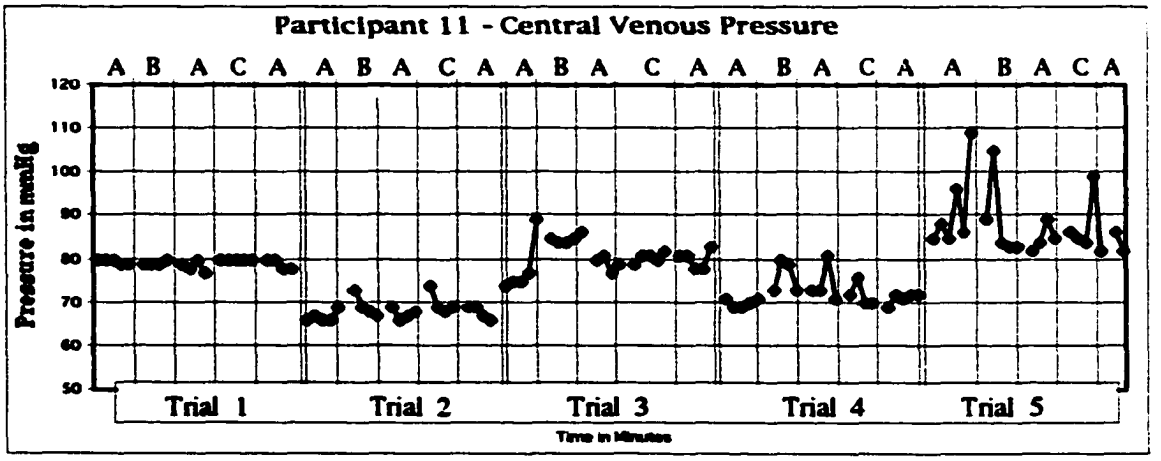
Results show great homogeneity between measures. While not as convincing as Participant 10, Participant 11 (Figure 4) reveals that with oxymetry there exists a difference in variability of responses between baselines and the Phase C condition (active mental tasks).

Figure 4: Participant 11 - Dependent Measures









Participant 1

History

Participant 1, a vigorous man of 74 years, was an avid outdoorsman who enjoyed fishing and hunting, after retiring from a career in aviation. He had lived all his adult life in rural Northern Saskatchewan where he and his wife also farmed. They were parents of three grown sons, all of whom followed their father into careers in aviation. The eldest son and his family (twin daughters) lived near their parents. The middle son and his family were relatively close, as they had a helicopter company within short flying distance. The youngest son was a pilot for a large airline company. He lived in the city with his wife and university-bound daughter. The world, for Participant 1 and his wife, centered upon one another and their family.

First hospitalization

Participant 1 had not been ill, but he had some hypertension that concerned his family physician. He had been a pack-a-day smoker all his adult life, had been complaining of shortness of breath, diagnosed as COPD (chronic obstructive pulmonary disease). He did not drink alcohol, but had become somewhat overweight and sedentary.

While at home on a Sunday in May, without warning, Participant 1 was struck with severe abdominal pain. He was taken to a nearby hospital emergency department where his family doctor diagnosed severe acute pancreatitis. The patient was immediately dispatched by S.T.A.R.S. (Shock Trauma Air Rescue Society)

helicopter to a large metropolitan acute care hospital in a city 300 miles away. Participant 1 was taken directly to surgery, then admitted to the Intensive Care Unit (ICU). During surgery no common bile duct obstruction was found, but it was confirmed that Participant 1 had gall stones which could cause difficulty later. Presenting problems included abdominal pain, agitation, decreased respiration, and low kidney function.

On Participant 1's 37th day in ICU, his wife and her daughter-in-law were approached by the researcher for consent to allow Participant 1 to participate in a study looking at the patient's experience in ICU and whether he heard and/or would recall things heard during the illness. The wife said that she had asked the Pastoral Care Intern if Participant 1 could hear, remember, etc.. She had been told that he would not remember his experience. She was keen to probe further, feeling that, "There is more going on than doctors think". She also felt that the researcher would be another person "rooting" for her husband, would visit him, providing more vigilance when she was away. She had many questions regarding the researcher's experience as an ICU patient and expressed thanks to have talked with someone who had "gone through it." The family took an explanation sheet and consent form to reread, discuss, and decide. They returned the next morning with the signed consent form.

The wife asked that the researcher not speak to her husband of politics or religion, as that might upset him. She hoped that the relaxation and imagery would help settle him, decreasing his agitation. (Participant 1 had been restrained physically by tying his

wrists to the bed frame, and pharmacologically by the administration of the antipsychotic drug *haloperidol* which was used to lessen his agitation. This action was prompted by his having "kicked a nurse", resulting in injury to her. Subsequently, several co-workers adopted a self-protective distance when dealing with him.)

The researcher was to begin her study on Participant 1's 39th day in ICU. At the time, he was too heavily sedated to be responsive to voice. His drug regimen had included a week or so of sedation with diazepam, haloperidol, and morphine so that he would not become distraught at having his arms and legs restrained. Restraint was needed to control his agitation and to protect himself and those caring for him. He was beginning to develop a marked tremor, and was devoid of voluntary movement, although he did obey nurses' commands on occasion. Morphine was withdrawn, and in a few days, Participant 1 was off diazepam so that he could 'wake up' a bit. His haloperidol was held for two days. The following notes chronicle some of the researcher's impressions:

(*Day 43)*

GCS-12/13

1200h. *Waited for respiratory to suction and settle. Otoscopic check indicated impacted cerumin bilaterally. Talk with [Participant 1] was taped for reference. Oxygen saturation levels went from 90 to 93, and heart rate went down, according to the nurse. Participant 1 seemed alert but relaxed when spoken to (he is ventilated, thus cannot speak).*

1800h. *Begin research protocol: Given a list of paired words to be recalled later. Shakes head yes and no appropriately, but seems confused often. Less tremor than yesterday.*

No Haldol.

Morphine drip 250mg/250cc @ 3mg/h = 3cc/h

(Day 44)

GCS-14

0430h. *Restless.* Valium 5mg

2000h. *Agitated and resistant, no tremor.*

Morphine drip 250mg/250cc @ 3mg/h = 3cc/h

(Day 45)

GCS-14

2000h. *Nurse had just settled [Participant 1] She was loud and disgusted that he had been pulling on tubes and was very "difficult". All the patients could easily hear her chastising tone.*

2045h. *Nurse on lunch break. Resident had removed cerumin. Proceeded with tympanometry (part of protocol to establish that [Participant 1] can hear the words adequately). Still no seal. He has an exaggerated reflex, but that is not accurate as it is difficult to position the handi-tymp as the pillow is in the way and may be collapsing the canal.*

Although recently sedated, [Participant 1] was very alert. He wanted to communicate, not relax. The nurse returned; told that [Participant 1] was in an awkward position for relaxation. His bed was rolled up high, he had slid down considerably and seemed uncomfortable. She exploded that she had just positioned him (not realizing that she had not touched him in at least an hour). He was repositioned on his right side. His restraints pulled his left arm behind him. He made continuous circular motions with his left index finger, which might have been to indicate that he wanted his left arm untied. Unable to comply, I tried to speak of relaxation to distract him. He was not comfortable enough to do relaxation exercises. [Participant 1] is getting very strong and can help with movement in bed. He can also reposition himself, constrained only by restraints and tubing. He indicated that he had pain/discomfort in the area of his groin, where he has a good deal of penile edema and some irritation. His nurse observed loudly that he couldn't have any more sedation. The target words were introduced without attempt to achieve a relaxed state. We spent a lot of time trying to communicate. He responded appropriately: e.g. When I said that I would lower the lights because I am not that pretty to look at, he chuckled. He responded that he did not recall my saying the words yesterday.

(Day 46)

GCS-14

[Participant 1] has had nothing but Valium and Tylenol since last night. He is more awake and responsive. There are no additional nursing notes in the past 24 hours. Strange. Things went well. [Participant 1] was responsive and relaxed and listened to "Serenity Place"(See Appendix C). *Slept after.*

(Day 49)

GCS-14

[Participant 1] in much pain- cramps, as he prepares for the big BM. He listened as best he could. Responded to instruction in breathing (prolong the exhalation, slow breathing and get all the CO_2 out) by pursing lips and imitating as best he could prolonged exhalation (less than two seconds). Gave words twice. Haloperidol and morphine again given.

Visited [Participant 1] and [his wife] as [Participant 1] was being 'plugged'. He is now able to breathe on his own for a short period. First and only thing he said today, "Hi, Mickey!"

The study

Although Participant 1, on this admission, never met the criterion of having a low level of consciousness, after day 50, he was judged to be too well to continue the intervention protocols. Had we continued, it would be difficult to determine if recall was from earlier or later exposure to the words. It would be necessary to be able to identify the conditions accruing to the period of recall.

Participant 1 was transferred to a regular medical unit on Day 65. He graduated from the ventilator a week after that and was 'plugged' so that he could begin to regain his voice. Four days later his voice was strong enough so that he could be interviewed for the study.

Memories

Participant 1 had an experience that was witnessed by the researcher and others. Later, he recounted the incident as it happened to him in his "idiosyncratic reality." The report from the "common reality" was quite different.

In an unrecorded conversation some four months later, October 14, 1993, the wife asked her husband, "Do you remember having your arms tied?" He nodded yes, thought a moment, then with the energy of new recall blurted, "But why did they tie my legs!" She explained that he had been kicking nurses. A big smile crossed his face. He beamed. Then he told us the freshly remembered incident. He was kicking because he was being attacked by 'natives' who had restrained his arms and wanted to tie his feet as well. So he kicked. If he kept kicking, they could not properly kill him. He was kicking to prevent being 'staked', drawn and quartered. He was kicking for his life!

Participant 1's ideosyncratic experience in ICU was very different than the consensual reality experienced by the rest of us. Yet, thanks to his ability to recall his 'phantasm' and our observations of the episodic incident, we were able gain the appreciation that Participant 1 was not trying to hurt the nurses with his kicking. Understanding intent can pave the way for creating safer working conditions for healthcare workers and reassurance of greater safety for the patient.

Three formal interviews were held with Participant 1. Two were recorded just before discharge on hospital days 76 and 80 in a regular medical ward. The third was three months after discharge,

the evening he returned for elective surgery. A partial transcript is included to illustrate more of the patient's experience.

M: Did you have any dreams or fantasies?
J: Yeah. They give me somethin', some medicine there. Everything was all in a jumble. They were killin' people and I don't know what all.
M: Was it like a war?
J: No. It was killin' them for money.
M: Oh, tell me about it.
J: Well, that's all I can remember.
M: Did you feel distressed about that?
J: They wanted me to help them. I said I wouldn't.
M: So what happened?
J: I guess it just faded away.
M: It faded away. Who do you think 'they' were?
J: Well, it would be the doctors and nurses.
M: So it was a medical setting, huu?
J: Yeah.
M: How were they killing people?
J: They would get people with large estates, where they could get their money.
M: That's interesting. And you think that that is a result of some of the medication?
J: They did give me Tylenol 5 that day!
M: And you usually don't take it that strong. . . As a matter of fact, Tylenol 3 is pretty strong for you, isn't it?
J: I wouldn't take that either! They wanted to give me that at night, but I wouldn't take it.
M: But you were one of them, weren't you?
J: They was trying to get me to go in with them.
M: So they wanted you to be one of them. . . you weren't going to be a victim. . .
J: No, I think I was afraid I was going to be a victim. I don't know.
M: But they wanted you to go in with them. . .What would have been your role?
J: I don't know.
M: But they wanted you to cooperate. . .

(Next interview two days later)

J: I haven't had any dreams at all.

M: Not night dreaming, but. . . I don't know what to call them. . . those ICU dreams. . . Did you have any feelings like you left the Unit? Like you left your body there; any out-of-body experience?

J: Yeah! Yeah, I had the feeling I was cut in half. Here was one half, and the other half was someplace else.

M: Yes. How interesting! Which half was. . . you were cut the long way?

J: Yeah.

M: Which half was somewhere else?

J: *(Gestures to left half of body)*

M: The left half?

J: Yeah!

M: And what did you see?

J: Well, I don't know. . .

M: Were you looking out of your left half or your right half?

J: I really don't know.

M: Isn't that interesting. Any ideas where your other half was?

J: I was just hoping they would bring it back and sew it back together again.

M: How did it make you feel to be without it?

J: Well, I just wasn't there!

M: This half was in the hospital and you were with the other half, hu?

J: No, I was with the one that was in the hospital. And I didn't know what they would do with the other half.

M: Do you remember hearing anything? (*Nods no*) Do you remember anyone talking? (*Nods no*) Conversations, or people telling you what to do?

J: Conversations was, I think, trying to get me to go along with murdering somebody. I guess I agreed with them. I was supposed to be an undertaker or something. Then, I got suspicious, and I told them no, I wasn't going through with it. It was, ah, you know, ah, there was some guy back there wondering weather they should keep me in the hospital. And he was gathering all the assets that we had, and he said, "Well, I guess they got enough that we can afford to keep him for a few days.

Following the unstructured interview, wherein it was hoped the patient would volunteer information with minimal or no prompting, an additional questionnaire was administered. The participant was asked if the items on the list were present in his experience or absent (see Table 6). These emotional terms often stimulate recall and the subjects spontaneously report associated scenarios, incidents, or perceptions. The list is a loose adaptation of the Experience Rating Scale reported by Kenneth Ring in his book, *Life at Death,* (1980).

Participant 1's dysphoric experiences were not uncommon. Participant 10 also had the experience of thinking she was being held for ransom and could buy her health for $20,000.00. Upon reflection, one can reason that the effects of medications and the toxins of illness, can impart the emotional coloring to one's experiences; however, we must look elsewhere for an understanding of the content of those experiences.

From Participant 1's interviews we learn that conscious or unconscious, the patient may be living in an ideosyncratic, rather than consensual, reality while in the ICU. Participant 10 and Participant 1 show us that the ability to recall events is relatively unaffected by weather the patient is conscious or unconscious when those events occur.

