PROJECT DEMONSTRATING EXCELLENCE/
DISSERTATION

Caregivers' Experience of Process-Oriented Coma Work : A Phenomenological Study

By

Hitomi Sakamoto

Submitted in partial fulfillment of the Requirements for the Degree of

Doctor of Philosophy
With a Concentration in
Psychology

December 11, 2004

Core Faculty: Sandra Hurlong, Ph.D.

Union Institute and University
Cincinnati, Ohio

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

UMI Number: 3168558

Copyright 2005 by
Sakamoto, Hitomi

All rights reserved.

INFORMATION TO USERS

The quality of this reproduction is dependent upon the quality of the copy submitted. Broken or indistinct print, colored or poor quality illustrations and photographs, print bleed-through, substandard margins, and improper alignment can adversely affect reproduction.

In the unlikely event that the author did not send a complete manuscript and there are missing pages, these will be noted. Also, if unauthorized copyright material had to be removed, a note will indicate the deletion.

UMI®

UMI Microform 3168558
Copyright 2005 by ProQuest Information and Learning Company.
All rights reserved. This microform edition is protected against unauthorized copying under Title 17, United States Code.

ProQuest Information and Learning Company
300 North Zeeb Road
P.O. Box 1346
Ann Arbor, MI 48106-1346

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

ABSTRACT

Caregivers' Experience of Process-Oriented Coma Work :

A Phenomenological Study

Hitomi Sakamoto

This phenomenological, qualitative study explored caregivers' experiences of a simulated "coma" or seemingly unresponsive state. The literature review examined historical and contemporary death-related attitudes in modern industrialized societies. It also examined issues regarding coma and near death experiences, including Process-oriented coma work methods. The participants included five women and one man. Each were of European-American ethnicity aged between 25 and 59 years, and each had varying degrees of experience in working with the comatose. Using Mindell's (1999) Process Work model of coma work, an individual session was conducted with each participant in order to facilitate a simulated coma state for 10-15 minutes. An in-depth, semi-structured interview was also conducted before and after each experiential session in order to understand the lived experience of the coma work and its meanings as perceived by the participants. Thematic analysis revealed two major themes of experience: "Unusual Physical and Non-Physical Experience" and "Implications of the Simulated Coma," each of which were further divided into sub-themes. The sub-themes for the former included: heightened senses, spontaneous visual images, altered perception of self and body, sense of comfort, sense of vulnerability, reduced connectedness from outer world, and connection with the sitter. The participants described how these experiences impacted

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

their personal and professional beliefs and attitudes towards seemingly unresponsive states. The latter theme, "Implications of the Simulated Coma," included: enhanced empathic connection with patients, attitudinal change toward patients, practical implications, enhanced reflection on mortality and own vulnerability to coma, appreciation for life, and enhanced interest in learning about coma. Implications of this study for the fields of terminal care and death education were discussed.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

ACKNOWLEDGMENTS

I would like to extend my deepest gratitude to my doctoral committee, Dr. Sandra Hurlong, Dr. Lee Spark Jones, Dr. Katherine Leonard, Dr. Pierre Morin, and Dr. Sandra DeWees, for their most generous spirit. They accompanied me on this journey by providing me with warm support and encouragement as well as practical suggestions and advice. My gratitude also goes to Dr. Kenneth Suslak, who played the critical role as the second core reader on my committee. I would like to sincerely thank Dr. Stephen Schuitevoerder, Robert King, and Yukio Fujimi for their membership on my study committee at the Process Work Center of Portland, and for their support and belief in me for all these years. Without their much needed advice, loving presence, and challenges, I would not be where I am today.

I am especially indebted to Drs. Arnold and Amy Mindell for pioneering these innovative approaches to people in seemingly non-responsive states. I am most fortunate to have encountered Process Work and its ability to integrate skills and feeling attitudes that allow for relating to people with diverse states of mind and experiences. I would also like to thank Dr. Gary Reiss, Dr. Pierre Morin, Dr. Ingrid Rose, Dr. Salome Schwarz, Stan Tomandl, Ann Jacob and the many others who are continuously researching and developing the field of coma work. Each of these people provided helpful suggestions and support for my studies.

Many thanks to Eva Steinebronn for helping me to connect with some of the research co-participants. Also, thanks to all my family, friends, teachers, therapist, and colleagues, who have always been there for me and have given me moral as well as practical support throughout this research process.

I am greatly appreciative of the research co-participants for taking part in this study and for allowing me to learn from them. I am deeply moved by their commitment to and

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

enthusiasm for their often challenging work with people in coma and/or dying states.

Finally, I am thankful to my late father for giving me the most profound experience while I accompanied him in his last days. What I experienced with him was the inspiration for this study.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

TABLE OF CONTENTS

ABSTRACT ii
ACKNOWLEGMENTS iv
TABLE OF CONTENTS vi
LIST OF TABLES
Table 3.1. Demographic Information of the Participants
Table 3.2. Data Collection Procedure
Table 4.1. Categories and Themes of Experience

CHAPTER 1. INTRODUCTION 1
1.01 Statement of the Problem 1
1.02 Personal Significance of the Study 5
1.03 Social Relevance 5
CHAPTER 2. REVIEW OF THE LITERATURE 9
2.01 Death in Western Societies 9
2.02 Death Awareness and its Implication for our Lives 13
2.03 Coma and Minimally Responsive States 18
2.04 Literature Review Summary 34

CHAPTER 3. RESEARCH METHODOLOGY AND DESIGN 36
3.01 Qualitative Research 36
3.02 Phenomenology 38
3.03 Phenomenological Research 40
3.04 Research Question and Rationale for the Choice of the Research Model 42
3.05 Selection of Participants 43
3.06 Researcher Subjectivity 58
3.07 Data Collection 60
3.08 Post-Interview Review 69
3.09 Transcription 70
3.10 Data Analysis 71
3.11 Evaluative Criteria 75
3.12 Protection of Human Subjects and Related Ethical Issues 77

CHAPTER 4. FINDINGS 80
4.01 Findings 80

CHAPTER 5. DISCUSSION 107

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

5.01 Overview of the Study 108
5.02 Limitations 109
5.03 Summary of Findings 111
5.04 Discussion: Implications and Recommendations.....114

GLOSSARY 133
REFERENCES 135

APPENDICES
Appendix A.
Appendix B.
Appendix C.
Appendix D.
Appendix E.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

CHAPTER 1:

INTRODUCTION

This chapter addresses the social context and relevance of the present research topic. A brief description of my personal experience will also be included to provide the subjective perspective from which I approach the research.

1. 01 Statement of the Problem

Although death is a condition from which we cannot escape, many people in industrialized Western societies tend to focus heavily on how to become younger and healthier. The view that old age, illness, death and dying are undesirable and are to be avoided is reflected in today's media. TV programs and magazine articles are filled with the latest news and information about innovative methods of anti-aging and life-extension. Perhaps the most extreme end of such means is cryonic suspension, which involves the lowering of temperature to halt metabolic decay. This is done in the hope that future medicine and science will save people whose physical conditions would presently lead to death. Despite the controversy, many people are seemingly willing to take the chance and pay a considerable amount of money to buy a possible ticket to immortality. In *Death Education in the Face of a Taboo*, Bertman (1974) illustrates how our society has increasingly avoided exposing children to the ideas of death. One of the ways she demonstrates this is through the examination of the ways in which the endings of children's stories, such as "Little Red Riding Hood," have been altered from their original

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

versions so that the theme of death is not so explicit or is completely avoided.

Throughout history, however, many cultural traditions worldwide have perceived death as an important and integral part of life and have provided frameworks for daily rituals regarding dying. For example, Tibetan Buddhism considers the actual point of death as the moment of potential spiritual realization. This tradition suggests ways to prepare for one's own death through daily meditation practice, and it presents ways to help others to die well.

For the past few decades, interest has grown in Western societies to study the positive aspects of death and dying. This interest includes an effort to study the role that death and dying play in giving meaning to life. Of particular interest are accounts given by people who have undergone life-threatening events that included near-death experiences. There have been reports from people who have had unexpectedly joyful and enlightening experiences while in the company of the dying. Much effort has also been made in the field of hospice and palliative care in order to make the final stages of life less painful and more meaningful. Access to multiple groups and organizations through web sites can provide information and support to those who are interested in viewing death and dying as something meaningful.

Currently, increasing numbers of universities are interested in including (or have already included) courses in thanatology. However, the number of graduate and undergraduate programs which confer a degree in thanatology is still limited, and the term "thanatology" is still unfamiliar to many. Smith (1998), a Buddhist practitioner and hospice worker, explains this tendency as follows:

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

> One reason is because study does not necessarily translate into personal change. Writing books and offering university courses can be the first indication that a subject is receiving the attention it deserves, but death requires much more from us than academic learning. When we read about death it remains distant, something that happens to other people.... A wide gap lies between recognizing the subject and letting it into our hearts. (p. 2)

As Smith pointed out, death, for most of us, remains something distant and not something we hold "in our hearts" on a daily basis. Often, it is our own imminent death—or that of loved ones—that forces us to come face-to-face with the issue. In a society where individualism is highly valued, people often end up "on their own" when situations propel(s) them to work on their relationships to life and death.

Among the issues that are related to death and dying is the state that is generally called "coma." This state often occurs near death or as a result of brain injury. Witnessing our loved ones go into a different state of consciousness near death is still shocking to many. We are at a loss of what to do when the person who is lying there feels somehow foreign and outside of our reach. This difficulty comes in part from our tendency to regard identity as a fixed state rather than a constantly changing one involving different levels of consciousness. Another source of difficulty is our lack of familiarity with our own altered states of consciousness. Although we experience altered states throughout the day, we tend to experience them as "not being ourselves," and we do not embrace them with awareness. As a result, it is difficult to respect or face such states in others, and we find ourselves frantically trying to bring the person back to a "normal" state of consciousness instead of seeing their experience as an important and meaningful process (Mindell, 1994).

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Today, more and more people in the field of terminal care recognize the importance of accompanying the final stages of people's lives with loving care and respect (e.g., De Hennezel, 1997). Most of the time, however, the effort to communicate with a patient ceases once they have entered into a coma or seemingly non-responsive, near death state. Family and caregivers believe that the patient becomes unreachable or "already dead." In a way, one could say that such a state is a form of death—the death of the old identity. But are they really unreachable, or is there someone "down there"?

The idea that the person in a coma may be going through potentially meaningful inner experiences, and, that it may be possible to communicate with them if we use the right "language," would relieve many people who accompany the dying either personally or professionally (Mindell, 1994). Process-oriented psychology (or Process Work), which was developed by Arnold Mindell and his colleagues, has presented an approach to comatose people based on such ideas. Process-oriented coma work assumes that the person is not simply "lost" but is going through potentially meaningful inner experiences—just as people do in other stages of life.

The present study focuses on a phenomenological investigation of Process-oriented "Coma Work," an approach that works with seemingly unresponsive states occurring near death or due to other causes. My research question is as follows: "How do professional caregivers of people in seemingly unresponsive states experience process-oriented coma work?" The form of the PDE is that of a traditional dissertation directed mainly at, but not limited to, people working in the field of terminal care.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

1.02 Personal Significance of the Study

My interest in the present study began four years ago when I was in the role of caregiver for my dying father. To my surprise, accompanying my comatose father in his last moments was not as difficult as I had expected. I had previously been exposed to the Process Work approach to coma, and by accompanying him in ways that the model suggested, I felt that the pain of losing him was eased. As a result, the time I spent with my father became a very rich and even joyful experience for me. Because of my previous training in Process Work, I was familiar with sitting and working with people in seemingly unresponsive states, and I learned about my own altered states of consciousness by simulating a coma state in myself. Observations made during Coma Work training courses also suggested that, when participants simulate the experience of being accompanied by a "sitter" or "coma worker," they often gain insight about their own altered states, death, and/or values of a coma state, even though they themselves are not in a medical coma (Mindell, 1999). This observation, coupled with my own experience, was a motivation to further investigate the categories of caregivers' experiences and the meanings that those experiences might hold for them.

1.03 Social Relevance

Studies of near-death experiences (e.g., Ring, 1984) and anecdotal experiences of people who were in a coma and then recovered (Blakely, 1990; Lawrence, 1998) suggest that not all people in unresponsive states are unconscious, nor are they necessarily in pain. While we might often imagine that they are unconscious or in pain, they may simply be in different states of consciousness. It is the caregivers of the comatose who often suffer

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

because they are not sure of what to do or of what their loved ones or patients may be going through. They are often overburdened with physical, emotional, and financial challenges, and they can become hopeless and burned out. Caregivers play such a crucial role in the system in which the comatose live, and they also have the potential to facilitate the inner worlds of the patients. For this reason, it is imperative to explore ways to support caregivers.