Table 6: Participant 1- Experience Rating Scale

(+ = Yes: - = No)

A. Feelings

Peacefulness	+
Calmness	+
Quiet	+
Serenity	+
Lightness	++
Warmth	+
Pleasantness	+
Joy, exhaltation	+
Painlessness	+
Relief	+
No fear	_
Relaxation	+
Resignation	+
Curiosity	+
Happiness	later
Anxiety	+
Fear	+
Anger	_
Dread	_
Dispair	+
Anguish	+
Boredom	_

B.Sense of movement

Quality	
Walking	_
Running	+
Floating	+
Flying	+
w/o body	+
Dreamlike	+
Feelings	
Peaceful	+
Exhilarating	_
Struggling	
Fearful	+
Panicky	+
Illumination	dim
Music	+
Human figures	+
Other People	_

Features of Location	
Dark void	_
Tunnel	_
Path, road	_
Garden	-
Valley	-
Meadow	-
Fields	-
City	+
Hospital	?
Home	-

C. Sense of space

Undistorted	
No sense of space	+
No boundary	

D. Sense of time

Undistorted	
No sense of time	+
Timelessness	

E. Bodily separation

Felt detatched, but did not see it.	+
Able to view body	_

F. Threshold Effect _

G. Unusual noises _

H.Life flashback ++

Complete	_
"little things"	+
Sense of sequence	_

I. Others present

Lonliness	+
Alone	+
Relative	+
Friend	+
Guide	
Voice (Jesus, god, a power)	+

Evil spirits, devil	+
Medical staff	+
Dead relative/ friend	_
Animals	_

J.Feeling on recovery

Anger	_
Resentment	_
Disappointment	+
Shock, surprise	+
Pain	++
Relief, peace	+
Happiness	+
Gladness, joy	+

K. Changes

Attitude toward life	
More appreciation	+
More caring, loving	+
Renewed purpose	_
Fear, vulnerability	_
More interest, curious,"give kids something"	+
Religious beliefs	
Stronger	+
Weaker	_
Other	_
Fear of death	
Greater	
Lesser	
None	+

L.Feel bodily weight

Ordinary weight	+
Light	
Weightless	
Heavy	_
No sense of body	+

M. Illumination

Color (s)	?
Hurt eyes	+

N. Idea of death

Nothing (ness)	
Body dies, soul survives	
Transitional state	+
Continuance of life at another level	?
Merge with universal consciousness	
Reincarnation ideas	
Peace	+
Bliss	?
A beautiful experience	?
A journey	?
No idea	
Don't want to think	+

Participant 1 spent 65 days in the intensive care unit (ICU) and another 21 days on a medical unit. Two months later, upon the recommendation of his family physician ("So you won't get caught in an emergency when a stone passes"), a healthy Participant 1 returned to the hospital for elective cholelithiasis. A week after return home, a third admission for abdominal pain revealed a cystic duct leak. During repair, Participant 1 suffered an acute myocardial infarction and cardiac arrest, from which he was resuscitated; however, he expired several days later. During the six month period of the conclusion of this patient's life he actively collaborated as an enthusiastic participant in this study.

Table 7: Participant 1 - Other Variables

#	GCS	Hour	Day	Medication	Dose	Time	Comments
1	15	1300	02	Morphine	2.5mg	(This information was Not recorded.)	
2	15	2340	02	Morphine	2.5mg		
3	15	1300	03	(Not recorded.)			
4	15	2200	03	Morphine	2.5mg		

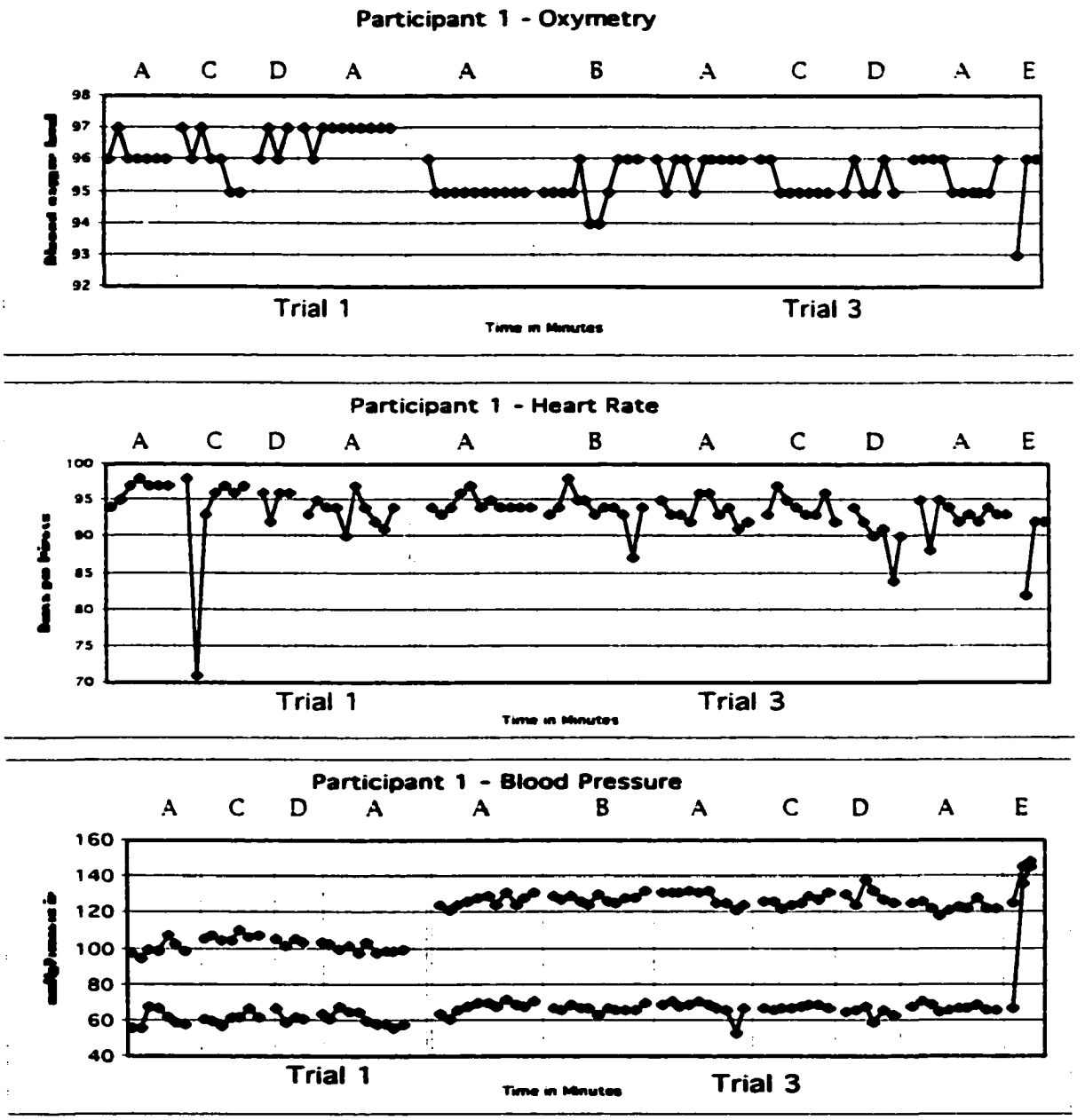
Table 7 shows several omissions in the data. The protocol was under development, and Participant 1 was not unconscious, as the others receiving this protocol would be. His results are included here to illustrate the process of development of procedure, as that was a main task of this study (originally a study in *grounded theory*).

Two trials only are presented in Figure 5, although four were recorded. Trial 2 was disrupted when the nurse needed to complete her routine before a shift change. During the final trial, unobserved, the battery of the camera failed.

Trial 1 was made up of two interventions: C and D. The protocol was ACDA. Again, A's were baselines. C intervention was, as with Participants 10 and 11, an introduction and explanation of the study, and asking the patient to do an active mental task, i.e. a progressive arithmetic problem. The D intervention was the request for the participant to count silently by fives for two minutes beginning on cue. The researcher sat quietly by the bedside as in the baseline conditions until signaling the two-minute interval.

Trial 3 was expanded to include the B (relaxation and imagery) condition, with another baseline before presentation of the phase C task. Phase D was presented immediately after the C task as it was only two minutes long and did replicate in every way except the a baseline phase. Instructions for the mental task in Phase D were given at the end of Phase C. After the two-minute time was called, a true baseline was given, followed by a condition E. Condition E consisted of instructions to remember a list of word pairs for later recall. Later, conditions C and E were combined, and the words were given as part of the active mental tasks of the C phase.

Figure 5: Participant 1 - Dependent Measures



On visual inspection, the most noticeable response is at the end of Trial 3. The participant appeared to make a heroic effort during phase E to memorize the words that he would later be asked to recognize. Unfortunately, he later had no recall of the trials, nor the

words, nor of the researcher prior to his ICU day 49 (see page 62) although he was fully conscious and free of psychotropic drugs, during the trial.

Participant 1's blood pressure response to the final E phase can be easily seen on visual inspection. His heart rate and blood pressure were more variable in all intervention conditions than in baselines.

We can see from Participant 1's example, there is a difference between the various interventions (B, C, D and E) which is regularly apparent whether it reaches a predetermined level of significance or not. The general pattern shows least variability between the A-B pair, next highest for A-C, and highest for A-D. Recall that C and E were later merged, and that D tended to have the most variability of any condition, for any participant when administered.

Participant 12

Participant 12, a 77 year-old retired trucker, was admitted to ICU through the emergency department with a suspected gastric lesion. He appeared to be awake and capable of giving informed consent upon admission to ICU. On the second day the family was informed that the patient was terminal with colon cancer. His condition was so far advanced that his outlook for life did not extend beyond a few days. By the third day (before which patients were not entered into the study) his condition had deteriorated to the extent that he was on life support and sedated to accept the ventilator. Both he and his wife had enthusiastically agreed to his participation in the study. They expressed the desire to have him contribute to new knowledge as a last legacy no matter how small that contribution

might be. It was "something constructive to do." Mrs. 12 also felt that the researcher would be one more person being concerned about her husband's well-being.

Mr. 12's contribution was impressive. In eight days, he underwent nine trials. Table 8 documents 'other' variables that existed concurrently with each trial. Week 1 consisted of six trials given in three days. The researcher visited and was present for 'rounds' the next two days. Three more trials were given on the next three days, after which, Participant 12 expired.

Table 8: Participant 12 – Other Variables

#	GCS	Hour	Day	Medication	Dose	Time	Comments
1	09	1330	03	Morphine Valium	2.5mg ?	1300 1300	No observable response
2	09	2100	03	Morphine	2.5mg	1600	Possible frown
3	09	1300	04	(no psychotropics)		(12h)	No observable response
4	09	2100	04	Morphine	5mg	?	No observable response
5		1300	05	(No psychotropics last 6 days			No observable response
6		2000	05	so patient can 'wake up' as			No observable response
7		2030	08	much as possible to say			Coughing
8		1500	09	goodbye to family))			Closed eye movements
9		1500	10				Moved left arm, face,yawn

Upon examination of Figure 6, the pattern is much as we first saw with Participant 11. Participant 12 seemed to stabilize for Trials 8 and 9. Where there was some slight variation, it occurred more frequently at the beginning of the first baseline or during a C intervention. The pattern changed radically the last two trials as the

measures varied wildly. This instability may reflect a life ending, as a top loosing stability as speed slows. Yet there appears to be a time-locked pattern emerging.

Figure 6: Participant 12 - Oxymetry

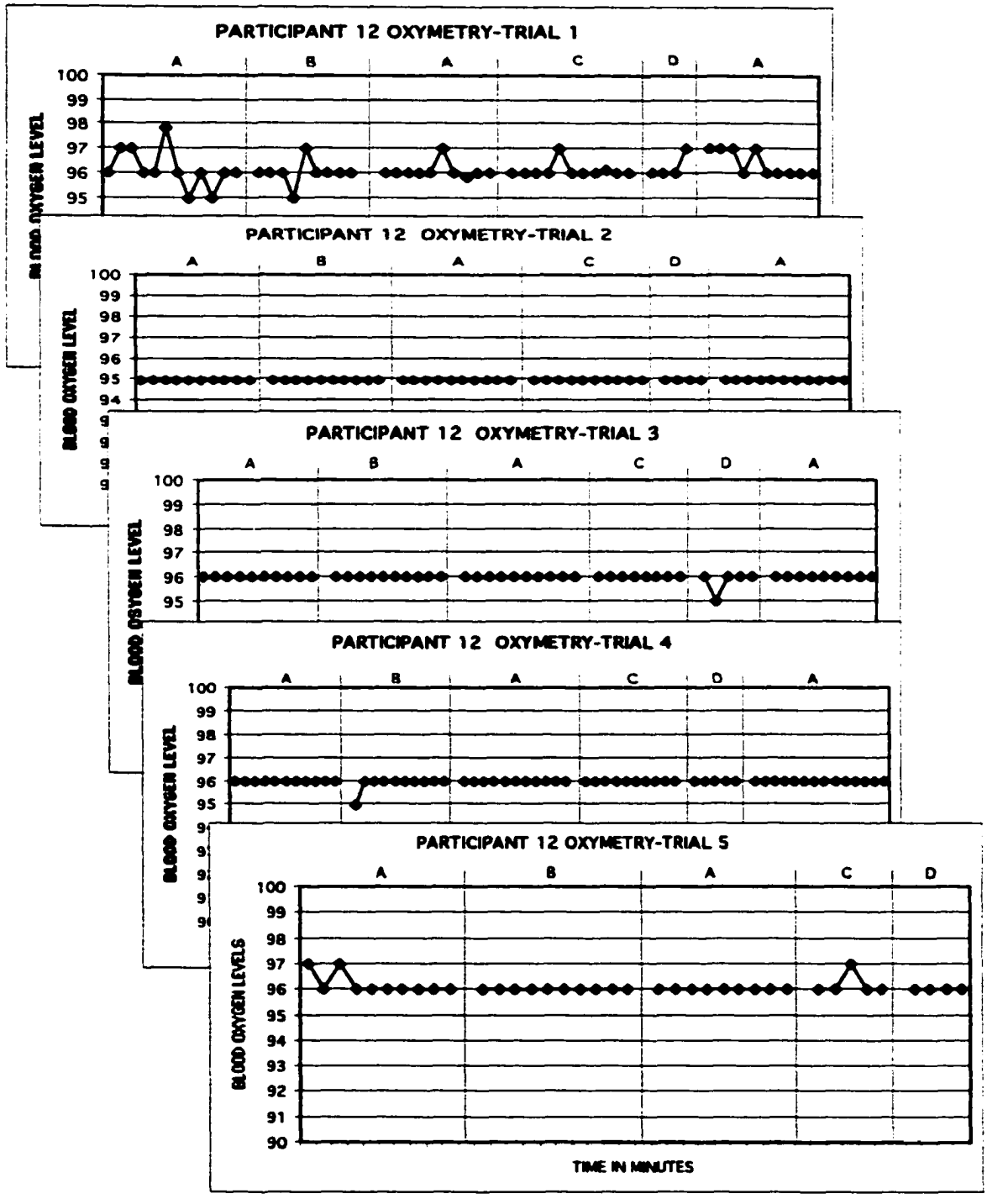


Figure 6: Participant 12 - Oxymetry (Continued)

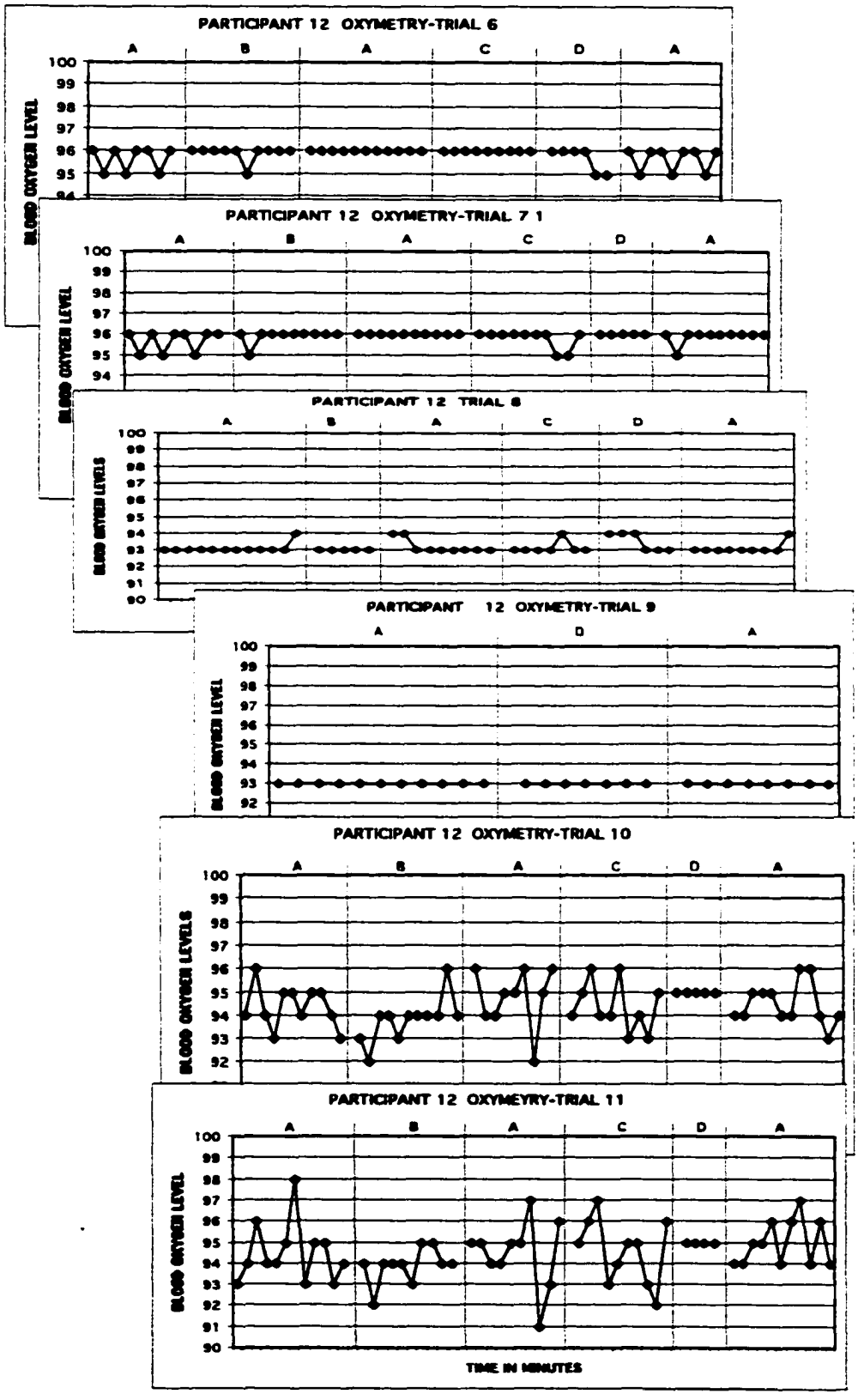


Figure 7: Participant 12 - Heart Rate

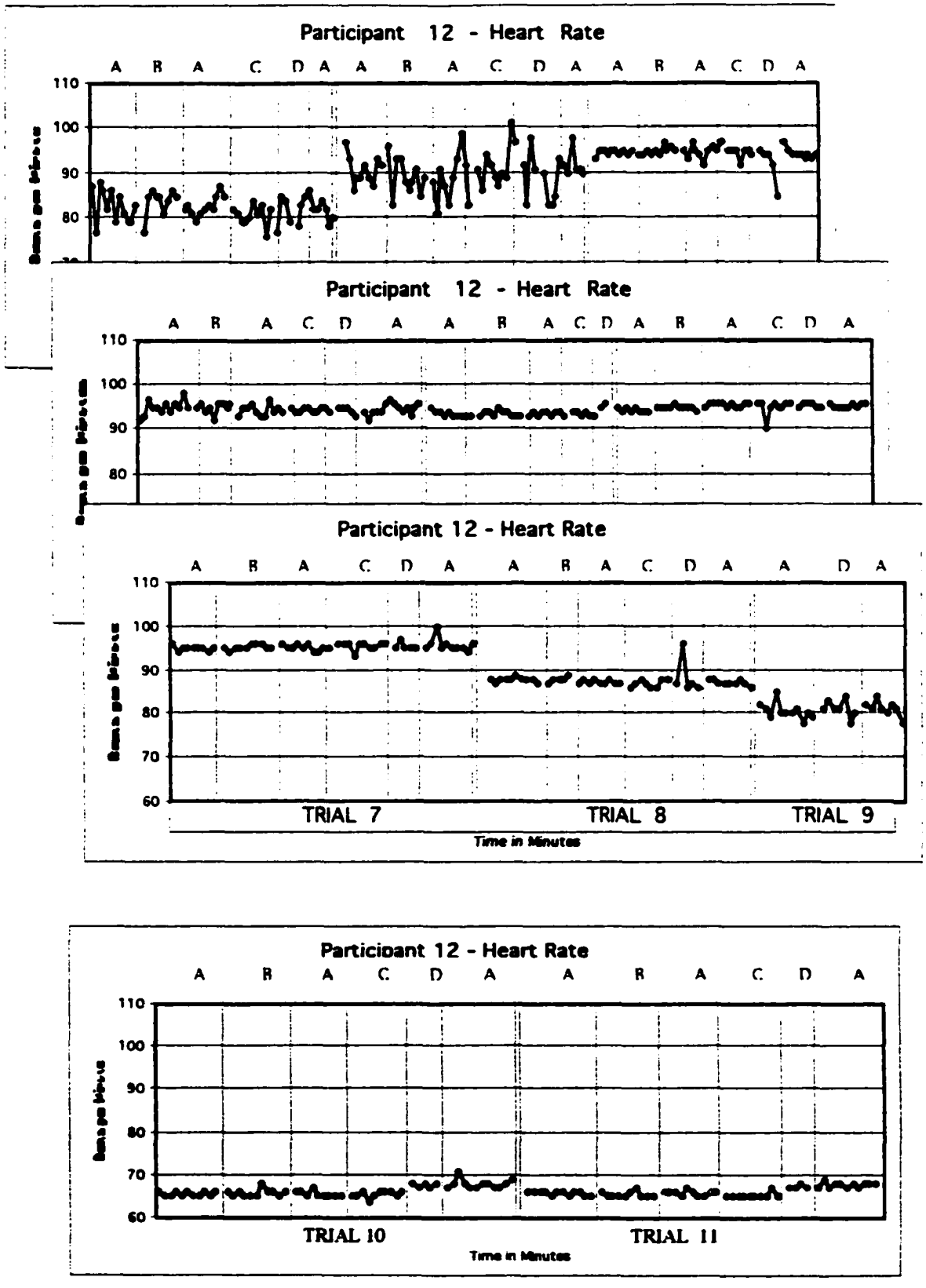


Figure 8: Participant 12 - Blood Pressure

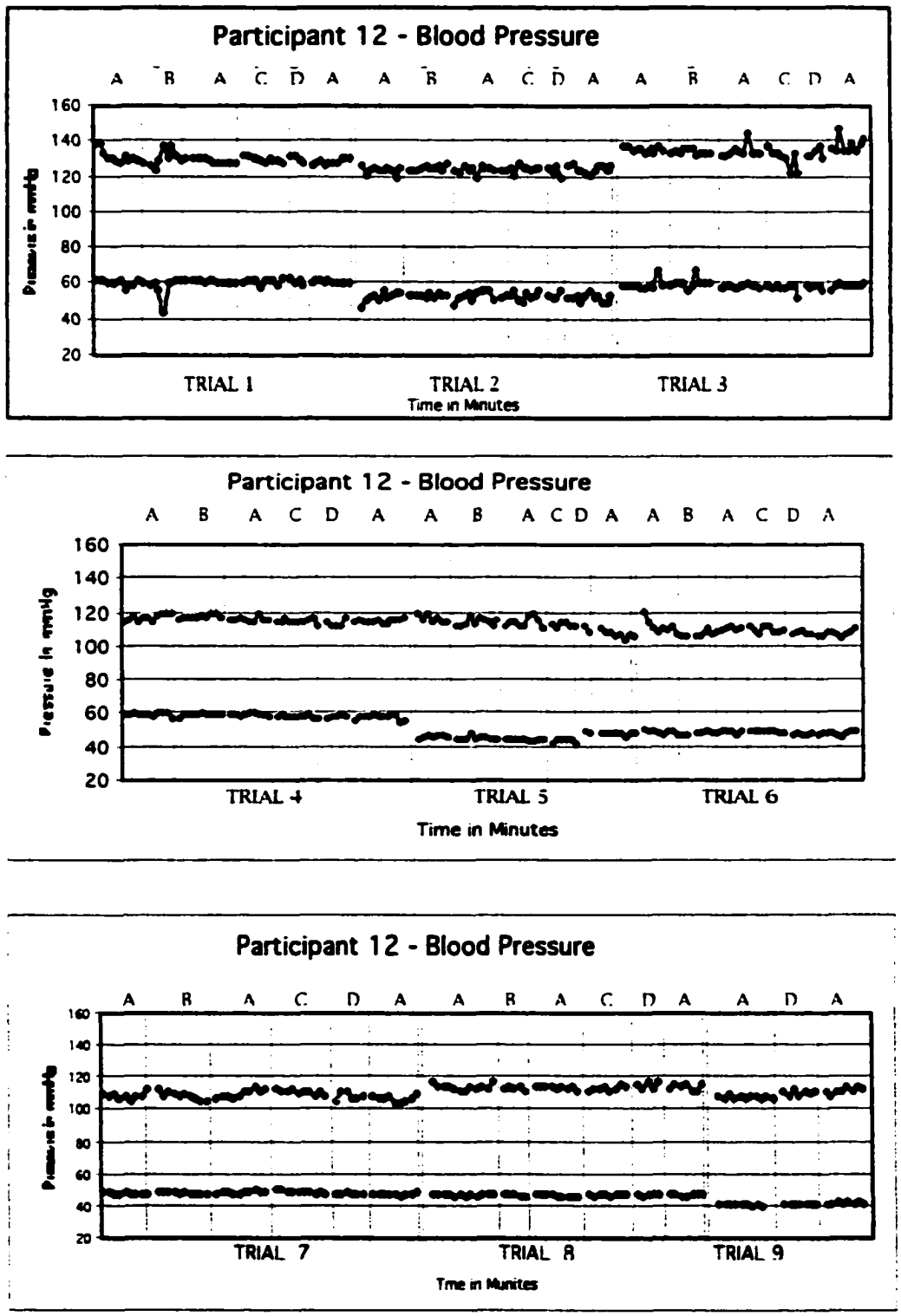
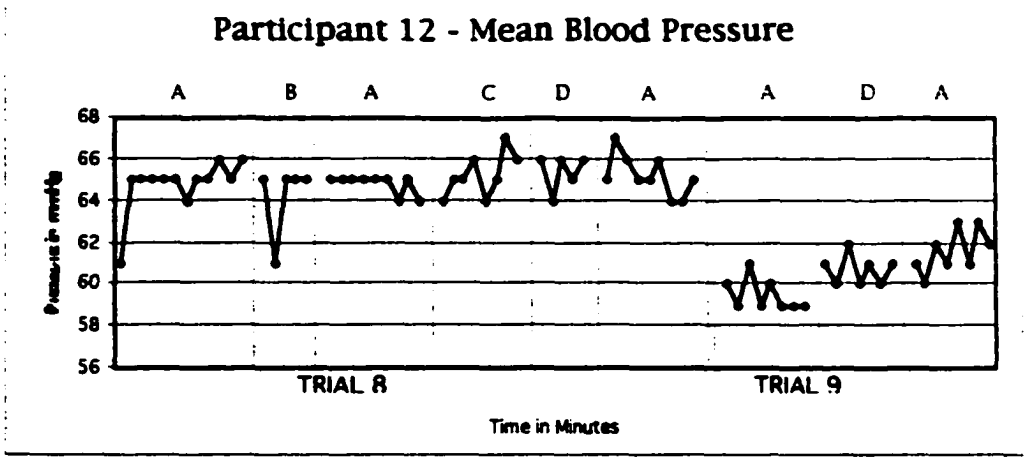


Figure 8: Participant 12 - Blood Pressure (Continued)



Note the A_2, C and D phases, which appear to replicate with the only steady measures in phase D, the phase found to be most volatile for unconscious patients who recovered. A further compression of the data is contained in Figures 7 - Heart rate, and 8 - Blood Pressure. Mean blood pressure for Trials 8 and 9 are also shown in Figure 8.

Participant 13

Participant 13, age 37 years, and her husband were the proprietors of a burgeoning city refrigeration business. They were the parents of a ten-year-old son and a teenage daughter, with a large extended family sprinkled over the western provinces.