The present study not only has implications for individuals concerned with people in seemingly unresponsive states, but it also addresses the larger systems in which they exist: e.g. family, medical systems, and the society as a whole. To use the concept of systems theory, both the individual in a coma and those who surround the individual compose a system in which the comatose person is an "identified patient." Other members in the system consider the comatose state as something "foreign" and often marginalize it as meaningless or as something which should not exist. As a result, the two positions become polarized, and the one stigmatized as the identified patient becomes isolated. According to the accounts of people who have been in a coma and came back, they often suffered isolation due to the way in which caregivers and/or medical systems ignored them or dealt with them in ways that did not follow their deep inner experience (Blakely, 1990). Another possible approach is to view the one in the designated patient's role as holding the potential of growth and change for the whole system, which may in turn, relieve both parties (Mindell, 1987). Using the family system as an example, Reiss (2004) suggests that a comatose person might hold a role in the family which is marginalized but may contain useful qualities for the rest of the family members. For example, in a goal-oriented and busy family, the slowness and inactivity of the comatose

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

person may be disavowed qualities. According to Reiss, in such cases, inviting the family members to access this disavowed quality and/or experience through the act of simulating a coma state in themselves appears to relieve the comatose person and even to awaken them. Reiss also reports that by doing so, the caregivers gain insights into both the inner world of the people they are caring for and into their own altered states of consciousness. "To become a comatose person," as opposed to their usual caregiver role, can be a huge relief. To expand this view to a more global level, A. P. Mindell (1988) suggests in *City Shadows* that comatose people who are considered "ill" may represent marginalized aspects of the society that are needing to be recognized and integrated.

As described above, there appears to be considerable inconsistency between the subjective experience of the people in seemingly unresponsive states and the perception of their caregivers. The experience of simulating coma while being accompanied by another person may serve as a stepping stone to bring the two worlds together. As to date, there has been no formal research on the caregiver's experience of the simulated coma and coma work experience. The present phenomenological investigation intends to demarcate possible categories of experiences that caregivers go through during simulated coma and to explore the possible implications on their professional and personal lives.

Chapter 2 will review the intellectual context of the issues relevant to the present research, including death, dying, and coma. Chapter 3 will present a brief summary of the philosophical underpinning of phenomenological methodology and a detailed description of my research method. The themes which emerged from the analysis of the data will be presented in Chapter 4. The final chapter will present a summary of the study and discuss

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

the implications of the findings. This will include a discussion regarding the issue of marginalization of impaired consciousness within the society, as well as the implications of the study for related education and training.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

CHAPTER 2:

REVIEW OF THE LITERATURE

The present chapter reviews historical and contemporary death-related attitudes in Western societies and focuses special attention on the United States, the emerging awareness of positive aspects of death and dying, and the issues of coma and near death experiences. This chapter also focuses on Process-oriented coma work methods.

2.01 Death in Western Societies

Although death is undeniably one of the most important and fundamental aspects of the human experience, it is often claimed that contemporary America is a death-denying society—one in which death has largely been hidden from people's awareness. Having studied death-related attitudes and practices in the United States, Gorer (1965) went so far as to call this attitudinal pattern "the pornography of death." He has termed it thus on the grounds that death is now seen as something dirty and indecent, as forbidden and unmentionable as sex was in the Victorian era.

Ariès (1981) describes the different historical patterns that can be seen in Western societies' attitudes toward death. According to Ariès, during the first ten centuries of the Christian era, death was familiar to people and was perceived as one of the risks of daily life. Death and the dead were not excluded from the public scene. People were buried in cemeteries, which also served as public squares where people strolled and socialized. Ariès claims that the first shift in people's awareness toward death coincided with the rise

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

of the concept of "the individual" around the eleventh century. Since that time, death has transformed from something that visits a community as a whole to something that threatens the individual.

Ariès (1981) goes on to describe how, throughout the centuries, attitudes changed as individuals and societies tried to come to terms with their relationships to death. In the late nineteenth and twentieth century, death became something forbidden and denied, especially in industrialized and urbanized areas of the Western world. As a result, anything in current public life that reminds one of death is considered taboo. The moment of death and the ceremonial funeral are frequently hidden from people's view, and the bereaved are often expected to mourn discreetly. Societies' over-emphasis on advances in medical technology has led people to view death as a "failure" or "accident" instead of as a natural and necessary phenomenon. Ariés concludes that death in contemporary Western societies no longer belongs to the dying person nor to their family, but instead to the bureaucrats.

This attitude is also reflected in the lack of scholarly achievement within the field. Until the middle of 20th century, death-related research and writing were limited, and there were few educational opportunities in thanatology (e.g., Feifel, 1963). However, such barriers are gradually being removed.

One of the prime movers in the "death awareness movement" (Pine, 1977, 1986) was Herman Feifel. In *The Meaning of Death* (1959) and his subsequent works, Feifel pioneered the investigation of personal meanings of death and the role of death in human life. Other scholars followed his example by conducting a wide range of death-related studies that had a defining impact on many facets of contemporary thanatology. Some of

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

these studies focused on topics such as care-giving practices in the field of terminal care, grief and loss, developmental aspects of death attitudes, and death education (Neimeyer & Fortner, 1997).

Another pioneer of the movement was the Swiss-American psychiatrist, Kübler-Ross. In *On Death and Dying*, Kübler-Ross (1969) presented her well-known stage-based model, which she formulated as the result of a series of interviews focused on psychosocial reactions in persons who were dying. Despite later criticisms of her theory by researchers, scholars, and clinicians, her contribution to bringing the issue of death and dying to public and professional attention cannot be underestimated. As Kübler-Ross states in the above mentioned book, her work is "simply an account of a new and challenging opportunity to refocus on the patient as a human being, to include him in dialogues, to learn from him the strengths and weaknesses of our hospital management of the patient" (p. xi).

Following the initiative of pioneers such as Feifel and Kübler-Ross, a wide range of articles, journals, and literature have been published in the field of death and dying, and a large number of death-related programs and organizations have been established. The educational field's increased interest in death, dying, and bereavement has led to the establishment of thanatology courses in graduate and undergraduate programs. However, despite the growing scholarly interest in the subject of death and dying, the issue continues to be largely ignored within the general public. As Ariés (1981) asserts, "The reopening of discussion on death has not shaken society's determination to repress the real image of death" (p. 592).

Kastenbaum (1972) suggests that one way to study death-related encounters,

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

attitudes, and practices in contemporary American society, is to examine the "death system." According to Kastenbaum, a death system is the "sociophysical network by which we mediate and express our relationship to mortality" (p. 310). Important contributors to America's contemporary death system include hospice programs and certain aspects of hospital services. Despite the growing awareness created by these agencies, Americans still tend to either avoid the topic of death or to use euphemisms when speaking about it. This lack of direct discussion may further contribute to the distancing of death from our lives.

Neaman and Silver (1983) assert that the American culture has disguised death and has "attempted to strip death of both its sting and its pride--in fact to kill death by robbing it of its direct and threatening name" (pp. 144-145). According to Corr, C., Corr, D., and Nabe (2000), while most people in the United States have limited personal experience with natural human death, they are exposed to it vicariously each day through violent or traumatic deaths shown in media and entertainment. Corr et al. suggest that America's contemporary death system is effective to a certain extent, but that it is also unbalanced, and that it sometimes hinders us from recognizing the reality of death.

Contrary to some tribal societies where death systems more or less successfully hold the whole community, urban societies leave the individual to find their own relationship to life and death. As May (1983) claims, it is important for us to face the "existential facts" about death not the statistical and abstract ones, and we need to recognize "that you and I must alone face the fact that at some unknown moment in the future we shall die" (p. 51).

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

2.02 Death Awareness and Its Implications for Our Lives

Although studies in the field of thanatology have focused largely on the "pain and suffering" associated with death and dying, there has also been a growing number of studies on the importance of death awareness and on the positive implications of death and dying in our lives. One approach to the investigation of such topics is the cross-cultural study of death and dying.

Cross-Cultural Study of Death and Dying

Studying how different cultures view death and dying can help Western societies understand that "the dominant pattern of death-related attitudes in the United States today is just one among many possible patterns" (Corr et al., 2000, p. 72). This understanding may help to create a more relative viewpoint toward death. In studying death and dying in other cultures, especially those of indigenous societies, some caution is warranted. Anthropologists sometimes have a tendency to trivialize a culture's approach to death by viewing their death rituals as something exotic. This narrow focus can create "ethnographic distance" (Danforth, 1982, p. 5) between the familiar "we" and the exotic "them." The author stresses the importance of realizing that both "we" and "they" share a common humanity in the face of death, and that "an investigation of the Other involves an exploration of the Self as well"(p. 6). On a different note, researchers of cross-cultural death practices point out the significant differentiation between public mourning behaviors and individual mourning processes. They also assert that studies of cultural practices and rituals should be supplemented with studies of mourner's personal experiences (e.g., Wellenkamp, 1991).

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

There are various cultural, social, racial, ethnic, and religious groups within United States, each of which has its own death system. Some of these death systems provide death education to their community members and offer extensive community support to both the dying and their family members. For example, in the Old Order Amish community in eastern Pennsylvania, the whole community (including children) participates in the process of a person's death and dying. Death is spoken about openly by the person who is dying, and people use the opportunity to prepare for and calmly accept their own death (Corr et al., 2000).

Barley (1995) reports on the ways in which cultural anthropology views various societal attitudes and practices surrounding death. He proposes that the concept of death in Western societies is a reflection of its inherent biases, and he warns of the danger in looking at the death practices of other cultures through ethnocentric filters. The death-related practices that Barley describes in his work contrast sharply with those of modern industrialized cultures. He points various cultures in which the connections between the living and the dead are strong. For example, the Dawayos tradition views death not as an end point, but as a continuing process, "and sometimes the process may even go into reverse and the dead may revive" (p. 47). Barley also notes that in some African societies, members of the community play the role of joking about and even insulting the deceased and bereaved. These community members are seen as having a "joking relationship" (p. 36) with the deceased and are important to the process. This, of course, is contrary to the tendency of Western funeral ceremonies to act quietly and respectfully towards the deceased.

While many death rituals appear to have a certain kind of lightness or joy associated

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

with them, it does not mean that fear of death is non-existent among cultures that exercise such rituals. One way that indigenous cultures demonstrate their reverence towards death is through ritual practices which symbolically try to take control and make meaning out of death. For example, Jones (1980) describes the ritual practices of Limbu culture in eastern Nepal as follows:

> All death is dangerous to the living, especially to close kinsmen. The danger is averted through prescribed ritual. Close relatives undergo a social death through isolation and are reborn at the mourning feast, where their connections to the deceased are severed. Death itself, though God-given and therefore unpredictable and inevitable, is made meaningful. Through ritual symbolism the living have exerted a control over death and reordered the universe by reaffirming social relations (p.29).

Among different cultures, Tibetan Buddhism is especially unique in that the actual point of death is valued as an opportunity for the most profound spiritual experience to come about. Practitioners engage in meditative practices in order to attain spiritual realization at the moment of death. In *The Tibetan Book of Living and Dying* (1993), Rinpoche claims that Western society trivializes death by either denying it or romanticizing it. He attempts to provide a comprehensive account of Tibetan Buddhist teachings, in which views of life and death are quite different from those of the West. Rinpoche introduces a teaching in which life and death are seen as "one whole," and in which the following steps are suggested in preparation for the actual point of death: direct and constant reflection on death, focus on the meanings of impermanence, and attention on the "nature of mind." These practices are strongly encouraged as preparation for death because death is the point at which the deepest "nature of mind" will reveal

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

itself most spontaneously and powerfully (Rinpoche, p.12).

Work with the Dying

Significant implications for the field of terminal care may be realized in viewing death not as something that should be avoided at all costs, but as something to be accepted as an opportunity for growth and as a natural part of life. When all available cure-oriented interventions have been attempted, and it appears that no benefits will result, the focus of care often shifts to palliative care. Palliative care involves addressing symptoms rather than the underlying causes (Twycross, 1995), and it also focuses on opportunities for growth at the end of life (Byock, 1997). In *Dying Well: The Prospect for Growth at the End of Life*, Byock portrays the current challenges and possibilities of hospice and palliative care. Through his patients' stories, he shows that dying does not have to be painful, and that, given the opportunity, people can grow significantly in the very last days of life.

Many accounts by people who have accompanied the dying (either professionally or personally) indicate that the experience was an important lesson for them, and that it had positive influences on their lives. For example, in *Death: The Final Stage of Growth*, Kubler-Ross (1975) attempts to demonstrate how death can be one of the most positive and creative elements of life, and that confrontation with death and dying can be enriching. De Hennezel (1997), a French psychologist who worked in a palliative care unit, reports stories in which people started to live fully in the face of death. Those same people began to experience significant transitions in their relationships to both themselves and their loved ones. De Hannezel points out that those who accompany the

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

dying seem to learn from them–they learn how to be supportive by staying present in the moment and by relating to the dying person as a unique individual. She also describes the palliative care unit as "the place where death is neither played down nor played up, simply accompanied, and which is not a house of death but of life" (p.95).

The book, *Tuesdays with Morrie* (Albom, 1997), is a recollection of the personal interactions that took place between the author and his former college professor who is dying of a terminal illness. In this moving story, Albom describes how his teacher tried to embrace life even more fully in the face of death and, by so doing, taught those around him important lessons about life. The following is a conversations quoted from the book:

> "Most of us all walk around as if we're sleep walking. We really don't experience the world fully, because we're half-asleep, doing things we automatically think we have to do."
> And facing death changes all that?
> "Oh, yes. You strip away all that stuff and you focus on the essentials.
> When you realize you are going to die, you see everything much differently."
> He sighed. 'Learn how to die, and you learn how to live' (p.83).

Levine (1982), in describing his work with the dying, explains the mechanism of the mind and the source of suffering from a Buddhisst standpoint. He proposed that if we open ourselves to the unknown and live each moment fully with clear awareness, then death becomes a mere transition of lifestyle–an opportunity to discover the path to revelation. Levine also asserts that, from this perspective, working with the dying becomes working with oneself, and that it is important for a caregiver to just "be."

In the field of bereavement, there is a growing trend to take a new look at the grieving process of those who have lost their beloved. While standard models of grief

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

tend to suggest that bereavement is a passive process of detachment over time (e.g., Worden, 1991; Rando, 1984, 1993), current trends have shifted toward exploring the active and transformative aspects of the grieving process. For example, researchers are beginning to recognize the positive ways in which loss can contribute to the quality of life, and they are finding that "the quality of some people's lives is in some ways better following their loved one's death than it was before" (Frantz, Farrell & Trolley, 2001, p.206). Lawrence and Tedeschi (2001) use the term "posttraumatic growth" to describe the transformative aspect of loss. They advice people in the helping professions to be aware of the client's emotional recovery as well as their potential for personal growth. Contrary to the general belief that work in the field of palliative care is depressing, Webster and Kristjanson (2002) conducted a study in which professionals in the filed described their profession as "a way of living." The participants also expressed that the theme of "vitality" is the meaningful core behind their profession.

In sum, the field of thanatology (which includes cross-cultural studies, bereavement and grief, and terminal care) is facilitating a growing awareness of the different aspects of death and dying. Existing views which regard death and dying negatively are quickly being supplemented with or replaced by approaches which recognize death and dying as important and transformative human experiences.

2.03 Coma and Minimally Responsive States

Overview of Coma

One of the states we may encounter while caring for the dying is the state generally called "coma." Apart from the fact that coma often occurs near death, it can further be

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

associated in that coma can *seem* like death. According to Young, Ropper, and Bolton (1998), the term "coma" is derived from the name, "Comus," in Greek mythology. Comus was the guardian of banquets where wine is served. The association of what is now called coma with alcohol use is interesting. As the above authors noted, consumption of alcohol can cause a spectrum of impairments of consciousness, ranging from slightly uninhibited behavior to an unresponsive sleep-like state. Under certain conditions, excess alcohol consumption can even lead people to death.

Humanity has long been fascinated by the coma state. It is the polar opposite of a waking "normal" state, and yet still different from sleep or physiological death. There have been many accounts, from different times and places in the world, of people who seemed dead and then came back to life. In *Otherworld Journeys: Accounts of Near-Death Experience in Medieval and Modern Times,* Zaleski (1987) reports various stories of people who had such experiences. An example can be found at the end of Plato's book, *The Republic*, which tells the story of a soldier named Er who "died" on the battlefield and then return to life. Er describes his journey as going to the light, experiencing a moment of judgment, and then being sent back to life. In the Middle Ages, there were many stories of near-death experiences, including tales of visionaries who went to "heaven" and returned with transforming messages (Zaleski). According to Ivan & Ventureyra (1982), around the eighteenth and nineteenth centuries, there was a growing recognition of the condition known to imitate death (what we would now call coma). Since coma could be and sometimes was perceived as death, there was an associated fear of premature burial. This fear lead to the invention of a gadget intended to help the outside know if a person was being buried alive.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

By the end of nineteenth century, the development of the compound microscope made it possible to examine the neuronal basis of brain function. As a result, neuron theory expanded, and brain function could be seen as a system of individual signaling elements–as neurons communicating with other neurons through synapses (Young et al., 1998). Further developments in medical science enhanced the understanding of the neurophysiology of consciousness. Today, coma is explained and treated medically, and it is considered the most severe functional disorder of the central nervous system (Kotchoubey, Lang, Bostanov, & Birbaumer, 2002).

According to Young et al. (1998), impaired consciousness (which includes coma) is commonly caused by physical and structural insults, inflammatory conditions, and metabolic, nutritional, and toxic encephalopathies. The deepest level of coma rarely lasts longer than one month and usually leads either to brain death or to a vegetative state. In the vegetative state, a person appears awake and sleep-awake patterns return, but the person remains unresponsive to outer or inner stimuli. The person may go through a range of conditions, each of which is categorized according to the person's apparent degree of awareness or responsiveness. There has been debate as to what states should be included as coma states. Some scientists restrict the use of the term coma to include only the deepest forms in which the eyes remain closed. Others include both vegetative states ("coma vigil") and post-vegetative states in the coma category (Mindell, 1999). In this study, the word "coma" will be used to refer to an array of states ranging from the deepest levels of coma to levels in which a person appears awake but seems unresponsive to outer stimuli.

Until just recently, medical science has primarily equated seeming

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

unresponsiveness with a lack of awareness. However, recent studies now show that some people in persistent vegetative or coma states are able to perceive and process aspects of their environment despite their apparent unconsciousness and inability to communicate. For example, Kotchoubey et al. (2002) conducted a study using event related brain potentials (ERPs), and they concluded that cortical process function exists in neurological patients whose cognitive abilities cannot be expressed in their behavior. Other studies using functional brain scanners indicate that some people in PVSs (Persistent Vegetative States) or coma states show islands of awareness that are documented through imaging techniques (e.g., Menon et al., 1998; Schiff et al, 2002). Such studies uncover new dimensions of apparent unconsciousness and should encourage medical science to seriously question current assessment and treatment practices applied to people diagnosed with impaired consciousness.

Communication within Coma

Discussing the various medical interventions for a coma state is beyond the scope of this review, but attention will be given to other non-medical approaches. Non-medical methods for assisting a coma state appear to be largely divided into two types: trying to arouse the person from the state by using various stimuli (e.g., Lewinn, 1985), and/or accepting the coma as a natural process (e.g., De Hennezel, 1997). The latter method includes trying not to disturb the coma state and trying to maintain an atmosphere of love and peace. This method is frequently implemented in the field of terminal care when comatose people are near death. Most caregivers, including medical staff and family members, cease their effort to communicate with the person once they are in a

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

coma—partly because they believe the person is unconscious, and partly because little is known about *how* to communicate with someone in a coma or deep, altered state of consciousness. This tendency may stem from the belief that coma and other deep, altered states are not meaningful aspects of our experience, and are instead something needing to be cured or corrected (Mindell, 1999).

Medical science often approaches varying levels of alertness in terms of related physiological and neurological dysfunction. As mentioned in the previous section, clinical assessment for levels of alertness is based on a set of criteria that requires "rational" expressive behaviors and responses to external stimuli. Such expression is absent in a coma state, which is considered the most severe disorder of brain function. Plum and Posner (1980) state that "Consciousness is the state of awareness of the self and the environment and coma is its opposite, i.e., the total absence of awareness of self and environment even when the subject is externally stimulated" (p. 1). Multi-Society Task Force on PVS characterizes both coma and persistent vegetative states as having no self-awareness (1994). However, the correspondence between the *seeming* absence of self-awareness and the *actual* absence of it is controversial. Recent studies show that a significant percentage of patients in PVSs were later discovered to have had awareness during that time. A survey conducted at London's Royal Hospital for Neuro-Disability showed that 17 of 40 patients who were diagnosed as being in PVSs were, in fact, aware (Andrews, Murphy, Munday and Littlewood, 1996). Similarly, the results of an American study showed that 18 of 49 people diagnosed to be in PVSs were later found to have had awareness (Childs, Mercer, and Childs, 1993). An interview study conducted by Lawrence (1998) shows that only 27% of unconscious or comatose patients reported no

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

recollections of their experience, while the remaining 73% reported different forms of internal and external awareness. The forms of awareness reported in this study included hearing sounds, feeling tactile sensations, experiencing distortions of consciousness, and having extrasensory experiences.

Velmans (2002) argues that the reductionist view of identifying consciousness primarily as a brain state (e.g., Crick, 1994) is a fallacy. He proposes that "for each individual there is *one* 'mental life' but *two* ways of knowing it: first-person knowledge and third-person knowledge" (p. 11), and that they are complementary. An approach that equates a lack of outer expression with an absence of awareness leads to the assumption that seemingly non-responsive people have no meaningful inner experiences or cognitive abilities. Such an approach would also interpret observable features such as tears, grimaces, vocalizations, and fragmentary movements as having no purposeful content or intent. However, with the recent discovery that apparent unresponsiveness may not equal unconsciousness, new approaches to patients in these states are warranted.

First-person narrative accounts by people who have actually experienced comatose states and then "regained consciousness" would provide invaluable resources for others who wish to understand the comatose experience. These accounts may help others to understand the needs and behaviors of people in varying levels of consciousness, just as studies of near-death experiences give us a greater understanding of what people close to death may go through. For example, subjective accounts reported by people who have had near-death experiences (Ring, 1984) suggest that, contrary to outward appearances, near death experiences are often exceedingly pleasant. So much so, in fact, that many of the survivors chose the word 'ecstatic' to describe them. Ring and other researchers in the

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

field (e.g., Flynn, 1982; Noyes, 1980) suggest that, in most cases, the altered states of consciousness that are experienced during near death experiences (NDEs) contribute to deep and consistent personal transformation.

Although studies on NDEs tend to stress the "blissful" experiences (possibly as a reaction against the grim and popular view of death and dying), it is important not to fall into the trap of over-glorifying or romanticizing death. Studies have also focused on the "frightening" experiences of people who are near death (e.g., Gibson, 1996; Bonenfant, 2001). An example is Lawrence's qualitative study (1998), in which three of the subjects reported seeing apparitions which they described as the Grim Reaper, and which they found to be very frightening and disconcerting.

The Diving Bell and the Butterfly (1997) is a memoir by J.D. Bauby, the former editor-in-chief of a French magazine. Bauby was afflicted with "locked-in syndrome," which is a state of full consciousness coupled with motor paralysis and is caused by specific local damage to the brain stem. A person with "locked-in syndrome" is totally aware but appears unresponsive to communication attempts from the outer world. The author was miraculously able to convey to his caregivers that he could use blinking as a way of communicating. In this way, he composed his entire book, dictating the words one letter at a time. Although this syndrome is different from a coma, Bauby's account has significant implications for the care of people with seemingly unresponsive states. In the book, he recounts the rich inner world behind his seeming unresponsiveness, describes his frustration with the experience and with the medical care system. He also shares his joy at being able to communicate about this state to others.

Wake Me When It's Over: A Journey to the Edge and Back (Blakely, 1990) is a

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

memoir about the author's experience of being in a coma for nine days. In the book, Blakely recounts her inner experience while in the coma and how this was crucial for her personal transformation. The book gives us a deeper understanding of the important and meaningful experiences that a comatose person may go through. Blakely describes the special altered state of consciousness she experienced during coma, her relatively clear awareness of the outer world, and the kinds of communication that were and were not helpful to her. The following is a sample description of her inner world:

> I heard and felt him, but couldn't speak or touch in return . . . In the benevolent atmosphere of my dream I felt more curiosity than alarm, if I could claim any feelings at all . . . Physically, I felt no attachment to my body. (p.52)

These above mentioned resources suggest that it is imperative to develop ways of communicating with people in comas or deep altered states of consciousness because very often they have awareness and are experiencing rich inner worlds.

Process Work Model of Working with Coma

Arnold Mindell is a former Jungian analyst and the founder of a modality of psychology called process-oriented psychology, also known as "Process Work." In his book, *Coma: Key to Awakening* (1989), he introduced an innovative approach to coma and near death states based on his Process Work theory and on his experience of working with people near death. Process Work is a phenomenological approach in that it attempts to perceive and describe people's experience in neutral terms, with little preconception or interpretation, and with an attitude of curiosity and respect (Mindell, 1992). Whether dealing with problems in everyday life, physical symptoms, relationship issues, or group

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

conflicts, the Process Work approach assumes that the interventions required can be found in the processes that are occurring. Thus, interventions are decided upon by following a client's process and modes of experience. Focus is placed on auditory, visual, kinesthetic, and body feeling sensations, rather than on preconceived ideas or pre-programmed interventions. For this reason, Process Work asserts that its approach is applicable to people who are not able to communicate verbally and/or to people in states other than "normal" waking consciousness.