No stranger to surgery or the ICU, patient had been admitted three years previously for a colectomy for megacolon and incontinence. She had been readmitted to have revision ileostomy that became more complex than anticipated. Participant 13 was entered into the study on the 6th day from her admission to ICU. As shown in Table 9, she was given four trials in three days, as she was

transferred to a regular surgical unit on the 9th ICU day. The researcher visited frequently to maintain rapport and to monitor Participant 13's progress. On the 14th day following ICU admission (5 days after transfer to the regular unit) a formal interview was conducted. Another was given on the 29th day; the day before she was transferred to a nearby rehabilitation hospital. Two months later, the day before the participant's discharge, a third interview was conducted.

During the interviews, Participant 13, like Participant 1, was given a facsimile of Ring's *Experience Rating Scale* (1980). Like Participant 1, she reported strong feelings of disassociation while being restrained (having her hands tied to the bed to prevent self-extubation). She had a life review and felt peacefulness when visiting with her deceased grandparents. She was aware of the presence of her twin who had been still born. She was able to move without her body and had the dysphoric feelings of drowning. Yet, she too denied awareness of the visits of the researcher until well after her discharge from ICU.

Table 9: Participant 13 – Other Variables

#	GCS	Hour	Day	Medication	Dose	Time	Comments
1	13	2145	06	Morphine Pavulon	2.5mg	1830	Nods appropriately Having dialysis
2	14	1830	07	Valium	2.5mg	1800	Responsive and cooperative
3	14	1230	08	Morphine	2.5mg	1000	Sitting
4	14	2015	08	Morphine Morphine Valium	2.5mg 2.5mg 2.5mg	1500 1700 2000	Awake and interactive

Results of Participant 13's physiological responses to the interventions are presented in Figures 9 to 11, which follow.

Figure 9: Participant 13 - Oxymetry

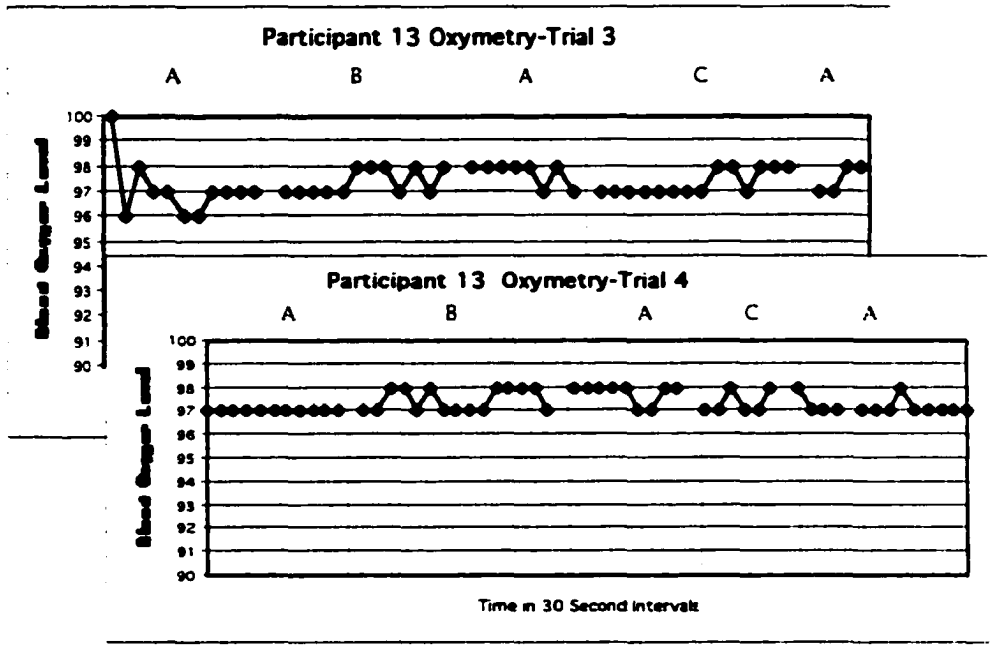


Figure 10: Participant 13 - Heart Rate

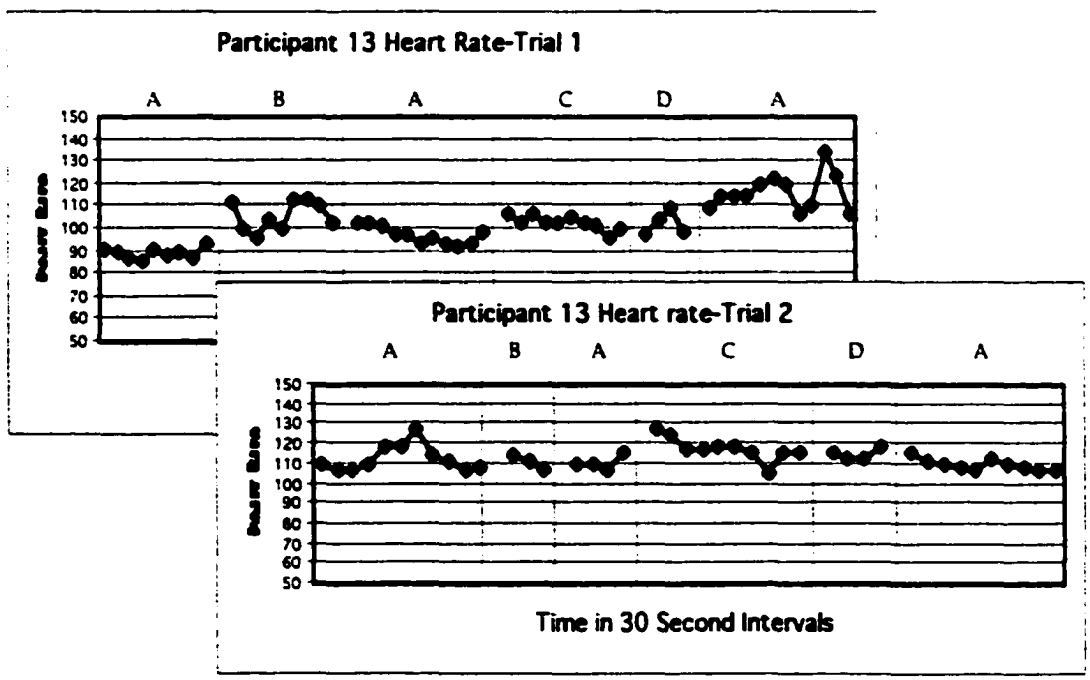


Figure 10: Participant 13 - Heart Rate (Continued)

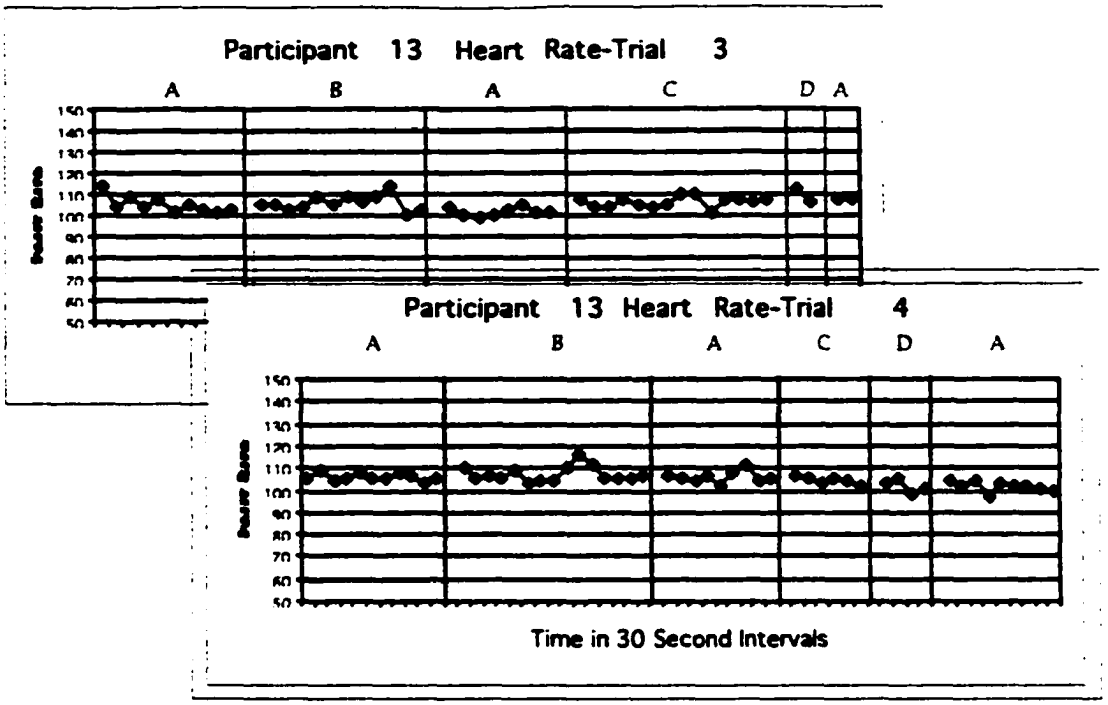


Figure 11: Participant 13-Blood Pressure

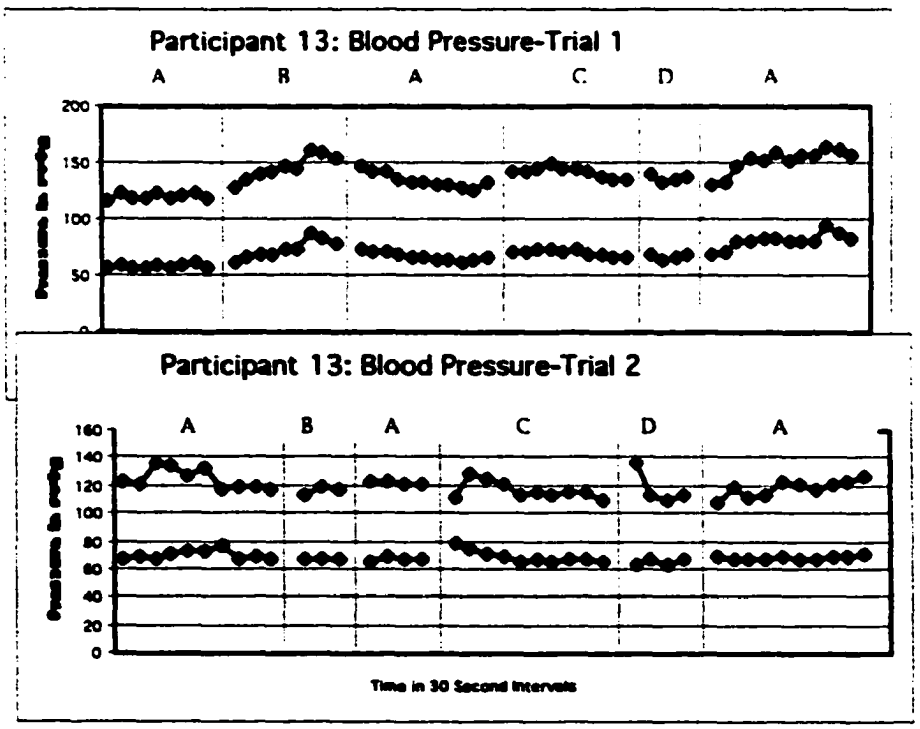
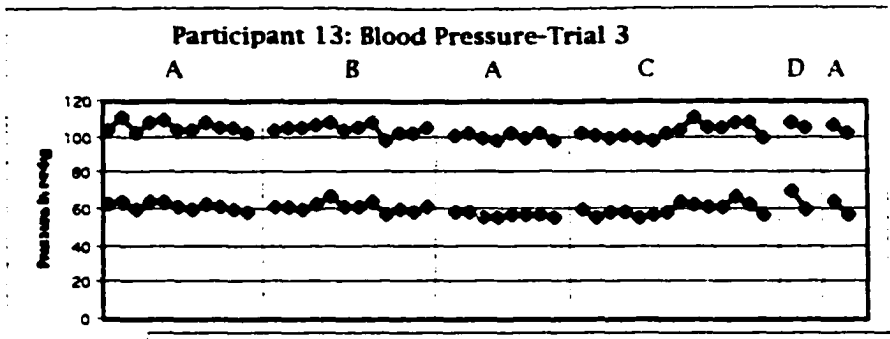
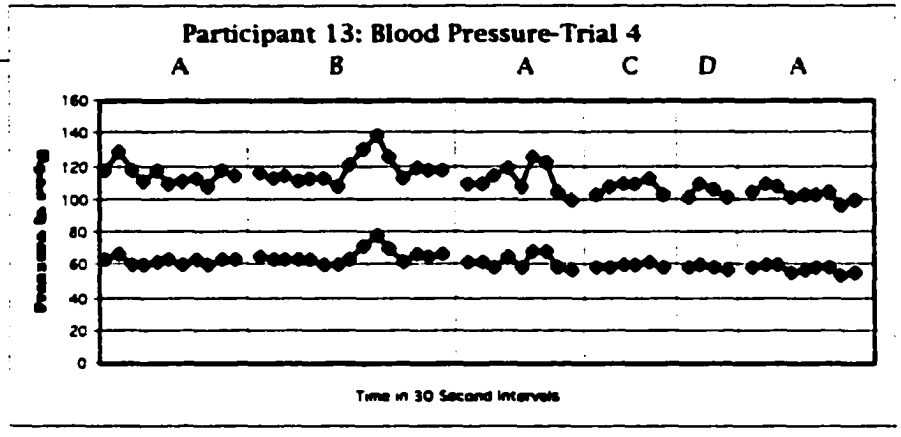
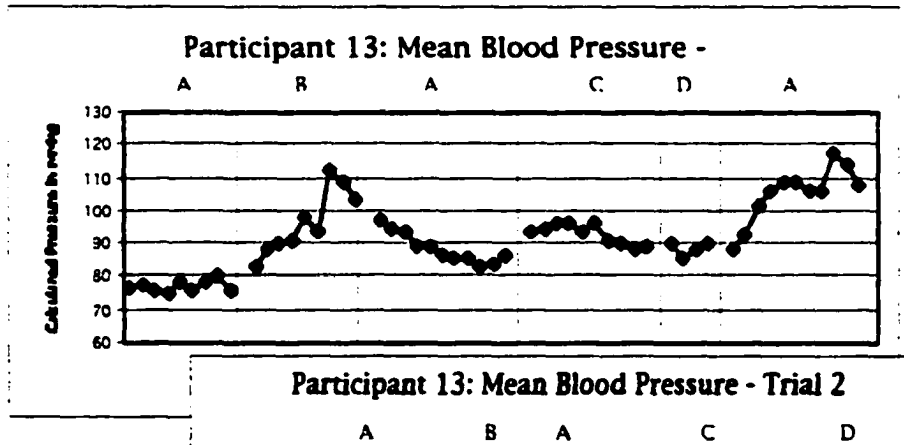
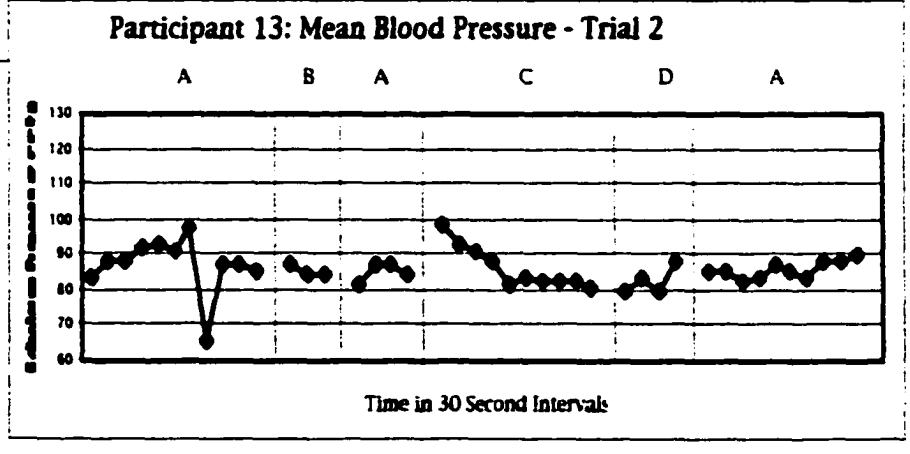


Figure 11: Participant 13-Blood Pressure (Continued)









The responses from each of Participant 13's trials were transcribed from the videotape at 30-second intervals. Her data were used to aid in future determination of the appropriate time interval for analysis. Were important data being obscured by the relatively long interval of one minute? Were there latencies that could not be seen by the length of time between data points? Finally, could the additional observations provide more confidence in the validity of statements of effect? Thirty-second intervals provided no discernable additional information.