Another aspect of Process Work theory that is relevant to the present discussion is the concept of primary identity and secondary identity. Primary identity is the familiar "I" that people are usually identified with, but people also have parts of themselves that are more unknown, and these parts are referred to as the secondary identity. Because these unknown or secondary parts are often disturbing, people tend to deny that these aspects exist (Goodbread, 1987). In order to facilitate wholeness, Process Work values embracing the parts that people regard as belonging to the "other". For example, I may identify myself with someone whose state of consciousness is relatively alert and clear, but it is more difficult for me to identify with the one whose consciousness is deeply altered and who is unresponsive to outer stimuli. When I do become momentarily identified with it, I might critically judge the state and strive to be more clear-minded by drinking coffee. However, if I embrace the state by staying with it and not denying it, the experience may provide me with meaningful information that would expand my sense of identity, and hence facilitate personal growth.

Process Work applies the same principle to working with groups. A group often has a collective identity with which the majority of its members are identified. The primary

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

group identity tends to marginalize the more unknown or secondary aspects of their collective, and may attempt to disavow those aspects and attribute them either to another group or to a minority position in the same group. Process Work's approach is geared, in part, toward encouraging the different roles within the group to embrace and to identify themselves with the position of the "other" (Mindell, 1997). For example, people suffering from a society's tendency to marginalize death, illness, and old age may be greatly relieved if people in general were more connected with the parts of themselves that are dying, ill, and aging.

The issue of how to regard and interact with coma states is controversial and involves many levels of medical and philosophical debate. The popular view of coma has been to regard it as a physical state that deviates from normal, and the goal of treatment has been to arouse the individual out of the state. This general approach holds true even for study groups investigating what they consider to be innovative approaches to coma. The Institute for the Achievement of Human Potential is one such organization, defining coma as "a pathological state of unconsciousness from which the patient has not yet achieved arousal" (LeWinn, 1985, p. 111). This institute has developed the "Coma Arousal Program" which attempts arousal through a series of sensory stimulations. While arousal may be the primary goal of certain approaches, A. P. Mindell (1994) presents the radical view that comatose patients may be going through potentially meaningful inner experiences that are waiting to be completed—that they may be "on an inner journey, dealing with that coma in the best way nature knows how" (Mindell, 1999, p. 11).

In *Coma: Key to Awakening* (1989), A. P. Mindell reports various cases in which people in a coma responded to the Process Work approach and appeared to have

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

enhanced experiences of self-transformation. Some of these people woke up from their coma state and, before they died, reported on their inner process. The focus of process-oriented coma work is not to awaken people from a coma (although this does sometimes happens during the course of the work), but instead to relate to the comatose person in ways adapted to their altered state and to assist them to follow their own inner experience. Process Work believes that people have the potential for growth in all states of consciousness, even up to the moment of death (Mindell, 1999). This idea corresponds with Blakely's (1990) account of her coma experience which lead to an important transformation of her personality and world-view.

According to A. P. Mindell (1994), coma states can be considered one of the deepest and most extreme forms of altered states of consciousness. The term "altered states of consciousness" was brought to scholarly attention by Tart (1969). An altered state of consciousness can be defined as any alteration from an "ordinary" conscious state in which a person is able to function reasonably well. Many people frequently experience different degrees of altered states of consciousness in everyday life. For example, the experiences of being tired, sleepy, moved by deep emotion, "crazy about someone," in meditation, or influenced by drugs or alcohol can all be considered altered states. Researchers have developed criteria for identifying altered states of consciousness (e.g., Glicksohn, 1991, 1993-94) which includes the following: direct references to the experience of an altered state of consciousness (use of such terms as "drifting" and "floating"), reports of alterations in thought, changes in body perceptions, and alterations of visual or auditory perceptions. According to A. S. Mindell (1999), altered states of consciousness, which are largely marginalized or considered unimportant in daily life,

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

may contain meaningful information when unfolded. In order for this unfolding to occur, people need modes of communication specifically adapted to the altered states they are working with—they need special ways of "accompanying people through the night time journey of coma by the light of the moon...by their own night time consciousness"(p. 19).

Callanan and Kelley (1992) worked as nurse practitioners in a hospice, and they point out how special awareness and symbolic communication styles are effective in understanding the needs and experience of the dying. Callanan and Kelley explain how the dying are often misunderstood and seen as confused because of their different communication styles and use of language. However, by keeping an open mind and by listening carefully, it is possible to understand their messages which are often attempts either to describe their experiences or to request the fulfillment of a need that will help lead them to a peaceful death. Process-oriented methods of coma work attempt to communicate even further with people who are in deep forms of altered states and who are seemingly unresponsive.

In *Coma: A Healing Journey* (1999), A. S. Mindell presents a step-by-step guide to coma work methods that family, friends and helpers can use when interacting with all types of coma. According to A. S. Mindell, coma work typically begins with the sitter (the one who accompanies the comatose person) "joining" the comatose person by matching his breathing rate. (For the sake of clarity, I will now refer to the sitter as "she" and the comatose person as "he".) After "joining", the sitter begins to speak in the rhythm of his breathing. She introduces herself and suggests that he trust and follow his inner experiences. The sitter may then ask permission to touch the comatose person's wrist. A. S. Mindell suggests touching the wrist because it is far from the rest of the body, making

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

it a gentle, non-intrusive way to make initial physical contact. While applying very gentle pressure to the wrist in rhythm with the breathing rate, the sitter continues to encourage him to follow his inner experiences while watching for any subtle signals. Slight movements, sounds, gestures, or twitches are all considered signals. The work then continues by noticing the subtle feedback and by helping the comatose person bring awareness to it without judgment or analysis. Completion of the process can be achieved by commenting on it or by gently amplifying it physically. While following these steps, it is often possible to establish a binary communication system in which subtle non-verbal signals (e.g., finger twitching or eye-ball movements) can be used to receive answers to yes or no questions.

An example of such communication is given in *Coma: A Healing Journey* (Mindell, 1999). In this book, there is a description of Arnold Mindell's work with a six-year-old boy who was in a coma and had a brain tumor. Mindell noticed that the boy's cheeks would sometimes turn red when he was asked questions, so Mindell set up a binary communication system: When the boy's skin became very red, it was interpreted as a answer meaning yes, and when there was no color change, the answer was assumed to mean no. The following is an account from the book:

> "Are you in a coma because you hate your brother and sister?"
> No response.
> "Are you in a coma because you don't want to go to school?"
> No response.
> After exhausting many possibilities, Arny asked his last question:
> "Are you in a coma because you want to be closer to God?"
> The little boy's cheeks grew bright red.
> At that point the father said, "No! He cannot become a priest!" (p. 28)

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Using the binary communication system, the coma worker continued to discuss with the child his religious desires. Mindell then worked with the parents on their opposition to their son becoming a priest. Later, the parents reported that the child had come out of the coma, and that today he is studying theology at a university.

Simulated Experience of Coma

Since the above mentioned approach requires that the caregivers relate to states of consciousness that are far from familiar, A. S. Mindell (1999) suggests that caregivers themselves become more familiar with their own deep altered states of consciousness. For this reason, A. S. Mindell also introduces various reflective exercises intended to assist readers to explore their own altered states, their ideas about life and death, and their degree of comfort with non-verbal avenues of communication. Such exercises typically require that the learner step into a "coma role" and be the recipient of coma work. In other words, A. S. Mindell suggests that readers, who are usually in the position of accompanying other people in these states, go beyond their everyday awareness and attempt to enter these states themselves.

The act of role-taking or "putting yourself in the other's place" is often called "simulation." In 1953, Kant mentioned simulation in reference to the field of philosophy, and, more recently, it has been discussed in reference to the philosophy of the mind and of psychology. Simulation theorists have different views regarding the process and nature of ascription (e.g., Goldman, 1989/1995; Gordon, 1986/1995; Harris, 1989). The concept of simulation is relevant to and sheds light on various topics including the nature of imagination, the differences between practical and theoretical reasoning, the nature of

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

emotion, and the development of new models in cognitive science and neuroanatomy (Heal, 1998).

While cognition studies have suggested that mental representation entails a simulation of the world (e.g., Shepard, 1984; Yates, 1985), researchers of altered states of consciousness have looked into the possibility of virtual reality (VR) simulating a state of consciousness (Glicksohn and Avnon, 1997). Tart (1990), in particular, has studied the use of VR in connection with the exploration of altered states of consciousness. These researchers suggest that, because of its immersive nature, VR could be used as an effective research tool in studying subjective experiences (Glicksohn and Avnon). Some researchers have already recognized simulation as a viable approach to the field of death and dying—especially in connection with near-death studies.

Near-Death-Experience (NDE) studies have shown that altered states of consciousness during NDEs have a strong, long-lasting, positive effect on individuals (e.g., Flynn, 1982; Noyes, 1980). Based on these findings, Quekelberghe, Gobel, and Hertweck (1995) expanded their research to show that, with the help of some deep relaxation and hypnotic methods, NDEs can be simulated relatively well and can lead to short-term positive mental attitudes.

Whether a simulation of experience actually corresponds to the "real" experience is an interesting and controversial issue, but it is outside of the scope of this study and will not be investigated here. However, in his book, *Understanding Other Minds from the Inside* (1998), Heal discusses the theory of simulationism and states:

> We should beware of the idea that simulationism is the proposal that mere awareness of another person--of his or her circumstances and behaviour--

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

> automatically produces in the observer, via some natural sensitivity, a simulation of the other's mental state. Simulationism ought not be the claim that we have some kind of quick route to knowledge of other minds, or that we can empathetically 'tune in' to others, or anything of this kind. (p. 87)

The main concern expressed here lies in the practical implications which simulation practice may have in the area of death and dying. In discussing the significance of NDE studies on our attitudes toward death and dying, Ring (1984) reports that NDE provides an "interior view of death" (p. 19) which is often very different from its outward appearance.

> We learn to view *death from the outside*. . . . When we conceive of death from this perspective, we may have images of physical deterioration and feelings of the pain of separation from the dying person. Thinking of death in this way, it is natural to fear it, even to be repulsed by it, and to avoid the subject of death as if it were still under some cultural taboo...The understanding of death suggested by near-death research . . . is an *interior view of death*. . . . This collective testimony . . . states that the experience of death is exceedingly pleasant. Indeed, the word "pleasant" is far too mild; "ecstatic" would be chosen by many survivors of this experience. (p. 19)

Ring further argues that such experiences supplement the external perspective and keep one from getting caught up solely in the more negative traditional views.

While it is not ethically plausible to produce a "real" NDE for an experiment, a simulation makes it possible to access a similar state or type of experience. The results of the simulated NDE study shows that some participants had novel and impressive experiences during simulation which included "a vivid memory of long-forgotten childhood scenes, strong ecstatic feelings, some spiritual visions, and in some cases, even anger or sadness when asked to re-enter the still-living body" (Quekelberghe et al., 1995, p. 163). This present study is closely connected with the NDE study, in that it involves a

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

simulation of the experience concerning death and dying, as well as an exploration of its implications. To my knowledge, there is no existing research on simulated coma experience in connection with Process-oriented coma work.

2.04 Literature Review Summary

Conditions such as death, dying, and deep altered states of consciousness deviate from cultural definitions of "normal" and/or "ordinary." For this reason, they are not valued by and are largely marginalized in contemporary Western societies. The subject is further complicated by complex legal, ethical and emotional issues concerning the continuance or discontinuance of life support.

Seemingly unresponsive states (which are generally called "coma") are the focus of the present study. The topic is controversial and could involve many levels of medical and philosophical debate. Attitudes, forms of care, and emotional states of the caregivers are largely dependent on the cultural views from which people originate. For example, a materialistic view (which includes the Western medical model) may regard unresponsive states as pathological and devoid of any subjective experience. However, models such as the philosophical study of consciousness would question this materialistic view.

Recent medical studies show that some people in persistent vegetative or coma states are able to perceive and process various aspects of their environment despite apparent unconsciousness and inability to communicate in rational ways. In addition, studies indicate that people who regain consciousness after a PVSs or coma states often recollect having had inner experiences while in these states. Assuming that at least some of these experiences are potentially meaningful for both the affected individual and their

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

caretakers, approaches have been developed to assist in unfolding and exploring the possible meanings before death or awakening occur.