Subjects 1 and 12, the only two to receive condition D (the active mental task without continuous instruction) had a different magnitude of response. Could this be explained by the fact that the participant was rapidly recovering, whereas the physical condition of participant 12 was deteriorating? As expected, there were greater differences between baselines and interventions than between interventions.

Implications for Future Study

The task of an exploratory study such as this is to generate questions that future studies might address. The task of future work will be to overcome limitations and delimitations that tended to obscure clarification of questions generated, such as the ones in the paragraphs above. For the most part, environmental limitations helped to preserve the usual context in which the ICU patient finds himself or herself. That, alone, is important to preserve in the interest of generalizability of indicators for applications generated

by a naturalistic study. Delimitations, those researcher-imposed restrictions, require future fine-tuning, as each needs to be scrutinized for significance, as well as effect.

Limitations

Limitations imposed by this study which might well be delimited in future work include:

1. *Medications.* Selection or categorization of patients according to features of medication regimens would help in the understanding of the roles and types of memory/experiences affected in unresponsive patients.

2. *Glasgow Coma Scale.* It was not clear that the GCS score had any relation to the patient's level of awareness, memory for events, nor the ability to be affected by the interventions.

3. *Communication abilities.* This study did nothing to clarify the effects of hearing problems on the dependent measures. Pre-admission communication skills might be profitable ground for exploration.

4. *Instrumentation.* Some data displayed on the monitors had the advantage of being available, but the disadvantage of being gross measures without sufficient resolution to identify patterns or small, but potently significant, changes in patient response.

5. *Number of subjects.* The survival of patients available for post-testing was very limited. From this study, however, we may estimate the number of patients necessary over a given period of time to have a sufficient number of participants complete the word

retrieval component intervention, and others requiring recall from implicit or explicit memory.

6. *Length of study.* The study was limited to the number of exposures to interventions and the type of data that could ultimately be used by the of speedpatients' recovery or demise. The patients who did not survive to actively participate may form, then, a separate population whose responses before death are unique and not reflected in the experience of survivors.

7. *Expectations for outcome (biases).* Although family, staff, and presumably self expectations for demise or recovery have not been heretofore mentioned in this dissertation, the author noted what appeared to be an elaborate, albeit implicit, system of "bias" in the delivery and use of healthcare services which might well influence health outcomes. This was illustrated explicitly in the unreported 'qualitative' data collected in association with the evidence presented in this chapter.

Delimitations

1. Length of study. The study was limited by the academic time constraints imposed by this researcher. Recommendations for further work would include not only the extension to involve more participants, but also a pre- and post-study component. A pre-study model could include a more complete history from family and a caregiver survey. A longitudinal study could acknowledge that some memories of events emerge many years following trauma. It would be important to investigate more fully the possible effects of elements of the ICU experience on subsequent mental and/or

physical health for the remainder of the life of the individual and consider the long term effects on family, healthcare dollars, etc..

2. *Exclusion and inclusion criteria.*

a. This study was hampered in obtaining sufficient numbers of participants by excluding patients who had less than *72 hours residence in the unit*, which is close to the average length of stay. The process of approaching family members was actually begun after 72 hours, and securing consent took additional time. Many patients were stable much sooner, or expired. Physicians could perhaps determine if a patient is stable enough to include earlier.

b. *GCS of 9 or lower* was a poor method of evaluating consciousness or unresponsiveness as there was some indication that patients who seem fully awake and aware have responses to the interventions that were indistinguishable from those judged to be unconscious. Further, GCS seemed to have little correlation with outcome.

c. *Patho-physiology* represented in the ICU in which the study was permitted excluded patient's whose admitting diagnoses were cardiac. In fact, a CICU adjoined. CICU patients, as a group, have uniform characteristics, treatments, and outcomes. Future exploration might well use this more homogeneous population.

3. *Interventions.*

Relaxation, imagery, and biofeedback. These interventions were not treated as distinct protocols in this study. Since a possible direction for study would be to distinguish

protocols that might actively produce benefit for the patient, distinguishing the effects of various protocols would be valuable.

Interviews, word lists, and questionnaires. These three approaches were all used to elicit information regarding the content of the patient's experience of, or memory of, both consensual and ideosyncratic reality. It is suggested that greater attention be given to the content and structure of these probes to better frame them in time and place relative to the 'objective' records. It proved important to use the least directive probe first, progressing to more directive questions and greater structure. That allowed the researcher to elaborate on spontaneous utterances, using a hierarchy of structure and scaffolding to elicit more information and draw out memory without contaminating the data by leading the participant, or planting false memory. However, most participants had difficulty providing the quantity and quality of text necessary for traditional qualitative analyses; therefore, methods for eliciting text using several levels of directiveness were necessary.

4. *Single-centre environment.* Multi-centre studies are valuable in that they level the effects of specific local routines and may include several researchers, thus limiting investigator bias or clinical proficiency. This study was delimited by the fact that the setting was in a large urban hospital. The factors affecting patient care and experience in smaller rural settings or diverse urban settings might produce vastly different results.

Discussion

Validity is threatened by both external and internal variability. Of major concern was the problem of selection bias and attrition. Only a few patients were able to complete the study because of high mortality and morbidity. This resulted in a unique group of survivors that would not necessarily be representative of the entire ICU patient population. Yet, the objective was to discover if *any* patient could hear and understand messages given verbally by someone at the bedside. Table 10 summarizes several instances during which we are confident that patients not only heard, but responded differentially to various verbal messages.

Table 10: Consistent differences between phases across subjects.

OXIMETRY							
S#	A-B	A-C	B-C	A-D	C-D	B-D	A-E
1	YES	no		no	no		almost
10	no	no	no				
11	no	YES	no				
12	YES	no	no	no	YES	YES	
13	no	no	no				

HEART RATE							
S#	A-B	A-C	B-C	A-D	C-D	B-D	A-E
1	no	YES		YES	no		no
10	YES	YES	YES				
11	YES	no	no				
12	no	no	no	no	no	no	
13	YES	YES	no				

SYSTOLIC BLOOD PRESSURE							
S#	A-B	A-C	B-C	A-D	C-D	B-D	A-E
1	no	YES		no	no		YES
10	no	YES	no				
11	no	no	no				
12	YES	YES	YES	no	no	YES	
13	YES	YES	no				

DIASTOLIC BLOOD PRESSURE							
S#	A-B	A-C	B-C	A-D	C-D	B-D	A-E
1	no	no		no	no		YES
10	no	no	no				
11	YES	no	no				
12		no	no				
13	YES	YES	no				

PULSE PRESSURE			
S#	A-B	A-C	B-C
11	YES	no	no

Major threats to internal validity, or generalizability of results, usually include time and circumstantial variables. Differences may

occur in memory processes according to time of presentation of stimuli (e.g. before or after medications, am/pm, etc.), multiple treatment effects, motivation, orientation and a host of 'state dependent' variables; that is, variables associated with the physical and emotional 'state' of the individual at the times of both stimulus presentation and recall. The use of the pre-experimental design is intended to ameliorate these problems. "Pre-experimental designs refer to demonstrations that do not completely rule out the influence of extraneous factors (Kazdin, 1984, p. 87)."

Medical regimens in ICU are likely to vary considerably between subjects. Presence of neurotoxins, medications, varying levels of consciousness, and many similar factors varied, uncontrolled. Controlled variables were presentation of stimuli and evaluation of responses. Thus, responses were illustrated by either positive or negative change in values of the dependent variables from baseline. From this one small control, it will be suggested that future research explore the possibility of the effects of order of presentation of interventions more closely. There was little variability of responses that could be linked to the uncontrolled conditions except the degree of illness, or, conversely, approach of health. The more ill the patient, the more notable the variability of responses and the closer values were to normalcy, the less pronounced the response, with a few exceptions.

Finally, we feel that the search for an appropriate method for studying that most ephemeral activity of the human mind we call consciousness was rewarded. It can be said that, regardless of the effects of the myriad of uncontrollable conditions affecting validity,

sometimes, some patients appear to hear and respond to what is said to them while they are deemed to be unconscious during critical illness. Moreover, there is indication that some patients are sometimes aware of the environment of consensual reality as elements of that environment intrude in dreams, phantasms, hallucinations, or whatever observers call 'altered states' which are later recalled and recounted by survivors. When recalling experiences, former ICU patients report 'being there', whether that 'there' is in consensual or idiosyncratic reality.

CHAPTER 5: THEORETICAL DISCUSSION

> *One photon is sufficient for decoherence in quantum mechanical systems . . . Decoherence surely allows us to inhabit separate worlds in which we can each usually do and perceive our own thing (Vaas, 1997).*

Audition

A very recent publication describes cerebral blood flow in five patients in a vegetative state (of hypoxic origin), age-matched with eighteen normal controls, in response to auditory stimulation with clicks.

> . . . the auditory primary cortexes were still activated during external stimulation, whereas hierarchically higher-order multi-modal association areas were not. Such a cascade of functional disconnections along the auditory cortical pathways, from the primary auditory areas to multimodal and limbic areas, suggests that the residual cortical processing observed in the vegetative state cannot lead to the integrative processes that are thought to be necessary for the attainment of the normal level of awareness (Fiore, et al., 2000).

The authors were asking questions similar to the ones addressed in this study. They established that the auditory stimulation was acknowledged by a time-linked response from the auditory cortices. We have long known that in humans and other mammals, the auditory system remains relatively intact for as much as 20 minutes after death, and is responsive to click stimulation. In animals from which we can isolate and extract the cochlea, such as the guinea pig, the end organ of hearing remains intact and

functional indefinitely if prepared properly. Thus, the results of this study are not surprising. Perhaps less predictable, is the failure to activate the frontal-parietal association areas. Yet, what would be the necessity of those areas to respond to clicks? The recognition of clicks is processed at the subcortical levels. This does not preclude the response of those areas in the alert, healthy individual; but those areas are not required for the response.

What if the Fiore, et al. had used phonemic stimulation instead of clicks? We know from ablation studies that cats can discriminate between phonemes at the level of the thalamus. Learning (left-right tasks) in cats was found by Harrison (1978) to take place in the lateral lemniscus (LL) in the pons, which is distal to the medial geniculate body (MGB) of the thalamus.

Since auditory stimulation is information from the external world, it is important to remember that the characteristics of the stimuli are of utmost importance to the organism. The auditory system is designed to locate the external source of the stimulus, then analyze the meaning the stimulus has for that individual. In the most holistic manner possible, the auditory system maintains the integrity of the stimuli by duplicating the frequency map of the cochlear epithelium (*tonotopic* organization) in all nuclei of the auditory system, even the cerebral cortex. This ensures the transmission of that information by an elaborate system of duplication and descussation of neurons at every level up the pathway, which becomes more elaborate and diffuse at each more central synapse.

> The important feature of the cat studies is that . . . the LL has the greatest communication with the reticular activating system (RAS) of any auditory nucleus. The RAS receives information from all sensory systems and forms an indirect route of communication between many parts of the brain . . . All ascending fibers appear to have synapses with neurons in the thalamus at the medial geniculate body (MGB), the last waystation from which the auditory radiations to the temporal lobe in the cortex originate (Spencer, 1988, p. 13).

The function of the MGB, according to Durrant and Lovrinic (1977) is to permit the detection of specific features of the stimulus and facilitate the processing of complex sounds such as speech.

If speech can be processed subcortically, Fiore, et al.'s final assumption (cited above, " . . . disconnections . . . cannot lead to the integrative processes that are thought to be necessary for the attainment of the normal level of awareness") is erroneous. The error having been using a 'top-down' interpretation of the data (with the added confusion of their use of the words, "level of awareness").

Issues

This study has generated a 'bottom-up' model of awareness and reality building in the living mind. First, this model is consistent with our knowledge of the body and its relationship to consensual reality (the external world) and to the mind's idiosyncratic features (the internal world). I propose that a fully operational cerebral cortex is *not* required for hearing nor interpreting incoming auditory information. This can be accomplished at subcortical levels largely because the auditory nerve enters the brainstem at an

anatomically distinct and relatively distant point from the cortex. It is such an evolutionarily ancient organ (from the lateral line of the fish), that it is well protected, maintained and utilized. Auditory experience of the world can be given meaning at subcortical levels as well. The system is rich in connections to areas containing memory, where language and all other learnings reside. If once, in the developmental history of the individual, he or she has thought a thought, had an experience, or learned something, it is never unlearned, nor forgotten - even at the most basic processing levels. Having *ever* applied cortical reasoning or processing skills to sensory information, the organism and the information are left changed forever. Sensory information is integrated, and used subsequently to identify and process new information. Thus, if, in the dying process, the cortex ceases to be operational, the "primitive brain" could utilize the lifetime of experience and learning to maintain the Self and build an adequate reality in which to operate. In the present study, concrete interpretations of things heard from the environment appeared to characterize that internal, ideosyncratic reality. It may be an indication, or even the hallmark, of subcortical thought; thought without the symbolic contributions often attributed to human cortical activity.

Does it follow from the foregoing argument that the 'vegetative', or non-responsive, adult could ". . . attain a normal level of awareness"? The model generated by the present study *would* support the thesis that unresponsive patients could have conscious *experiences*; a term we might equate with *levels of awareness*. One might assume the authors, Fiore, et al., mean, when

they say 'normal', that participation in consensual reality can be observed by another. But one can never view the qualia of experience without the experiencer. Never with a PET scan alone! Reality is the product of mentation.

As long as the thalamus is operational, it is logical to postulate that the individual may have a full range of auditory experiences. Moreover, through the process of *synesthesia*, brain cells devoted to other sensory systems might be recruited for audition without loosing their original identity. The result would be that auditory information could produce visual images. The substance of creativity may not be eliminated, and may also contribute, in the creation of a complex idiosyncratic reality in which the Self may flourish.

> . . . The child perceives only personally meaningful objects, and that what he perceives is not so much the objects as their meanings . . . The young child's perceptions are *synesthetic*. That is, there are no clear dividing lines among the various sense modalities . . . This view overlooks both the evolutionary history of the senses, which indicates that specialized modalities have differentiated out of a *sensorium commune*, or generalized (probably electrochemical) receptor surface, and the evidence is indicating that synesthetic effects are far more common in children than in adults (Church, 1961, p. 10).

For our purpose, we must call attention to the findings of Alkire and Haier (2000), who report that several studies revealed the thalamus to be a primary target site for the effects of anesthetics on human consciousness. This has led them to hypothesize that the essential common neurophysiological mechanism underlying

anesthetic induced unconsciousness is likely to be, as with sleep-induced unconsciousness, a hyperpolarization block of thalamocortical neurons.

> . . .the plethora of effects anesthetics have on cellular functioning ultimately all converge on a single neuroanatomic/neurophysiologic system, thus providing for a unitary physiologic theory of narcosis related to consciousness (Alkire and Haier, 2000).

The implication of this author's theoretical construct is that if the thalamus is operational, the individual can build a complete internal reality without higher cortical contribution.

Intelligence, critical illness, and chaos

> Overall, the musical humm of the receptors as they bind to their many ligands, often in the far-flung parts of the organism, creates an integration of structure and function that allows the organism to run smoothly, intelligently (Pert, 1997, p. 27).

Intelligence, the activity of the mind, takes place in the body! Intelligence guides our actions on the basis of what we perceive. Auditory messages arise outside the body, so the perception and interpretation of environmental auditory stimuli is very much a part of what we are. The important role of language is that it is the meaningful part of the auditory environment in the organization of human intelligence.

Ruelle (1991, p. 158) sees neuroscience as being concerned with brain 'hardware' problems and psychology as being concerned with 'software' problems. He sees need for amalgamation of disciplines to tackle what he characterizes as an engineering

problem, that is the understanding of intelligence. "Our brain and intelligence have a basis consisting of gadgetry strictly geared to surviving in a certain type of environment (p. 160)."

The ICU creates a situation working at odds with natural evolutionary determinates by resuscitation and maintenance of those who might have had an earlier demise. Patients may have bizarre experiences related to existential changes. Commonly, a first question by a critically ill patient to his or her doctor is, "Am I dying?". This is not a plea for divine intervention; it is a practical question. It asks for existential clarification. "What is this unusual relationship with you, the world, with my body, that I am experiencing?"

We might introduce therapies in the form of manipulation of the auditory environment to exclude negative images and provide direct suggestion or 'coaching' for restoration of function, orientation, adjustment of body schema, or other objectives in the promotion of improved mental, as well as physical health. The patient no longer can be viewed as an amalgamation of sub-sets, of diverse systems. The patient reflects his or her whole in every part; and the whole includes both mind and body, each of which replicate the other.

Illness affects the subsequent existence of the patient and of all who are connected to the event; the emotions of family, the knowledge of caregivers, etc.. It affects every aspect of the structure, function, being, and existential relationships of all. It alters the future trajectory of every part of the 'system' and thus, becomes a part of the original condition upon which the future universe depends.

The rise of holistic thinking

Chaos theory has arisen from physics because of the inconguence of the theory of relativity and quantum mechanics with the older Newtonian mechanics to become the New Science. The New Science is holistic, not predictable, and leaves the old Cartesian dichotomies behind. In terms from the new physics of quantum mechanics, life is seen as a 'system'. In a lively and engaging fashion, Combs and Holland (1990) review the shift brought about in the last century in physics by the mounting number of questions the old mechanistic world of Newton failed to explain. Einstein's general theory of relativity liberated thinking and Heisenberg's quantum theory began to restructure it. The "new physics" leans strongly on the notion of wholeness;

> The cosmos is of-a-piece, not empty, but filled with itself, much as a painting is filled with itself. There are foreground and background regions, but the canvas is continuous . . . the universe as a continuous, unbroken fabric . . . (Combs and Holland, 1990, p. xxiii).

Motion and action are also, as is everything, dynamic, continuous and unbroken; it is *the holomovement.*

Dependence on initial condition is part of quantum mechanics. Creativity and life are in the nature of the universe. Life creates unpredictable futures, although the past (initial condition) can be determined from even the tiniest fragment of the present (like a hologram of time: known in the parlance as the 'holomovement').

Cells with resting potentials fire intermittently, as voltage rises. In the case of resting potentials, the firing is random

between cells because there has been no stimulus organizing the cells, causing them to discharge simultaneously. In Chaos terms, a stimulus would be called a 'strange attractor'. Any variable introduced into a system (a stranger) will attract elements (an attractor) or the flow of the system. The introduction of a strange attractor into a system changes the trajectory of the movement of the system. It introduces the element of non-determinism, or unpredictability of the future.

In 1977 The Nobel Prize in chemistry was awarded to Ilya Prigogine for demonstrating that when complex systems are placed in a flow of energy they can restructure themselves into higher orders of organization. Individual molecules bouncing around chaotically can be carried about in large currents and become part of them without losing their own identities. This tendency for higher-order structures to emerge from lower-order ones is seen in the behavior of complex patterns of individual cells or even in the behavior of entire societies (Combs & Holland, 1990, p. 43). This replication of patterns at various levels are illustrated by "fractals" such as 'The Mandelbrot Set' (See: Jantsch, 1980). Fractals are patterns, such as the tree-like (dendritic) pattern, that replicates, such that a microscopic view might be represented at the galactic level. A palm frond might look like a coastline with fiords, or a galactic gas pattern.

Chaos is anti-deterministic, but at the same time it is deterministic in that it states that systems tend to replicate, or re-establish themselves in the absence of strange attractors

(intervening variables). The oscillations between chaos and organized systems is primarily the effect of energy.

Information is the fuel of the holomovement. David Bohm is the physicist who has done the most retrofitting of his theories of chaos and the new physics to psychology to produce a unified theory of mind and matter. He used the term *active information* ('to put into a form') in its literal sense, to describe the manner in which form and shape are given to movement (Bohm, 1990, p. 279). It is said that most, if not all, living things produce some form of information (words, structures, DNA, etc.). Perhaps it will be said that all things do.

Like the hologram's opposite, the lens analogy, we have come to expect a sharper image to be produced by a smaller piece, or over a smaller projected area. This sharpness is equated with greater detail, which, in turn, we equate with more information. With the hologram, the smaller the piece of the whole, the fuzzier the image, but the information in pieces, small or large, is complete. The larger the image or greater the parts, the more easily we see the detail, while comprehending the whole.

Wholeness implies *non-locality*. It will be difficult to stop relying on location of function to understand neural events. Candace Pert, Research Professor, Department of Biophysics and Physiology, Georgetown University School of Medicine, discoverer of the brain's opiate receptor, may help point the way to a resolution by employing her biochemical research perspective in the formulation of a unified theory of emotion (Grodzki, 1995).

The discovery of an endogenous substance that fit the body's opiate receptor is known as the Hughes-Kosterlitz findings. Dr. Pert has identified many peptide ligands throughout the body which she calls "molecules of emotion" (Pert, 1997, p. 25). Ligands and their receptors have come to be seen as "information molecules" - the basic units of a language used by cells throughout the organism to communicate across systems (often in extra-cellular fluid) such as the endocrine, neurological, gastrointestinal, and even the immune system. "I prefer a broad term coined originally by the late Francis Schmitt of MIT-*informational substances* -because it points to their common function, that of messenger molecules distributing information throughout the organism" (p. 176). She writes that;

> . . . we do store some memory in the brain, but by far, the deeper, older messages are stored in the body and must be accessed through the body. Your body is your subconscious mind (Pert, 1997, p. 306).

If chaos is anything it is NOT linear (Combs and Holland, 1990). Linear models by nature go from one quality or quantity to another, going from a healthy 'normal' to the pathologic. Most of the literature generated in the 1960's by interest in hallucinogenic and other psychotrophic chemicals, with 'altered states' research (see Tart, 1969) generated by psychotherapeutic techniques, religious cults, brainwashing, psychogenic healing, sensory deprivation, etc., is currently being resurrected and re-examined under the light of the new thinking generated by the rise of holistic ideology or Chaos theory (Ruelle, 1991; Gleick, 1987).

In 1988, John Lilly participated in his own ketamine experiments, taking the drug thousands of times, then recording his immediate descriptions of the experience. A more recent inquirer, Karl Jansen (1995), published an impressive treatise on his experiments, *Using ketamine to induce the Near-Death Experience*, in which he states the phenomena are due to blockading glutamate neuro- transmitter binding sites (which can kill brain cells). Ketamine, he asserted, prevented excitotoxicity, thus protecting brain cells from death and producing an altered state of consciousness.

Ketamine studies have begun to integrate the Bodymind data in a scientifically formal pursuit. These are the needed Holistic re-examinations recommended by Ruelle (1991) and Gleick (1987). At the same time, Chaos theory would dictate we accept the notion that all states of consciousness (all alternates, 'part-persons', ego states, or what have you) could exist simultaneously as well as sequentially.

The Dying Mind: Evidence of the Dissolution of the Self

There has been considerable research regarding physical processes when death is imminent. There has been little scientific attention to the dying experience and processes taking place in the mind in preparation for death. How does the mind die, if it does? Does it follow the same time-line as the dying body? Can it survive

longer, or cease to exist sooner? Is the Self independent of mind or is it dependent?

As the body fails and perceptual information regarding *consensual* reality is corrupted or diminishes, the Self might attempt to construct an internal reality, or frame of reference, in which the representation of the body (schema/percept/thematization) can exist, and from which the dissociated Self can view the body as an object. As construction material, the Self uses the only data it can access, memory. To this is added the literal interpretation of any residual external sensory data. No metaphor, nor abstract symbolism, is used to construct the new environment once shutdown of cortical functions (by damage, drugs, or other means) has occurred. This is, perhaps, the hallmark of subcortical thought. Future research will determine if the presence of symbolism is the distinguishing feature of cortical thought, and if that distinguishes dreams from the phantasms of end of life experiences.

There is some evidence that, in response to the threat of physical death, the mindbody dissolves and prepares to accept reorganization into whatever form ensues from death. This is the culmination of the reversal of a life-long emphasis on 'individuation.' From a holistic point of view, the proposed model postulates consciousness as the point of view of the Self and the creation of an individual Self as the main objective of life. Might this simply be another model of other natural structures - that of separation and merging - the ebb and flow of the Holomovement?

Implications for Research and Therapy

Does the auditory environment 'get through' to the unconscious patient? If it does, then does it influence the individual? How might it influence the individual? How might the auditory environment of the ICU be altered to facilitate patient cooperation, recovery, and emotional wellbeing? Implications for further research should clearly point toward future practices as well as documenting various changes introduced into the auditory environment. The effective of use of suggestion at various levels of consciousness can be measured when the patient has regained full health or orientation. Sleep cycles and levels of cognitive arousal, as well as effects of medications on cognition, can be monitored by technologies such as topographic mapping of ongoing activity, scanning for blood flow and temperature, imaging, etc.. Underlying all is the need to establish a foundation of credibility for the hypothesis that an open communication channel from the environment to the patient's active intellect exists, however disoriented one may be from the disruption of reality caused by illness and treatment.

We need to generate some hypotheses as to the nature of the mentation that produced the patients' illness reality. The normal reaction to trauma is dissociation. Although patients can often (in 60.7%, or 17 of the 28 trials in this study) hear what is happening in consensual reality, they exist largely in an idiosyncratic reality forced by the trauma.

We should restate a view developed by Pert, as she has generated hypotheses that can give us a new way to think about a unified theory of mentation AND body. With a unified theory, we can entertain the effects of disruption of the holistic balance of the Bodymind brought about by life-threatening illness or the dying experience.

> The concept of a network, stressing the interconnectedness of all systems of the organism, has a number of paradigm-breaking implications. In the popular lexicon, these kinds of connection between body and brain have long been referred to as "the power of the mind over the body." But in light of my research, that phrase does not describe accurately what is happening. Mind does not dominate body, it *becomes* body - body and mind are one. I see the process of communication we have demonstrated, the flow of information throughout the whole organism, as evidence that the body is the actual outward manifestation, in physical space, of the mind. *Bodymind*, a term first proposed by Dianne Connelly, reflects the understanding, derived from Chinese medicine, that the body is inseparable from the wind. And when we explore the role that emotions play in the body, as expressed through the neuropeptide molecules, it will become clear how emotions can be seen as the key to the understanding of disease. (Pert, 1999, p.187)

This paper is the result of pre-experimental exploration of the topic of the patient's experience of dying. The applicable results have been in the implications for further research that this study has revealed it's primary value.

To illustrate the interpretation of specific elements in the patient's auditory environment in ICU, here is a presentation of a

portion of an interview with patient who recalled events, which were documented in consensual reality in her medical chart.