In general, however, there is a large gap that lies between the people who are going through such experiences and those who surround them. In response to this, the field of terminal care encourages caregivers to develop their own death awareness in order to be more effective (e.g., Worden, 1976, 1991). Unfortunately, little effort is actually made by either professional caregivers or the general public to bring themselves closer to the experience of "the other side." One method that supports this approach encourages the caregiver to experientially simulate the role of the one in a coma. This type of simulation may help to bring the two worlds closer together. An in-depth exploration of simulation experiences may reveal relevant information for the field of thanatology, and it may also have implications for terminal care and death education.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

CHAPTER 3:

RESEARCH METHODOLOGY AND DESGINS

This chapter presents a discussion of the research method chosen for this study. In the first part of the chapter, I will discuss qualitative research, the rationale for using a phenomenological research strategy, and the theoretical underpinning of this approach. In the second part of the chapter, I will present my research question followed by specific components of the research design.

3.01 Qualitative Research

Because the purpose of this research is to study how the Process Work approach to coma and near death is experienced by caregivers and patients in seemingly unresponsive states, a qualitative research model was more appropriate than a quantitative one.

Quantitative research is a mode of inquiry aimed at gaining empirical facts through controlled experiments and mathematical or quantitative measurements, and it has been the prevalent mode of inquiry in the field of natural science (Van Manen, 1990). Procedures of experimentation and quantitative analysis that are characteristic of the natural science method have been applied to fields of human sciences such as behavioral social sciences (Van Manen, 1990). However, the application of qualitative research methods to the human sciences was often unsuccessful, because "the natural sciences were invented primarily to deal with phenomena of nature and not experienced phenomena" (Giorgi, 1985, p. 1). Qualitative research emerged out of the discontent felt

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

toward conventional methods and out of the need for an approach more suitable for studying human experiential phenomena. Qualitative research allows for the study of "'Persons,' or beings that have 'consciousness' and that 'act purposefully' in and on the world by creating objects of 'meaning' that are 'expressions' of how human beings exist in the world" (Van Manen, 1990, p. 4).

Both approaches serve different purposes, and both have their advantages and disadvantages. While the quantitative approach enables the researcher to study large samples and provides for a broad set of findings with isolated variables, it does not allow for significant information to be obtained from smaller numbers of people. Conversely, while the qualitative approach provides rich and detailed information on individual life experience, it reduces generalizability (Patton, 2002).

Within the qualitative research framework, there are various research models that can be used depending on the focus of study. As a preface to introducing transcendental phenomenology, Moustakas (1994) delineated five example models of different qualitative research models: ethnography, grounded research theory, hermeneutics, empirical phenomenology, and heuristics. While these and other models of qualitative research have varying theoretical underpinnings, methods of data collection, and analysis, they also have common features which distinguish them from quantitative research methodologies. Qualitative inquiry is typically "based on testing a theory composed of variables, measured with numbers, and analyzed with statistical procedures, in order to determine whether the predictive generalizations of the theory hold true" (Creswell, 1994, p. 3). On the other hand, according to Moustakas, the common features of qualitative research include the following: focusing on the wholeness of the experience, searching

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

for meanings and essences of experience, obtaining descriptions of experience through first-person accounts, formulating questions and problems that reflect the interest, continuing involvement, and the personal commitment of the researcher (p. 21).

As Lincoln and Guba (1985) point out, naturalistic studies, which encompass qualitative methods, are often targets of criticism. These criticisms are based on the studies being too subjective and not scientific enough, and they are put forth by more conventional inquirers. How to maintain a study's trustworthiness and rigor is a critical issue for researchers who engage in qualitative inquiry. The details of assailability of naturalistic inquiry and evaluative criteria will be discussed in a later section.

3.02 Phenomenology

The phenomenological approach used in the present study has its roots in philosophy. The term "phenomenology" was introduced into philosophy as early as 1765 and was referred to by both Kant and Hegel (Kockelmans, 1967). Phenomenology, as a major philosophical tradition, was established by Edmund E. Husserl in the early 20th century. "Phenomenon" refers to what appears in consciousness as opposed to what is considered the real object. Husserl's basic philosophical assumption is that there is no separate reality for people, and that we can only know our experiences and make sense of the world through our senses (Patton, 2002). In other words, the emphasis is not on finding empirical facts or on analysis of physical objects, but instead on knowledge that is rooted in meanings (Moustakas, 1994). This does not mean that phenomenologists hold to a view of subjectivism. Rather, a phenomenological approach is a rigorous effort to "describe how the world is constituted and experienced through conscious acts" (Van

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Manen, 1990, p. 184). It also recognizes that "self and world are inseparable components of meaning" (Moustakas, p. 28).

Phenomenology aims to describe the world as we meet it in the immediate, lived experience. Husserl calls this interface going "back to the things themselves" (1970, p. 252). Similarly, in *Phenomenology of Perception* (1962), Merleau-Ponty suggests that turning towards phenomena is a way to "re-achieve a direct and primitive contact with the world"—to "seize the meaning of the world as that meaning comes into being" (p. vii). Moreover, in phenomenology significance is give to the description of what is seized through such process. In *Ideas* (1931), Husserl argues that "the decisive factor lies before all in the absolutely faithful description of that which lies before one in phenomenological purity, and in keeping at a distance all interpretation that transcend the given" (p. 262). Inquirers of phenomenology are required to have disciplined awareness and to set aside their biases before gazing upon what lies before them. It is a non-linear, emergent process in which the phenomenologist examines the meanings of a phenomenon. This examination continues until the meanings are fully unfolded and understood—until "a perceptual closure is realized" (Moustakas, 1994, p. 73). Moustakas describes this rhythmic process of phenomenological investigation as follows:

> The shift from a phenomenon and our perception of it to reflective examination of our conscious experience of it occurs throughout a phenomenological study. Each time new components of an experience emerges, different acts of consciousness direct us to new understandings of the experience. The intentional experience becomes increasingly articulated in its features and qualities and as a whole as we consider it again and again. (pp. 72-73)

These basic attitudes and processes of investigation are reflected in phenomenological

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

research strategies and will be discussed in detail in the section that follows.

3.03 Phenomenological Research

As Patton (2002) points out, the term "phenomenology" has been used in multiple ways by authors of various research models (p. 104). Sometimes the term is used to refer to a point of view, and other times it is used to indicate specific research models and strategies. Examples of the latter usage can be seen in terms such as empirical phenomenology (Giorgi et al., 1975), transcendental phenomenology (Moustakas, 1994), and heumeneutic phenomenology (Van Manen, 1990). Despite the variations, the common aim of phenomenological researchers is to explore "how human beings make sense of experience and transform experience into consciousness, both individually and as shared meaning" (Patton, p. 104). In summarizing the basic features of phenomenological research, Van Manen states that phenomenological research is the study of lived experience, the explication of phenomena as they present themselves to consciousness, the study of essences, and the description of the experiential meanings we live as we live them.

Phenomenological methodologies derive from these features of investigation. In his search for a research model that allowed for "a rigorous attitude toward soft phenomena" (1985, p. viii), Giorgi describes how he came to choose the phenomenological approach:

> Phenomenology is precisely the discipline that tries to discover and account for the presence of meanings in the stream of consciousness. It is the discipline that tries to sort out and systematize meanings and if a way could be found to do qualitative research perhaps it would be by exploring the phenomenological approach. (p. 6)

Phenomenological research is a rigorous approach that requires the full

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

engagement of the "researcher as instrument." In other words, the researcher must be committed from the conception of the investigation through to the analysis and interpretation of the data. Giorge (1985) also identifies two descriptive levels of his empirical phenomenological approach. In the first level, original data is comprised of naïve descriptions obtained through open-ended questions and dialogue. These in-depth interviews result in thick descriptive narratives of people's "lived experience" of the phenomenon. What is obtained in these narratives provides the basis for the reflective structural analysis of the next phase. In this second level, the researcher describes the structures of the experience based on reflective analysis and interpretation of the naïve descriptions. In other words, this is the phase in which the essences of the experience are derived (p. 69).

Van Manen (1990) explains the term "essence" as follows:

> By essence we do not mean some kind of mysterious entity or discovery, nor some ultimate core or residue of meaning. Rather, the term "essence" may be understood as a linguistic construction, a description of a phenomenon. A good description that constitutes the essence of something is construed so that the structure of a lived experience is revealed to us in such a fashion that we are now able to grasp the nature and significance of this experience in a hitherto unseen way. (p. 39)

My present study applies the steps of "meaning condensation" as delineated by Giorgi (1975) in his empirical phenomenological research. I decided to implement these steps in order to obtain descriptions of such essences. This method involves condensation of expressed meanings into more and more essential meanings. As Kvale explains in

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

InterViews: An Introduction to Qualitative Research Interviewing (1996), "empirical phenomenological method may serve to analyze extensive and often complex interview texts by looking for natural meaning units and explicating their main themes" (p. 196). The detailed steps taken for this study are described in a following section.

3.04 Research Question and Rational for the Choice of the Research Model

The research question upon which this study is based is "How do professional caregivers of people in seemingly unresponsive states experience process-oriented coma work?"

One of the crucial points in assisting people in comas, in seemingly unresponsive states, and/or in near death states is for the helpers to become familiar with their own altered states of consciousness. It is also essential that they examine their feelings and ideas about death and dying. A common Process-oriented method for training in coma work involves imagining that you are in a coma state. An essential part of the experience is to also simulate being accompanied by "caregivers" who are using the special attitudes and skills mentioned above (Mindell, 1999). Observations made during such training courses suggests that, even if the people experiencing the imagined states are not medically dying or comatose, they often gain insight into their own altered states and may even "value" the coma state. Such insights may lead to new ideas of how to assist people in these conditions.

My research assumption is as follows: Recipients of Process-oriented coma work may have experiences that significantly impact their care-giving towards people in seemingly unresponsive or dying states. It may also enhance their understanding of and

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

empathy toward deeply altered or near death states, and it may influence their attitudes and approach to carrying out professional tasks. Training of this sort could be an important addition to death education and to the field of terminal care.

I have chosen a phenomenological model as a guiding framework and an interview study as the main strategy for answering the above research question. Among various models within the qualitative research framework, phenomenology aims to "elucidate the meaning, structure, and essence of the lived experience of a phenomenon for a person or group of people" (Patton, 2002, p. 482). The primary focus is on people's experience and how they interpret the world. This approach allows the inquirer to study the participants' worlds without losing their unique qualities and wholeness. This model also provides methodological strategies for exploring the lived experience of research participants. The steps of inquiry used were influenced by the strategies of empirical phenomenological research as delineated by Giorgi (1975, 1985).

3.05 Selection of Participants

The purpose of this research is to study deeply how aspects of the Process Work model of coma and near death work are experienced by the professional caregivers of those in a seemingly unresponsive state. As a result, purposeful sampling technique was decided upon as the appropriate sampling approach. Purposeful sampling technique emphasizes the selection of information-rich cases for in-depth understanding of the questions under investigation (Patton, 2002). The participants selected for this research met the following requirements:

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

1. Their job description had to include giving care to people who are in seemingly unresponsive or minimally responsive states.
2. They could not have had prior experience with Process-oriented coma work as a client nor could they have attended classes or seminars on the topic.
3. They had to be willing to participate in a tape-recorded interview and a follow-up interview.
4. They had to be interested in understanding the nature and meanings of Process-oriented coma work.
5. They had to be able to read and write English.

The flyers for inviting participation in the research were distributed to individual people and organizations as well as to seminar sites affiliated with end-of-life care. A copy of the flyer is appended (see Appendix A).

Among various sampling strategies, snow-ball sampling was utilized as the main approach. Snowball or chain sampling is an approach that locates participants by asking well-situated people to recommend information-rich informants or critical cases (Patton, 2002). I was introduced to the first participant, a 25 year-old nurse, by a personal friend of mine, who used to share the same workplace with her. Following the interview, the nurse took the flyer to her workplace and spoke with some of her other colleagues. As a result, one of her colleagues also became interested in participating in the research and contacted me. The Director of Nursing at this organization also showed interest in participating and volunteered to speak with her colleagues both before and after her own interview took place. As a result of these efforts, three additional participants were

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

located within the same organization. I found yet another participant at a hospice facility in the town I reside in.

In total, five females and one male, all of European-American ethnicity, were recruited for the present study. The sample size of six was determined to be an appropriate workload for this dissertation considering the time needed for collecting data and creating detailed analyses. A male person of African-American ethnicity who had had the experience of providing end-of-life care to his wife was also interviewed in order to acquire comparative data.

The participants ranged in age from 25 to 59 years, had varied degrees of experience in the field, and held different positions in their work settings. The ratio of gender is not equal but reflects roughly the gender basis of the profession. Because of the limited availability of participants within the designated timeframe, diversity in profession was not ensured. For example, most of the participants worked in the field of nursing, and all were Caucasian with the exception of the one man who was interviewed for comparative case analysis. While the present study does not aim for a generalization of findings, another study may want to sample people from different ethnic backgrounds and different professions (e.g., doctors or hospice volunteers).