> *My experiences in my dissociated reality seemed to have a desert coastline setting. I did not know until recently that the U.S.- Mid-east military action known as "Desert Storm" had begun and was over while I was ill in the ICU. I was told that the TV and radio carried much coverage and that I was being told world news by family and visitors who were attempting to orient me toward the world. I can see now how that influenced my illness experience. I also began to have very distressing 'hockey dreams', only to find later that during my illness, our local hockey club was in the playoffs and everyone was watching games on TV and talking about them. I realize now that there must have been a lot of violence reported or discussed and that I was very sensitive to the violent images.*
>
> *The unit was noisy, full of the hustle and bustle of a busy barnyard. There were swans and geese, a bear, a kangaroo, many chickens. I had a Swan-Ganz catheter as part of the monitoring regalia, was on a Bear 5 ventilator, had kangaroo pumps (I don't know where), and, at one time, had a PEEP of 12, which delighted my family. That was my noisy barnyard!*
>
> *Later, I was in a cold and dark polar-white world, quiet; waiting to recover. Only a large bird watched and waited until the dawn. I can only speculate as to the local of the igloo, but I am sure that silent bird was the ventilator alarm which, at one point, I felt I had learned to control. I certainly knew the significance of the alarm and knew it was my cry for help should I need it, for at other times I practiced setting off that alarm to attract attention.*
>
> *These scenes were, I believe, directed by the things I heard in ICU. My 'art line' was one of my proudest possessions, as it allowed me to pursue artistic mental*

> *activities while in my in my alternate, dissociated settings. I painted, wrote and illustrated children's books, and heard them read at night to children who were preparing for sleep under their own teepees. I waited with anticipation for the day I would have my own teepee. I did not know of the ICU use of 'arterial lines' or the 'T-piece' when weaning patients from the ventilator until well after my illness. While ill, I rode gleefully around the countryside in a Rolls Royce (" . . . the Rolls Royce of monitors," had been a physician's comment).*

This patient had vivid memories of her experiences in her idiosyncratic reality. Elements of this alternate reality could be seen to have been suggested by things heard in ICU. The patients in this study, who were later interviewed, had similar accounts.

We can verify the co-occurrence of the patient's experience with the event in consensual reality. We did in the account of Participant 10, who later correctly recalled that a word was *not* one of the words given to her. We did in the account of Participant 1's experience of being tied to the stake and kicking for his life in the Indian village, and his being restrained in ICU and kicking at the nurses. Moreover, we do in the comparison of ICU language and procedures related above.

These illustrations of the differences between consensual and idiosyncratic reality are based on the sensory information available to the patient that forces the individual to create the alternate reality. The characteristics of translation of information from one to the other state include a literal interpretation of words and phrases based on the patient's prior experiences and learnings. There is ample indication in this study that the patient can respond to the

'message'; therefore, careful control over those messages should be exercised to avoid doing harm to the patient.

Another issue emerges. Can the dissociated patient be recalled from that idiosyncratic reality back to consensual reality to hear certain messages and/or respond to instructions? The non-participant patient continues with documented recollections:

> *I was 'recalled' several times to the unit, where my body lay. The first time, I was being asked by my best friend to do something. She explained that they (the physicians) were considering placing me in an experimental program for use of a drug that my family hoped might save my life. In order to be eligible for placing me on the experimental protocol, my blood creatinine levels needed to be below 600 until the next morning. My friend suggested some images. I recall my silent reaction was, "What the [expletive] is creatinine and how can I control that?" Her explanation included a description of the kidney's cleaning a dirty substance from the blood. In my mind, I began to fit my kidney cells with aprons and give them brooms with which to sweep all blood cells clean from dirt and other refuse. After a night of sweeping, I was exhausted, but my blood had remained clean enough so I could be entered into the study!*

An examination of this patient's chart and family notes indicated that they had been approached with an explanation of the study on the 3rd ICU day. The study was commenced on the 5th day. At 1100h of the 4th day, the patient's creatinine level was 540 umol/L. A family update was given at 1300h, after which the imagery instruction was given by the friend (who masqueraded as a daughter). The patient had a GCS of 3. Medications included

fentenyl and Diprivan for sedation, and Pavulon for muscle relaxation. The lab report shows that creatinine levels were 529 at 1630h, 506 at 2230h, and continued to fall the next day to 488 umol/L. Although the patient could not physically respond, an active intellect was fully in contact with consensual reality, and responding mentally to the request to participate in maintaining her own physical condition. Of course, there is no proof that the imagery had any effect on blood creatinine levels, but at least the values did not rise during that period of time.

Future study could well capitalize on this ability of some patients to mentally respond and become caregiver associates, participating in their own wellbeing or recovery. The effectiveness of that activity will doubtlessly be determined in the near future.

> *I was called back by music. When it was time to leave, my daughters would put on looped music tapes before they left. The music would play all night. This recalled me to the unit. I knew it was for me; it was my favorite music. That signaled the time to rest and sleep. I do not think I could have found my way back sometimes, had I not heard my music; and I was frequently oh, so exhausted!*

Music, regardless of other benefits, can be an excellent masker of ambient sound and possibly harmful conversation held within earshot of the patient. We have seen how the messages of radio and television can be distressing. It is unlikely that music could transmit distressing images with such ease. Of course, individual experience could produce distress. The physiological effects of music in an

unstable or disordered system would be an exciting area for future research.

To which ICU messages did our 'participant observer' attend?

I recall the physiotherapist explaining that he was going to exercise the muscles in my legs. He did not mention that he was aware of my knee replacements. I was worried he did not know and would inadvertently force the leg to bend more than 90 degrees and break it. So, I mustered enough strength to lock the knee in a straight position from which he could bend it not at all! He was right to tell me what he was going to do, but he didn't tell me enough to secure my consent and cooperation.

Many times nurses and others were telling me what they were going to do or were doing. It made me feel 'nursed'. Although I was doing my own thing, in some other place, certain people and certain things would call me back. I remember a gentle voice saying, "I am going to cover your eyes with this cool, wet cloth so they won't dry out so fast." I had not been aware of my discomfort until I felt the cloth, but a wave of appreciation and affection for the one who thought of my comfort enveloped me. Music called me back. I always was present in the unit during rounds. If I heard the hum of the doctor's discussions up the hall, I became quite alert and attempted to listen so I could remember what they said. Often, I thought they were talking about me when they were not. That was sometimes very scary and did generate some strange happenings in my other place. If I could feel someone touching me, I knew they were at my bedside. That made me feel secure.

When I say I came back, I was usually disoriented - and was for several weeks after leaving the ICU. Being present in the ICU was not synonymous with leaving my own temporary home in a parallel universe. I was

> *visiting the real ICU that contained my body, but the whole thing was in my own world, the one in which I could move about and think and decorate. I do recall nurses checking to see if I could orient to time, and place. I thought these were silly questions, didn't know, and didn't care; so I seldom attempted to respond, as responding required a great deal of energy.*

The occasion of the nurse applying cold packs to the patient's eyes was identified as the 7th ICU day, prior to her first dialysis treatment, at which time she was so swollen with edema that her eyelids had turned inside out. The chart indicates that she had a GCS of 3 the entire day, was pavulonized, and sedated with Diprivan. Although, as reported earlier, Diprivan has been found to produce marked amnesia (Veselis, et al, 1992), this patient had a vivid and accurate memory of an occurrence while being infused with the drug.

To understand quality of life issues, we must interpret our information from within the context of individual experience. The foregoing recitation of individual incidents is not anecdotal because of the documentation of the patient's experience on one hand, and the hospital chart on the other. Each record reinforces the other and we can finally assess the patient's experience of a *known* event. In addition, we have the reported observations of the event from those who know the individual's history and personality best, family and friends.

One of the stated objectives of this study was to create a credible reference for the presence of intelligent mentation in persons unable to respond to verbal stimuli by voluntary means. On visual inspection of patient responses to our interventions, 17 of the

28 physiological changes in one or more of the dependent variables appeared to be associated in time with an intervention. Variations were less or non-existent during baseline periods. That could, by our definition, represent a response rate demonstrable in approximately 60% of the trials. In future studies, variables such as accompanying medications and medication schedules, pre-existing conditions, admission diagnoses, educational levels, language ability, etc. can be controlled and yield additional information or increase the number of positive trials. There was indication in retrospect, that outcome might be an important variable.

Finally, we must learn the character of the patient's inner world and how our consensual realty can impinge on that adversely or for benefit. Vygotsky shed light on human "inner speech", that speech almost without words, with which we all converse with ourselves.

> The specific semantic structure of inner speech also contributes to abbreaction . . . [We found] three main semantic peculiarities of inner speech, 1) preponderance of the sense of a word over its *meaning* . . .The sense of a word . . . is the sum of all the psychological events aroused in our consciousness by the word. Meaning is only a part of the sense. 2.) tendency to use agglutination, and 3) 'influx of sense' - the senses that different words flow into one another literally influence one another-so that the earlier ones are contained in, and modify, the later ones (p. 245-46). . . A single word is so saturated with sense that it becomes an idiosyncratic concentrate of sense . . . [I]nner speech would be incomprehensible even if fully recorded (Vygotsky, 1986, p. 244).

It is no wonder that the inner world of the patient is difficult to recall and later report. This "inner speech" is, according to Bain (1996) and Vygotsky (1986), one talking to one's Self. It is this dialogue that creates consciousness, a reality in the mind, a setting for the Self. At those times, one knows that one is alive!

Final Word

This study was a valuable exercise in developing methods for studying individual experience without relying on the participants ability to fully collaborate or fluently describe the experience. It did not impose, nor intrude on the participant's quality of life or death, nor upon their medical or spiritual treatments. It did provide insight into the 'life-world' of the dying, although it did not provide total, nor perhaps adequate, control over all confounding variables. Yet, there is sufficient insight provided to improve further explorations in understanding the dying experience.

Some hypotheses can be advanced regarding the nature of individual consciousness based on the observations made during this study. The first postulate is that consciousness is all or nothing. Although observers may report levels of consciousness, emergence phenomena, or other signs attributed to more or less consciousness, the experiencer is either consciousness or not. When 'regaining consciousness' one may be aware of being disoriented, or not; but that awareness itself is a conscious event. Further to that observation, consciousness, as it is experienced, has no identifiable 'just noticeable difference' (JND). One is conscious or not as one is pregnant or not. That is, one cannot identify being more or less

conscious along a continuum. Yet one can be more or less aware of things. When consciousness requires a specific object, one is conscious 'of something'. The word 'conscious', in this case, is synonymous with the word 'aware'. This implies the direction of 'attention'. This is an entirely different event than 'being conscious'.

Second, consciousness is not usually explicitly volitional. One does not choose to be conscious, nor unconscious (although some train to reach in-between states through meditation, and other means). One might choose to go to sleep or to daydream, or to create another reality, but consciousness while in other states is not automatically obliterated. There is some objective evidence that comatose individuals cycle through sleep states. What do we call the non-sleep states under those conditions? Are they in wakeful coma, or conscious coma?

Third, consciousness can occur from within or without the body. It occurs without the sensation of existing within the body in phenomena such as the out-of-body experience, during threatened or occurrence of trauma, during prayer or meditation, etc. In fact, most any disruption of body image or schema will tend to place conscious experience outside the body.

Fourth, consciousness occurs only in the presence of the Self. Whenever the individual is conscious, he or she can identify their 'me'. There is little doubt that he or she retains his or her own identity, and all that is experienced, that happens to him or her, with or without the body. Depersonalization fails to separate the individual from whatever form he or she takes as a conscious experiencer. A concomitant of the requirement of the presence of

the Self would necessarily be that infants, not having developed the construct of Self through the process of individuation from the parent or caregiver, could not have fully human conscious experience. The 'me' would not be identifiable. It would be interesting to learn if a child's Self emerges with the ability to identify mother in the mirror. Could one then speculate that a child's conscious experience begins with a 'me' concept that is through the parent's eyes?

Fifth, consciousness is phenomenal. It does not occur without a perceived context. The conscious experiencer always provides a context or reality setting in which the 'being' takes place. The sense of being somewhere is not necessarily consistent with consensual reality.

Sixth and last, a reality-based, conscious Self can exist either totally within, or within and outside of the individual. Only the individual can report the characteristics of the conscious experience. This author will continue to see consciousness as neither a state, nor a process. Because of the dependence of consciousness on the presence of Self, it can only be thought of as the point of view of the Self. Baars (1997) writes of consciousness as the spotlight on the stage in the Cartesian theatre of the mind. This would appear to be a model close to the one proposed here. Perhaps this concept will become elaborated and a vehicle for entertaining new knowledge about consciousness, the most enigmatic mystery of life.

A hypothetical model of a hypothetical patient's experience in life-threatening circumstances might contain these postulates:

1. Consciousness is the point view of the Self.
2. Consensual reality is structured by filters and biases which influence individual experience by placing one in a context that allows a limited or sequential view of all that could be experienced.
3. Healthy individuals, as stable systems, resist disruption, and take little energy to maintain. Illness can be reflected by fragile and unstable responses and the great energy required to maintain function.
4. Dying, or the perception of imminent death, is an event that creates its own reality.
5. An ideosycratic reality as a response to trauma (with attendant loss of trust, autonomy, power, and even recall) is often constructed by ICU patients.
6. Those who are critically ill may exist in a creative and stimulating alternate state of being.
7. Ideosyncratic realities of ICU patients share some common characteristics. (I.e. dissociation, influence from auditory environment, literal linguistic denotations, architypical thinking, and the use of cultural categorizations and attributes). Some cognitive features can be at odds with the patient's usual moral or ethical codes.
8. Patients may hear and understand events taking place in consensual reality. This allows the possibility of giving the patient psychological and/or spiritual aid, comfort, distress, etc.
9. Improvement in the patient's ICU experience could be potentiated in several ways. Among these are mobilizing the patient to aid in

his or her own cure; offering to act as a surrogate or sentinel for a patient during sleep, sedation or periods of vulnerability; or preventing negative sequelae by giving early intervention for psychogenic reactions as they occur. Pain control and long term complications might weil be avoided during acute stages of illness, and a painless, fear-free death accomplished with total awareness and feelings of care and affection.

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APPENDIX A.

Ethics Committee Approvals

The Intensive Care Unit auditory environment
M. Spencer, Dr. R. Johnston
Primary Reviewer: Dr. D. Manca

Ms Spencer presented the study. She indicated that she recalls bizarre experiences from the time she was a patient in ICU. People may hear a lot more and remember things resulting in an experience from the ICU environment. This proposal is to establish whether or not there is an explicit or implicit memory of the ICU experience.

Dr. Manca critiqued the study. She indicated that it appeared to be an excellent study combining qualitative and quantitative methodology. She questioned if the patient interview had been developed. The researcher indicated that the interview will be developed with the pilot study. She will transcribe all the recorded information. The interviews will be analyzed phenomenologically. Two judges will critique the material analyzed and both are required to agree before the item will be accepted. This will minimize bias from the researcher.

Dr. Peliowski indicated that patients may have a negative or a positive experience while in ICU and queried whether this could influence the patient's recall. Ms Spencer indicated that she would expect this to affect the explicit memory but not implicit memory,

Dr. Leson inquired whether only English-speaking patients would be studied. Ms Spencer indicated "yes."

Ms Thomas indicated concerns that with the recorder in the room, staff discussions or other families in the next room could be taped. There was concern about recording conversations from patients in the next bed. It was indicated that only patients in private rooms would be studied.

Dr. Noseworthy questioned who, in fact, are the study subjects. Are they not all the individuals who input into the auditory environment? Ms Spencer indicated that the patient is the study subject. The other people who input into the auditory environment are not identifiable.

Still the question put to the committee was "Does everybody need to give consent, every possible possible person whose voice may be recorded? The other extreme would be that no-one except the patient is required to consent to being recorded. How can the staff in the ICU environment be engaged to determine if they are

comfortable with the study?" Ms Spencer indicated that she had developed a nurse-volunteer participation form. This was circulated to the committee members. Ms Thomas indicated that this form would still not cover people who came to visit in the next room. Ms Spencer indicated that a nurse should inform those visitors that recording is taking place.

Dr. Grace stated that a number of people need to be educated. Ms Spencer must talk to the ICU staff explaining that they will be recording the ICU environment and that the nurse involved in the patient's care could sign a consent form. A sign must be visible indicating that random tape recordings were being made so that visitors would be aware. The visitors would have the option of having the tape recorder turned off when they did not want their conversations recorded.

Dr. Noseworthy indicated that some changes may pollute the study environment so that it does not resemble a true ICU environment.

Dr. Grace felt that anytime one conducts a study, there is alteration of the environment. Dr. Grace indicated that he would be comfortable if some of these safeguards were in place to help smooth things over.

Dr. Grace indicated concerns with less than 20 subjects as this could be a very low number. The researcher indicated a minimum of 15 to 20 would be used. Dr. Grace also indicated that biases could result from the patient selections.

Dr. Noseworthy expressed some concerns with prompted messages. The worst scenario would be where a message was given that could damage the patient. Once the taped messages that will be played to the patients are developed, they should be reviewed by the Chair.

Dr. Fitzgerald clarified from whom consent is to be sought. The consent is to be obtained from the family, surrogate or patient, with the approval of the physician. No patient unable to give consent can be studied without family consent.

MOTION: Dr. Grace/Dr. Manca "That the study be approved, with the understanding that the messages given to the patient be reviewed by the Chairman, all visitors are advised of the study with the option to turn off the recorder, and the above-mentioned changes involving the consent are included." CARRIED with the proviso attached

Royal Alexandra
HOSPITAL

10240 Kingsway
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Canada T5H 3V9
Phone (403) 477-4111

MEDICAL STAFF OFFICE
11 March 1993

Ms M. Spencer
10922 76 Ave.
Edmonton, Alta.
T6G 0J7

Dear Ms Spencer:

I am pleased to inform you that the Investigational Review Committee, at the meeting of 11 February 1993 and the Medical Advisory Committee at the meeting of 3 March 1993 approved your protocol and consent form, "The Intensive Care Unit auditory environment."

The Medical Advisory Committee of the Royal Alexandra Hospital has passed a motion which requires all investigators to provide the Investigational Review Committee with a progress report one year following approval of the trial. In addition, these progress reports will include the number of patients enrolled and the current state of completion of the study. Such reports will be required for the committee to provide a reapproval as may be required by supervisory agencies. The investigators are also required to submit the results of their research to the Chairman of the Quality Control Committee and Chairman of the Investigational Review Committee.

Yours truly,

A. Voth, M.D.
Chairman
Investigational Review Committee

AV/mj

PS When writing to the Committee regarding a protocol that has been approved, it would be most helpful if you would include the date of approval and name of the principal investigator in your correspondence. If any changes are being made, please highlight. AV

April 5, 1993

From: Department of Educational Psychology
Research and Ethics Committee

The Research and Ethics Committee of the Department of Educational Psychology has reviewed the attached proposal and finds it acceptable with respect to ethical matters.

Applicants: Dr. Bruce Bain on behalf of Marlene Spencer (graduate student).

Title: The ICU Auditory Environment

Participating Agency(ies):

Recommended Change:

_____ _____
Chairman or Designate, Research and Ethics Committee

Date

June 7, 1993
10922 - 76 Ave.
Edmonton, AB T0G 0J7

A. Voth, M.D., Chairman,
Investigational Review Committee
Royal Alexandra Hospital
10240 Kingsway
Edmonton, AB T5H 3V9

Re: "The Intensive Care Unit auditory environment", approved 11/02/93 and 03/03/93. Principal investigator: Dr. Richard Johnston.

Dear Dr. Voth:

After much discussion with staff, I would like to eliminate reference to recording ambient sound of the ICU from the Study Information Sheet. Instead, I have emphasized that patient-researcher interviews will be recorded. This has been approved by my supervisory committee. Decision as to when and how to implement the ambient sound recording will be either discarded from the study, or will be introduced later, after further discussion with my supervisors. Please advise if this alteration is acceptable to you and/or your committee. I would like to begin data collection immediately.

Thank you again.

Sincerely,

Marlene Spencer
(438-4350)

Royal Alexandra HOSPITAL

10240 Kingsway
Edmonton, Alberta
Canada T5H 3V9
Phone (403) 477-4111

MEDICAL STAFF OFFICE
31 May 1993

Ms Marlene Spencer
10922 76 Ave.
Edmonton, Alta.
T0G 0J7

RE: The Intensive Care Unit auditory environment

Dear Ms Spencer:

I have reviewed your proposed changes to this protocol as well as your proposed notices for the ICU. None of these present any ethical concerns so they are approved as presented.

I wish you much success in this unusual study.

Yours sincerely,

A. Voth

AV/mj
1 June 93

Arnold Voth, M.D.
Chairman
Investigational Review Committee

APPENDIX B.

Forms

STUDY INFORMATION SHEET

Title of Study: Critical Illness and the ICU Auditory Environment

Investigator: Marlene 'Mickey' Spencer (telephone: 439-6234)

Supervisors: Dr. Bruce Bain, University of Alberta, Dpt. Ed. Psych., Dr. Richard Johnston, Dr. Tom Noseworthy, Dr. Allan Shustack, ICU, Royal Alexandra Hospital

Background: It is assumed that critically ill patients who are sedated, or unconscious have no memory of things that are said to them. It is also assumed that patients who seem to interact with family members and staff in a somewhat normal manner, sometimes talking, joking, or complaining, despite injury or illness, would remember that. But one hears reports that some people anesthetized for surgery have overheard conversations in the surgical suite that promote a sense of well-being or cause distress. Additionally, many people who seemed quite alert and responsive in the ICU claim later to have no memory of the time spent in the unit.

As one patient who spent a considerable length of time in the ICU, I have developed an interest in understanding what other patients do and do not recall of their illness/injury. I have recovered sufficiently to return to the University of Alberta as a doctoral student where I have been encouraged to study critical care medicine from the patient's point of view. Based on my training and interest in Audiology (the study of hearing), I have designed the study described below.

The Study: Each day, the researcher will visit the patient, give deep relaxation training, wellness messages, and suggestions to remember certain words or phrases. All visits between the researcher and patient will be documented by tape recording. Later, when discharged from the ICU, the patient will (with his or her permission) be visited and interviewed about what he/she remembers. Recall of the target words or phrases will be counted and compared to the patient's level of consciousness at the time the words were given.

Consent: I have been given permission to ask you to allow me to collect information from you (or your relative) while you are (your relative is) a patient in the ICU. Later, during recovery, I will again ask permission of you (your relative) for interviews. Permission can be withdrawn at any time by calling the telephone number given above. All information will be confidential; names and identifying information will not be transcribed from the tapes.

FAMILY CONSENT FORM

Title of Research Project:

Critical Illness and the ICU Auditory Environment

Consent:

I acknowledge that the research procedures described on the Information Sheet, and of which I have a copy, have been explained to me, and that any questions that I have asked have been answered to my satisfaction. In addition, I know that I may contact the person designated on this form if I have further questions either now or in the future. I understand that the researcher will ask the patient for permission to proceed with the study as soon as the patient is able to give informed consent. I have been assured that personal records relating to this study will be kept confidential. I understand that I am free to withdraw my consent at any time. I further understand that if the study is not undertaken, or if it is discontinued at any time, the quality of the medical care for my relative will in no way be affected. I understand that if any knowledge gained from the study is forthcoming that could influence my decision to authorize that my relative continue in this study, I will be promptly informed.

Date: _____ Name _____

Witness: _____ Signature of person authorized to sign on behalf of the subject (relative, guardian, etc.)

Investigator: _____

Telephone: 438-4350 _____

PATIENT VOLUNTEER CONSENT FORM

Title of Research Project:

The ICU Auditory Environment

Consent:

I acknowledge that the research procedures described on the Information Sheet, and of which I have a copy, have been explained to me, and that any questions that I have asked have been answered to my satisfaction. I understand that information has been collected during my illness. This consent authorizes the person specified below to use that information for research purposes and to interview me to secure further information. I know that I may contact that person if I have further questions or if I want to withdraw from the study at any time. I have been assured that personal records and tape recordings relating to this study will be kept confidential and that my identity will be protected. I may discuss the results of the study with the undersigned if I so desire.

Date: _____ **Name** _____

Witness: _____ **Signature of subject**

Investigator _____ _____

Telephone: 438-4350

This patient's participation in the research project of Marlene Spencer requires that the researcher have one uninterrupted (excluding necessary care, of course) half hour period of time twice a day (approximately once each shift) with the patient, during which time data will be collected from monitoring equipment by video tape recording. This phase will last for approximately a week, depending on the patient's level of consciousness. So that data collection does not interfere with family visitation, and so that staff can plan ahead, the next data collection time is:

If the planned next visit conflicts with other activities, please call Mickey at **439-6234**. Please leave suggested alternate time on the answering tape and make a note on this sheet.

NOTICE

THIS PATIENT IS PARTICIPATING IN A RESEARCH STUDY

TO BETTER UNDERSTAND THE PATIENT'S ICU EXPERIENCE
A TAPE RECORDER IS USED TO SAMPLE THE LOUDNESS AND TYPES OF SOUNDS THAT THE PATIENT MIGHT HEAR

****

THE TAPE RUNS 15 MINUTES OF EVERY FOUR HOURS

YOUR CONVERSATION MIGHT BE TAPED

AT YOUR REQUEST
THE NURSE CAN DISABLE THE TAPE RECORDER, HOWEVER

YOUR PARTICIPATION WOULD BE APPRECIATED

••••••••••••••••

CONFIDENTIALITY

WILL BE CLOSELY GUARDED

ONLY THE RESEARCHER WILL HAVE ACCESS TO TAPERECORDINGS
NAMES, RELATIONSHIPS, OR OTHER IDENTIFYING OR PERSONAL INFORMATION WILL BE DELETED FROM THE TRANSCRIPT

••••••••••••••••

THIS STUDY IS INDEPENDENT OF THE MEDICAL WORK OF THE UNIT AND PARTICIPATION OR REFUSAL TO PARTICIPATE WILL IN NO WAY AFFECT THE PATIENT'S MEDICAL CARE

APPENDIX C.

Intervention Protocols

STIMULUS SHEET

TREATMENT I - PAIRED ASSOCIATES

Subject: _____ Bed: _____ Gender: M F Age: _____

Date							
Day							
Time							
GCS							

I. LIST A[1]

Later, as you become well, I will say some words. After each word I say, I will ask you to say the first word that comes to your mind. So that I will know that you can hear me now, when I say the word

twins, you say **bell**;

when I say **wire**, you say **cowboy**.

toothbrush - poor

greyhound - duckpond

three - star

II. When you are getting well, you will hear me say, **"I wonder what time it is."** When I say, **"I wonder what time it is."**, you might **pull on your left ear**, so that I will know that you have heard me.

---

[1] Words are from the C.I.D. (Central Institute for the Deaf) AuditoryTests W-1 and W-22 (Technisonic Studios, Inc., 1201 Brentwood. Blvd., St. Louis, Missouri 63117.)

STIMULUS SHEET- B

Subject: _____ Bed: _____ Gender: M F Age: _____

NO	DAY	DATE	ICU	TIME	NURSE	GCS	MEDS	STIMULI
1								
2								
3								
4								
5								
6								
7								

Carrier phrase: **(Later, as you become well, I will say some words:) When I say the word _____, you say _____.**

LIST B[1]

SMART	**TREE**
SEND	**OATMEAL**
ARMCHAIR	**CAP**
SUNSET	**BIRTHDAY**
LAUGH	**TOE**

IDEOMOTOR SUGGESTION

When you are getting well, you will hear me say,

"I thiink it will rain today".

When I say, "I think it will rain today", you might

pull on your right ear,

so that I will know that you have heard me.

---

[1]Words are from the C.I.D. (Central Institute for the Deaf) Auditotry Test W-1 and W-22 (Technisonic Studios, Inc., 1201 Brentwood Blvd., St. Louis, Missouri 63117).

SCORE SHEET

TREATMENT I - PAIRED ASSOCIATE SPONDIAC WORDS

Subject: _____ Ward: _____ Bed: _____ Date: _____

Physician: _____ Interview Number: _____

SCORE	FIRST	SECOND	BOTH	STIMULI
				greyhound - duckpond
				schoolboy - sidewalk
				toothbrush - hotdog
				lighthouse - racecar
				pancake - mushroom
				mousetrap - hardware
				eardrum - workshop
				headlight - horseshoe
				birthday - armchair
				southeast - icecream
				baseball - oatmeal
				stairway - hairbrush
				cowboy - farewell
				iceberg - grandson
				northwest-drawbridge
				railroad - doormat
				playground - hothouse
				daybreak - airplane
				woodwork - sunset
				cupcake - football

NO	DAY	DATE	ICU	TIME	NURSE	GCS	MEDS	STIMULI

smart tree
send oatmeal
armchair cap
sunset birthday
laugh toe

I think it will rain today.
Pull right ear.

Subject #12 Bed