Table 3.1 shows the demographic information of the participants at the time of the interviews. The demographic information includes: gender, ethnicity, age, profession, work site, and length of time in the profession or in providing care to people in the unresponsive states. In order to ensure confidentiality, I used a pseudonym to identify each participant.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Table 3.1. Demographic Information of the Participants

	Name	*Gender*	*Ethnicity*	*Age*	*Profession*	*Work Site*	*Period*
1	Susan	Female	Caucasian	25	Registered Nurse	Trauma unit, hospital	1 year 6 months
2	Wendy	Female	Caucasian	27	Registered Nurse	Trauma unit, hospital	1 year 3 months
3	Jan	Female	Caucasian	38	Director of Nurse	AIDS hospice	10 years
4	Dianne	Female	Caucasian	44	Certified Medication Aide/ Nursing Coordinator	AIDS hospice	5 years
5	Christy	Female	Caucasian	27	Medical Assistant	AIDS hospice	8 years
6	David	Male	Caucasian	59	Medical Aide	AIDS hospice	15 years
7	Sidney	Male	African American	43	Student	Family caregiver	2 years

At the time of the interview, Jan had worked at her present work site for one year, but had had a total of 10 years experience as a nurse practitioner. Christy had worked for seven years in home nursing care as well as in hospitals before she came to work for the present work site. David had worked as an AIDS hospice volunteer for 13 years before entering the Nursing Department Staff at his present work site. Additional demographic information and a brief summary of their relevant personal and professional views are presented below. This includes information such as how they view and interact with people in seemingly unresponsive states, and what kind of attitudes they hold toward

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

their own possible coma states. The choice of approach to simulate a coma was left up to each participant. The chosen approaches are also described as they lay relevant groundwork for later analyses.

Participant #1: Susan

Susan was introduced to me by a friend who had been a co-sitter with her at a local general hospital the previous year. At the time of the interview, Susan had been working as a registered nurse at the hospital "trauma unit" for a year and a half. She frequently dealt with coma patients and neurologically injured patients. She accepted an employment offer from another hospital and moved to another state soon after the follow-up interview. She was thrilled by the new position, which she felt would be challenging, require a more critical level of care, and provide new opportunities.

At the time of the interview, Susan's hospital work mainly involved assessing and caring for patients with head injuries and working with their families. The people to whom she provided care included both comatose patients and conscious patients with other neurological injuries. After a year and a half, she became comfortable working with patients who could not communicate verbally. Her main approach to them was to read their vital signs, guess into their states, and provide treatment accordingly. For example, if the blood pressure and/or heart rate were high, she would guess that the patient was in pain and give them medication. Susan felt that the issue of coma or persistent vegetative states involves something that is unknown for her, as she gave the example of a patient who had been pronounced as brain dead but eventually regained consciousness. She also excitedly reported a story about how a colleague correctly forecasted that a particular

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

patient was going to wake up. To Susan, this patient looked the same as any of the other comatose patient. This experience excited and astonished her, and she told me that she is still trying work out how the other colleague knew that consciousness would be regained. In giving care to her unresponsive patients, Susan tries to imagine herself in their place, and she makes attempts to frequently talk to them while in their rooms. She reported that although the job is challenging, she enjoys nursing and is passionate about her career in the helping profession. Susan also expressed that the theme of this study was interesting to her, and that she was happy to take part in the research.

In an effort to simulate a coma, Susan tried to imagine the coma states and outward expressions of people she has cared for, and she tried to put herself in their shoes. With these images and feelings in mind, she then listened to my voice as I lead her through the simulation.

Participant #2: Wendy

Wendy, a colleague of Susan's and an R.N. at the same the trauma unit, contacted me after seeing the flyer (Appendix A) that Susan brought to their workplace. She told me that she was interested in participating in the research and we proceeded from there. At the time of the interview, Wendy had been working at the hospital for a year and three months. She is currently going to school to advance her career and to become a Family Nurse Practitioner. She frequently deals with coma and neurologically injured patients. Wendy originally wanted to work exclusively with coma patients because she is intrigued by the mysteries of the mind and brain and by how neuro-assessments correlate with actual prognoses. She enjoys her current work involving multi-levels of care.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Wendy often finds herself emotionally involved with the comatose patients—especially those who are close to her age or seem to have a similar kind of life style to her. She frequently and fearfully thinks of the possibility of ending up in a comatose state, and she imagines ways in which she would like her husband to support her if that were the case. When Wendy does not have as much emotional involvement with a patient, she still tries to remind herself to treat them as individuals and to not get stuck in a stale routine. She also believes that comas and/or trauma injuries could provide opportunities for life-change.

Wendy can sometimes tell whether a patient is going to come out of a coma or not based on their appearance. She also feels that the human body has its own natural process. For example, she believes that when the body starts getting repeated infections it may be the body's way of saying that it is dying (even if the infection itself can be fought off with medication). Wendy also commented on how there is much that remains undiscovered within the area of coma states, and she excitedly reported the case of a patient who came out of his coma despite all medical diagnosis that he was going to die.

As for communication with comatose patients, Wendy has received some messages in forms such as the gripping of fingers or blinking of eyes. She has also observed that some patients are more responsive with the family members than with other people.

In order to simulate a coma in this study, Wendy began by trying to think of various experiences she had had with her patients. However, this approach did not work very well, so she gave up that effort and decided to pursue an approach that was more comfortable for her. Wendy found it "easier and easier to get there" as she followed spontaneous visual images that arose within her. These images will be described in detail in a later

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

section.

Participant #3: Jan

At the time of the interview, Jan had been the Director of Nurses at a local AIDS hospice for a year and a half, and prior to that she had worked as a nurse for 10 years. Jan expressed that she enjoys her work at the hospice, and that it keeps her busy with a variety of tasks including: supervising and supporting the nursing staff and providing direct care to the residents. Normally, ten to twelve people with AIDS reside in the hospice. Most of them come to the facility to live out the last months of their lives, but some come to receive temporary care. Prior to the interview, I had met Jan when I came to visit one of my clients at the facility. The client was a temporary resident at the hospice facility, but, up until that point, I had had no direct contact with Jan. Jan was very supportive of the research and helped me to locate three other participants (Dianne, Christy, and David), all of whom were also staff members at the hospice. Jan spoke with each of them, distributed flyers to them, and offered to fill in for them while their interview was being conducted. She came across to me as a very energetic, vibrant, and efficient person.

The nature of the hospice facility provides Jan with a number of opportunities to sit with people in unresponsive, near death states. She describes this experience as wonderful at times and emotionally draining at other times. She often finds herself wondering what the patients' lives have been like before the condition, and what might be going on in the inner worlds of their states now. Jan confessed that, being a person who likes to keep herself busy with variety of tasks, it is sometimes difficult for her to just sit

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

and be present with the patients.

When giving care to coma patients, Jan assumes that they are able to hear her and sometimes talks to them or asks them to give her signals in answer to her questions. She has, for example, asked patients to squeeze her hand to indicate a yes answer, but she has not yet felt that anyone answered back. She says that her attempts are more an aspect of nursing assessment than of communication on a human level. Jan also reports that she had not imagined herself in a comatose or near death state prior to the interview.

In order to simulate a coma, Jan began by thinking about what she would feel if she were in a coma and had no control over her situation. It was a scary thought for her, so it was difficult to get in touch with a simulated coma state in that way. Instead, Jan decided to relax and free up her thoughts. Throughout the duration of the coma work session, she reports having vacillated between these two states.

Participant #4: Dianne

Dianne works as a Nursing Coordinator at the same AIDS hospice. At the time of the interview, she had been working at the hospice for five years. Dianne works as both a CMA (Certified Medication Aide) and as a NC (Nurse Coordinator). Her responsibilities as a CMA are providing nursing care and administering medications to patients, while her NC position involves maintaining order in the daily functioning of the facility. She enjoys working in the hospice environment, and likes getting to know the patients and developing relationships with them.

A few years prior to the interview, one of Dianne's colleagues at the hospice tried to describe to her an approach to coma work. The colleague described a process in which

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

the caretaker focused on being with and breathing with the comatose person in an attempt to meet them in the space where they were. However, Dianne never actually saw anyone conducting a coma work session, nor had she been the recipient of one. This prior knowledge was part of the reason Dianne became interested in participating in this study.

Dianne has had a number of opportunities to sit with people at the end of their lives. Initially, she feared doing the wrong thing, but now she is more comfortable just sitting and being with them. She feels that the end of life could be the most meaningful and magical time for people. She recounted a number of occasions where people near to death were aware of or talking to "other presences." These experiences seemed to create a sense of peace, and an "anticipation of being reunited with somebody or going to a place that is good for them." When such instances occur, Dianne feels that it is not appropriate for her to be an active part of it, and she tries to be there quietly without interrupting. Being in the presence of dying people has changed her perception of dying and given her opportunity to ponder her own mortality and spirituality. While these experiences have overall diminished her fears of death and what may follow, she is still afraid of the process of dying. She also worries that if she were in a seemingly unresponsive state, she may lose control over her destiny and have to end her life in a "very cold and clinical environment."

Dianne's approach to accompanying people in comas or seemingly unresponsive states is different with each patient and is partially based on her relationship with them or her prior knowledge about them. For example, if a patient (prior to their unresponsive state) told her what they wanted at the end of their lives, she tries to carry out those wishes. If she does not have sufficient information about the patient, she tries to intuit

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

what they may want according to her past experience with them.

In order to simulate a coma, Dianne first tried to relax, remove herself from the outer world, and let go. Then she tried to focus on and be open to what I was doing. She does not think the effort was one hundred per cent successful.

Participant #5: Christy

At the time of the interview, Christy had worked as a medical assistant at the same AIDS hospice for one year. Prior to that, she had worked for seven years doing in-home and hospital care. As a medical assistant, Christy deals with multiple tasks regarding residents' daily care. She is very enthusiastic about her work at the hospice, where she enjoys watching residents grow and helping them physically, mentally, and socially. Her work also involves sitting with the dying at the very end of their lives and taking care of their physical needs. She describes the experience of sitting with the dying as wonderful and rewarding. She is also of the opinion that caretakers have to have "the right kind of heart for it"—something deeper than compassion—to be able to accompany the dying.

When she sits with people who are in unresponsive states at the end of their lives, Christy makes a point of always calling them by name, telling them what she is going to do, and saying whatever comes to her mind. She often reassures them that they are not alone and that they are cared for. This attitude is influenced in part by her own strong belief that people should never die alone, and by her hope that when it is her time for dying someone will accompany her. Physical contact, such as holding hands or petting, is also an important aspect of her accompaniment. Christy has observed that some comatose people are more vocal than others. When a patient moans in response to being moved, she

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

frequently assumes it is a sign that they are in pain.

For Christy, thinking about what it would be like if she were in a coma is fascinating. She wonders if she would be able to hear someone talking to her, feel their touch, or see things. She also wonders where her mind might be while in a coma state.

Participant #6: David

At the time of the interview, David had been employed for two years as a medical aid by the same AIDS hospice. Before that, he had been a volunteer there for five years, and he had also volunteered at another AIDS hospice where a dying friend had been admitted. His responsibilities as a medical aid involve giving medication and dealing with the physical and emotional care of the residents. He likes being a part of the staff team and working in the hospice environment.

David sometimes stays a few hours beyond his shift in order to sit with some of the residents who are in unresponsive states. He holds their hands, talks to them, and/or gives them physical care as needed. When he talks to them, David tries to be "positive." He may tell them that he loves them, tell them a joke, or even make things up. A few times when a resident was clearly near death but seemed to be holding on, he told them that it was alright to go. Because there are only 10 to 12 residents in the facility, and because the staff and the residents can become like a family, David often feels emotionally involved when residents approach the end of their lives. He cares a great deal about people with disease and feels that the hospice is where he belongs.

David has had thoughts about his own mortality or potential coma state. These reflections may be due in part to having been diagnosed with cancer five years ago.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

In the interview prior to the coma simulation, David commented that if he had to die the next day, he felt that he would be ready and would only need to take care of a few more things. Before the coma work session, he also half-jokingly reported that he was sure it was going to be a horrible experience for him. This feeling was based on the fact that he had hated a similar experience in which he had simulated a patient being bathed as a part of his nurse training. He expressed not having liked the bath simulation because he felt like he had no control.

In his effort to simulate a coma, David tried to remember his past experiences in the hospital where he was diagnosed with cancer. He tried telling himself that he had cancer and that he was going to die.

A few days prior to the follow-up interview, David had lost his dog. The dog had been with him for over 15 years, and he reported that the experience had been very emotional and had made a big impact on him.

David was the last person with whom I conducted the follow-up interview. The interview immediately followed a two-hour Process-oriented coma workshop, which I held for a group of the hospice staff. After being a participant in this study, the Director of Nurses (Jan) requested the workshop because she was enthusiastic about disseminating the information among other staff members. It was conducted within the time scheduled for their monthly in-service study group, which regularly invites lecturers for the education and training. Although the timing of the workshop concerned me, I chose to accept the request—partly because finding another time to hold the workshop proved difficult for both parties, and partly because it seemed unethical to value the objectivity of the research over the possible benefits that might result for the residents and the staff.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

In the workshop, I spoke about the basic theory of Process Work and Process-oriented coma work. Then, using a workshop participant who did not take part in my research, I demonstrated how to look for signals in comatose patients and presented basic coma work steps towards working with people in these states. The workshop received good feedback from the participants, and David even expressed that he thought it was the best in-service he had ever attended at the facility.

During the follow-up interview, David kept mixing up what he experienced in the workshop and what he experienced a week before in the simulation. As a result, extra care and probing were needed to filter out the responses that I was looking for. Although I tried to distinguish, to the best of my ability, the two sets of David's experiences, it would be unrealistic to claim that his memory of the simulation was not influenced by the workshop experience. By then, the workshop had already become a part of his life-world and therefore a phenomenological filter.

Participant #7: Sidney

Sidney was a family caregiver to his wife, who died of cancer about a year prior to the interview. The interview data of Sidney will be treated as comparative data in the present study.

Prior to the interview, Sidney had some knowledge of Process Work because his wife's therapist was a faculty member of the Process Work Center of Portland. However, he had little direct exposure to Process-oriented coma work because he was not present when the therapist conducted coma work sessions with his wife. Sidney only heard the report of those sessions from the therapist at a later time. After consenting to participate

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

in this research, he wrote me an email message in which he recounted the final moments of his wife's life. He described in detail how she fell into the coma and eventually died when he was absent from the room for only a short period of time. In the interview, he stated that he appreciated the opportunity to remember this part of their lives and to write it down on paper for the first time.

Sidney is a doctoral student of psychology. His prior experience includes working in a coroner's office, where he had a number of opportunities to observe the process of human bodies decomposing. These experiences made him reflect on the mortal and transient nature of life. Sidney has also had two friends, who were medically diagnosed as dead, come back to life. These events contributed to his belief that some form of energy continues on even after people die physically.

During the last months of her life, his wife's primary caregivers were Sidney's sister and a hospital nurse. Sidney said that he was forced to come to terms with the fact that he was no longer the primary person in her life. When he sat with his wife in her seemingly unresponsive state, he would always talk to her and hold her hands. Although Sidney did not detect any response back from her, he was with the "knowing" that she was somehow aware of his presence. The fact that she passed away during his absence was a great disappointment for him. Because of his long-held belief that the deceased remain in the environment in some other form, he continued to talk to his wife even after her physical body was dead. Sidney described having accompanied his partner's dying process as a "rite of passage," and expresses that it was a significant and extremely emotional experience for him. At the time of the interview, he was living by himself and was not partnered.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

In order to simulate a coma, Sidney tried to imagine and recreate the sense of an out of the body, near death experience that a friend experienced and once described to him. He also considered me as a "point person" with the outer world.

3.06 Researcher Subjectivity

I am a Japanese woman studying in the United States. At the time of the interviews, I was a 39 year-old doctoral candidate in Interdisciplinary Studies in Art and Science. In addition, I was a learner at the Process Work Center of Portland, which is a private institute for therapists in training toward a certification in Process Work. The latter program involves both didactic and experiential training in the forms of class and workshop attendance, individual and group supervisions (including live supervision with clients and case consultations), and individual therapy for personal growth. The founder of the institute, Arnold Mindell, developed the method of working with people in unresponsive states and called it "coma work" (see also Chapter 2, Literature Review). Coma work is the focus of the present study. Coma work classes, workshops, and supervision sessions are offered by certified process work therapists who have extensive training in the field. I have been enrolled in the Process Work program since December of 1999. At the time of the interviews, I was in the final phase of the training program and had taken multiple classes and supervision sessions in coma work.

I have worked as a certified clinical psychologist in Japan since 1995. I have provided individual and couples counseling as well as mental health consultation and education in various settings. As a part of my training as a corporate mental health educator, I studied Autogenic Training techniques. In these techniques, a therapist induces

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

relaxation in clients by using words and a tones of voice similar to those used in hypnotic suggestion.

As described in the introductory chapter, I was in the role of a family caregiver when my father was dying of a heart disease. When my father became unresponsive in the last stage of his dying process, I used some of the coma work techniques that I had learned in Process Work. In implementing these techniques into my father's care, I also found that they were helpful to me. I am of the opinion that some people in comatose states may be aware of the outer world despite their seeming unresponsiveness. I also believe that comatose people may be experiencing states of consciousness that are simply different from their "waking consciousness." In addition, I believe that people in comatose states may be going through very important and meaningful experiences, and that it is important to accompany them with curiosity and respect.

3.07 Data Collection

Based on the phenomenological framework chosen for this study, the interview was considered appropriate to elicit descriptions of participants' experiences in order to answer the following research question: "How do professional caregivers of people in seemingly unresponsive states experience process-oriented coma work?" One to one interviews were used as a primary strategy for gathering data. The interview instrumentation used for the study was the "interview guide approach," as suggested by Patton (2002). In this approach, "topics and issues to be covered are specified in advance

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

in outline form but the interviewer decides sequence and wording of questions in the course of the interview" (Patton, p. 349). Participants were asked to clarify and elaborate on words, phrases, and statements which were not clear to the researcher. The researcher focused on understanding the lived experience of the coma work sessions and the corresponding meanings as they were perceived by the participants. The interview guide used for the initial and follow-up interviews is described in a later section.

The interviews were conducted prior to, immediately following, and one to three weeks after the coma work experience. The interview prior to the coma work experience was conducted in order to understand the participants' backgrounds and to elicit a context for their experience. I conducted all of the interviews and coma work sessions. The procedure for the coma work sessions will be described in a later section. For each participant, the initial interview (including the coma work session) lasted anywhere from 60 to 90 minutes, the follow-up interview lasted about 30 minutes, and the coma work session themselves lasted around 15 to 20 minutes.

There are several ways to record interviews, each of which has its advantages and disadvantages. For example, Kvale (1996) pointed out that, while videotaping has the advantage of capturing visual as well as auditory aspects of the interview, immediate note-taking by the interviewer may be better at capturing the social atmosphere and personal interaction. Taking this into account, I selected audiotape recording, videotape recording, and immediate post-interview note-taking as the methods of documentation.

The interview sites varied. The initial and follow-up interviews with Susan and Wendy were conducted at my residence because it was suitable and convenient for both the interviews and the coma work sessions. The rest of the interviews were conducted

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

(upon their request) at the hospice where they worked. The initial interviews with the three remaining participants (Jan, Dianne, Christy) took place in a small office within the hospice facility. More suitable rooms were not available at the time, so we chose an office where we were least likely to be disturbed. These coma work sessions were conducted with the participants lying on a quilt on the floor. The initial interview with David was conducted in an unoccupied residential room at his workplace. David's interviews prior to and following the coma work session were conducted on the sofa, and his coma work session was conducted while lying on the bed. The follow-up interviews for all four of the hospice workers were conducted in the hospice's living room. Both the initial interview and the follow-up interview with Sidney were conducted in a private session room at a counseling agency where I was an intern.

Table 3.2 shows the outline of the data-collection procedure. It is followed by a detailed description of the procedure.

Table 3.2 Data-Collection Procedure

	Description of the Procedure
1	Collecting signed informed consent forms, participant release agreement forms, and demographic data sheets.
2	Welcoming participants and briefly introducing the interview procedure.
3	Interviewing the participants' about their background information.
4	Conducting coma work sessions.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

5	Interviewing participants about their experience of the coma work sessions.
6	Conducting follow-up interviews.

Collecting Signed Informed Consent Forms, Participant Release Agreement Forms, and Demographic Data Sheets

After the initial contact and verbal consent, a letter describing the details of the interview procedure (Appendix B) were sent to the participants, as was as a consent form (Appendix C), participant release agreement form (Appendix D), and a demographic data sheet (Appendix E).

On the day of the initial interview, I collected the signed forms and demographic sheets before proceeding with the interview. Participants who had given verbal consent either showed up for the interview with the signed forms or consented to sign the forms before the interview began. Any questions that came up before, during, and/or after the interviews were answered and clarified through discussion.

Brief Introduction

Following the collection of the consent forms, participants were given another brief introduction to the researcher and a description of the interview procedure. The prompt used to clarify the interview procedure was as follows:

> First, I will interview you about your experience as a professional caregiver. Then, after a brief introduction and exercise description, I will ask you to experience a

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

coma work session, which will take about 15 to 20 minutes in total. The explanation of coma work will be given just before the experience. After the session, I will interview you about your experience. Approximately 1 to 3 weeks later, I would like you to sit with me for a brief follow-up interview.

Interview on Participants' Background Information

Prior to the coma work sessions, participants were interviewed briefly about their lives as professional caregivers. The following questionnaire was used to guide the interview:

- What does your normal work-day look like?
- How is it for you to be around people in comatose or unresponsive states? How is it for you to be with a person who is alive but not responsive?
- What is going on inside of you when you are giving care to these people? Are there any experiences or stories that stand out for you?
- Have you had different experiences with different people in comas? For example, have you ever felt that some comatose people are more active while others are farther away? Do you sometimes feel that someone is there and trying to communicate with you?
- Have you ever considered trying to communicate with them? Why or why not? If you did try, what did you do?
- Have you ever imagined a future in which you might be in a coma? If you have, what was it like to imagine it? If you haven't, what do you imagine a coma to be

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

like?

Coma Work Session

Following the preliminary interview, the participants were given a brief introduction to Process-oriented coma work, and basic principles and skills involved in the work were explained. The following prompt was used to guide the introduction and was written by me under supervision of a certified Process Work therapist:

> What I would like you to experience today is a way of working with people in unresponsive states called Coma Work. It is a special way of relating and communicating with people in unresponsive states, which involves noticing, respecting, supporting and responding to what the person's body is doing. I am interested in understanding deeply what you experience and what happens to you when you go through this way of working with a coma. I will interview you about it immediately after the experience. It helps greatly if you can immerse yourself in the experience, be open to it, and notice as best as you can what you experience.
>
> You may choose to remain seated or to lie down during the coma work session, whichever is most comfortable for you. I am going to ask you to close your eyes, and imagine being in a comatose state. Some people imagine their coma state to be very quiet, while others imagine it to be very noisy and physically active. Please feel free to be in your own unique coma state.
>
> First, I will sit quietly with you and begin pacing my breathing with yours. I will then start speaking to you. If it is OK with you, I will place my fingers on your

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

wrist and press it lightly. How would you feel about that? Depending on how I notice your body responding, I may ask you to bring awareness to a particular area or movement of your body, or I may support the experience verbally or physically. How would you feel about me supporting the movement of your body physically? Is there any part of your body that you would not feel comfortable being touched?

The session will take about fifteen to twenty minutes. All you have to do is notice the experience, and allow it to just be what it is.

The participants were invited to ask questions at any point during the above introduction. In most cases, the introduction turned into a dialogue. When I mentioned that there might be physical contact, any sign of hesitation was carefully scrutinized. When a participant gave the instruction to avoid contact with certain body parts, I strictly adhered to it.

Following the introduction, participants were asked to simulate a coma according to the instructions listed above. After that, I began to accompany them by using Process-oriented coma work methods. Using the steps described by A. S. Mindell (1999), I sat with the participant and began pacing my breathing with theirs. After approximately one minute, I brought my face closer to the person's ear and spoke during the person's exhale. The tone of voice that was used for each participant depended on my perception of the coma state's "atmosphere." For most of them, I spoke in a relatively soft voice—softer than the voice I use for daily conversation. The basic steps used in the present study were in accordance with A. S. Mindell's suggested coma work methods. What follows is a list of the techniques and statements used in the coma work.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

(Note: "....." refers to a pause.)

1. Introducing myself:

"Hello, (the name of the person). This is Hitomi. I'm here.....I'm going to be with you for a while.....It's so nice to be here with you."

2. Encouraging the person to trust and follow their inner and outer experience:

"All you have to do.....is follow what is happening inside of you.....experiment with trusting in it.....Whatever it is that you might be experiencing.....that will show us the way."

3. Joining the person by touching their wrist:

"In a minute, I will touch your wrist with my fingers.....(placing my fingers gently on one wrist and pressing down lightly with their inhale.)

4. Bringing awareness to modes of experience:

"You might be feeling things.....or you might be seeing things.....or hearing things.....or making movements.....If you are feeling something, then feel it (pause for a reaction).....if you are seeing something, then look at it (pause for a reaction).....if you are hearing something, then listen (pause for a reaction).....if you are moving, then follow these movement (pause for a reaction)....."

5. Supporting the signals verbally or physically:

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

According to how responses were perceived, I supported the participants verbally and/or physically. For example, when I perceived body movement, I supported the movement with my hands and watched for the feedback. If the movement continued or enhanced, I continued in that direction. If the movement disappeared, I considered it negative feedback and looked for other signs. Some of the prompts that I used for verbal encouragement included, "Oh, that eyebrow," "Yes, those lips move, I see them," "Wow, a big breath! That's important," "I saw your mouth move. Yes, you are saying something," "I like the way you use your fingers. Yes, I feel them squeezing my hand. Wow, I know you are there," "Oh, that sound, what an amazing sound! I heard it," "Oh, you are experiencing that," "Little movements are interesting, yes, moving," "Go ahead and follow your movements now, even if you don't know where they are going," and "Uh-huh, oh, yeah, mmm, that is right."

6. Closing:

" (the name of the person), it is time to close for now. It was such a pleasure sitting with you." The person in the simulated coma was then asked to take their time in opening their eyes and preparing for the interview.

Interview on the Experience of the Coma Work Session

Immediately following the above session, each participant was interviewed on his or her experience. I focused on gathering information on the lived experience of the coma work sessions and on the meanings it held for the participants. The outline of the

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

questionnaire prepared for the initial interview was as follows:

- How do you feel now?
- What did you do to try to simulate a coma?
- Would you please recall and describe the experience you just had while simulating the coma? What stands out for you about the experience? What was the experience like for you?
- How was it for you to take the role of a comatose person?
- What did I do that was either helpful or not helpful?
- Do you have any thoughts or feelings about how this experience may impact your work with comatose patients?
- What meaning does the experience have for you?
- Is there anything else that you would like to add?

Follow-Up Interview

A follow-up interview was conducted with each participant approximately one to three weeks after the initial interview. This broad time-span was due to the schedule availability of both the researcher and the participants. The following is the outline of the questionnaire used in the follow-up interview:

- How has your week been? What's been happening during the past week?
- Can you take a moment and remember the experience we had a week ago? Would

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

you please describe the experience again? What was the experience like for you? What stands out for you about the experience?

- Have you noticed any ways in which you are feeling or experiencing comatose people or comatose states differently? What aspects of the experience do you feel contributed to that difference, if any?
- Have you noticed any ways in which you are feeling or experiencing your views toward your own possible comatose states differently? What aspects of the experience do you feel contributed to that difference, if any?

3.08 Post-Interview Review

Following the recommendation of Patton (2002), immediately after the initial and follow-up interviews, I recorded details about the setting and observations about the interviews. The memos taken during the course of the interviews and the data analyses included the following information:

1. Description of the conditions under which the interviews were conducted.
2. Description of the activities, non-verbal information, and atmosphere as they were perceived by the researcher during the interviews.
3. Description of the researcher's own experiences including insights and feelings.
4. Brief evaluations of how the data collection went.

Any change that was considered necessary as a result of the evaluation was reflected in the next interviews.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

3.09 Transcription

In *InterViews* (1996), Kvale discusses the issue of transcription reliability and validity, and argues that "Transcripts are not copies or representations of some original reality, they are interpretative constructions that are useful tools for given purposes"(p. 165). Because transcription always involves the subjective choices and judgments of the transcriber, it is never really possible for a written text to be the exact reflection of oral language. As a result, Kvale suggests that a more constructive approach is to select a style of transcribing that is most suitable for the research purpose.

Because this study involves condensation and categorization of experiences and meanings as they are reported by participants, a detailed description of non-verbal aspects of communication may not be as critical. For example, the exact length of pauses and in-depth descriptions of emotional expressions may not be as important in this study as they would be for a sociolinguistic or psychological analysis. However, omitting all the non-verbal information or transforming statements into a more formal style may deprive the transcribed text of important information necessary for the analyses. Accordingly, the main style of transcription used in this study was audiotape recording. Audiotaping was used because of its high acoustic quality. The statements were transcribed word for word and included repetitions and grammatical errors. Pauses were recorded by using multiple periods to roughly suggest differing lengths of time. Italics were used to show when certain words were emphasized, and emotional expressions such as laughter and sighing were recorded whenever they were perceived by the transcriber.

In order to secure a uniform style of transcription and due to limited financial

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

resources, I transcribed all of the tapes myself.

3.10 Data Analysis

The data analysis strategy applied to the present study was influenced by the phenomenologically-based meaning condensation method. This method was employed by Giorgi (1985, 1989) and others such as Worthen & McNeill (2002), and involves a condensation of the expressed meanings into more and more essential "meaning units" (Giorgi, 1985, p. 10). It also involves explicating the main themes. The method was combined with an organizing system that was influenced by the data organization method suggested by Tesch (1990). The basic steps that were taken for data analyses are described below.

In this study, I performed the analyses of data under the immediate supervision of Lee Spark Jones, Ph.D., who has extensive experience as a qualitative researcher. Any disagreement regarding the identification of the meaning of units and themes or the interpretation of the findings were resolved through dialogue.

It should also be noted that attention and awareness of the researcher's underlying beliefs were consistently taken into account. We attempted to follow the points raised by Kvale (1996) in *InterViews: An Introduction to Qualitative Research Interviewing*. In this book, Kvale discusses the issue of the pervasiveness of interpretation and he states that "analysis is not an isolated stage, but permeates an entire interview inquiry." (p. 205) In other words, it begins with the interview design and continues on through the course of interview, the transcription, and finally the data analyses.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Preparing a Preliminary Organizing System

Step 1: Obtaining a Sense of the Whole

Two of the documents appeared to contain more information than the others and these documents were read first. In an attempt to grasp a sense of the whole, they were read three or four times before any analyses were conducted. This served as a foundation for the next step of discriminating meaning units.

Step 2: Identifying Meaning Units and Topics

This step consisted of identifying meaning units within the description of the two documents by noticing the experienced transitions in meaning. The shifts in meaning were marked by slashes in the transcript. Simultaneously, temporary topic headings for each unit were written in the margin and were used later for data organization.

Step 3: Making the List of Topics

After the two data sets were read and the topics were temporarily identified, a list of all topics was made to serve as the preliminary organizing system. It should be noted that, although this basic system was also used to organize the remaining data sets, I was continually refining it as the analysis progressed by adding new topics and discarding irrelevant ones. This refining process continued until the last data was analyzed, by which time categories and themes prevalent to the entire data were identified.

Meaning Condensation

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Step 1: Identifying Meaning Units

The above mentioned procedure for identifying meaning units was also used for the remaining documents. After reading each document three to four times to obtain a sense of the whole, meaning units were identified by noticing the experienced transitions in meaning. At the same time, temporary topic headings were written in the margin and referred to the list of topics made in the above-mentioned steps.

Step 2: Discriminating Meaning Units within a Psychological Perspective and Focus on the Phenomenon Being Researched

This step consisted of identifying the relevancy of meaning units to the specific purpose of the study. In this case, the focus of relevancy was on the caregivers' experiences of the Process-oriented approach to coma. Any meaning units that were considered irrelevant to the research question were discarded. The relevant meaning units were grammatically corrected and repetitions were removed, so that more direct expressions of meaning could be achieved without losing the essence. First-person narrative styles were kept, and meaning units with the same topics were assembled in one place.

Step 3: Articulating the Meaning Units

This step consisted of transforming the meaning units which were in participants' everyday expressions into more psychological language. The meaning units under each topic were examined with the intent of elucidating "the psychological aspects in a depth appropriate for the understanding of the events . . . [through] a process of reflection and

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

imaginative variation" (Giorgi, 1985, pp. 17-18). At this point, the first-person narratives were transformed into the third-person narratives, and the temporary topics were turned into themes with more descriptive wording.

Step 4: Arriving at the Essence of the Experience of Coma Work

This final step of the analyses consisted of refining and distilling the most essential components of each interview in its entirety. The essential meanings arrived at through the preceding steps were all tied together into a descriptive statement for each participant.

Steps 1 through 4 were repeated for all the interview transcripts. The lists of meaning units in Step 3 formed the basis for the next group analyses. The group analyses were conducted in four steps as described in the following.

Group Analysis

Step 1: Compiling the Lists of Meaning Units

This step consisted of assembling the meaning units of all of the participants into one place under the same themes. The complete list of essential meaning units organized under different categories and themes had the mark of participant's initials after each unit. By this time, the data were divided in two major themes, each with several sub-themes. This list was then used to structure the flow of the research report in the findings section.

Step 2: Identifying Common Meanings

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Meanings shared by two or more participants were identified within the above-mentioned list. Meaning units reported by only one participant were saved for later discussion.

Step 3: Generating Meaning Structure for the Caregivers' Experience of Coma Work

The descriptive statements of all participants arrived at in Step 4 of the individual analyses were read once again in order to obtain the sense of the whole. After that, the common meaning units identified in Step 2 were used to generate a general descriptive statement of the meaning of the caregivers' experiences of coma work.

3.11 Evaluative Criteria

Although there has been an increasing acceptance of qualitative methods in the field of social science, what constitutes good interpretation in qualitative research still remains a controversial issue. In quantitative research, the quality depends on the appropriateness of instrument construction and on the way it is administered. The credibility of qualitative methods "hinges to a great extent on the skill, competence, and rigor of the person doing fieldwork" (Patton, p. 14). As Merrick (1999) argues, one needs to "acknowledge the human element involved and to consider, as part of the method, the strengths and limitations of the personal instrument" (p. 25). Consequently, various researchers of qualitative methodology have discussed and explored the issue of research soundness, and have suggested alternative criteria for qualitative research. The alternative criteria would either replace or translate positivist's criteria of validity, reliability, and objectivity.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Within the qualitative research framework, views of evaluative criteria differ according to the underlying philosophical stance of each position. Denzin and Lincoln (1994) summarized four positions: the positivist, postpositivist, constructivists, and poststructuralist positions. This study's approach to evaluation is roughly situated within the postpositivist position, which, despite considerable debate over what constitutes qualitative research criteria, agrees that alternative criteria unique to qualitative research are needed. For example, Lincoln and Guba (1985) suggest "parallel criteria" as an alternative. In this approach, credibility, transferability, dependability, and confirmability correspond respectively to the positivist's criteria of internal validity, external validity, reliability, and objectivity. Later researchers, such as Merrick (1999), suggest trustworthiness, reflexivity, and representation as alternative criteria for evaluation of quality. Kvale (1996) summarized the issue of validity in a postmodern era as follows:

> In a postmodern era, the foundations of true and valid knowledge in a medieval absolute God or a modern objective reality have dissolved. The conception of knowledge as a mirror of reality is replaced by knowledge as a social construction of reality. Truth is constituted through a dialogue; valid knowledge claims emerge as conflicting interpretations and action possibilities are discussed and negotiated among the members of a community. (p. 239)

Accordingly, various tactics to enhance quality of research have been suggested. Kvale (1996) stressed the importance of addressing the issues of verification throughout an interview investigation, and he summarized validity issues at seven stages of inquiry, including: thematizing, designing, interviewing, transcribing, analyzing, validating, and reporting (p. 237). Based on the recommendations of Kvale (1996), Maxwell (1996), and

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

others, I used the following strategies to facilitate the soundness of this study: constant effort to reflect on and identify my own bias, collection of comprehensive data, proactive effort to identify as many alternative explanations as possible and to identify discrepant and negative cases, solicitation of feedback from others, providing the co-researchers with a chance to react to the study's data and conclusions, and providing rich and thick descriptions.

3.12 Protection of Human Subjects and Related Ethical Issues

The characteristics unique to qualitative methods can serve as strengths but can also entail ethical dilemmas unique to this approach. Cieurzo and Keitel (1999) identify two aspects of qualitative research which distinguish it from qualitative methods and produce significant ethical ramifications. The first aspect is the emergent design of qualitative research, which makes it difficult to fully inform the research participants of the potential consequences of the research. Constant changes occur throughout the research process and they cannot all be foreseen. The second is the humanistic aspect of the qualitative research. Because qualitative research involves the researcher (the human being as an instrument interacting with other human beings), various risks and ethical issues exist which require special attention. The issues specific to in-depth interviewing (which was the main strategy used for data collection in this study) include dual role situations that may arise between the two parties and emotionally difficult situations that may occur because of the intense and flexible nature of the strategies.

As Cieurzo and Keitel (1999) point out, ethical considerations are something to be addressed prior to and during the research process as well as after the research is

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

completed. It is challenging yet imperative to be constantly sensitive to and aware of the impact that the researcher may have on the participants. There is an inherent power difference between the two parties. As Cieurzo and Keitel state:

> Qualitative researchers need to reflect on the potential harm the research process could cause for participants and to recognize how their own presence, personal experiences, and biases can affect research findings. Sensitivity to the experiences of those being studied should not be an afterthought, but rather an important consideration at the beginning of the research process. The notion of giving back to others will benefit not only the people being studied but also the researcher and the profession as a whole. (p. 74)

Accordingly, ethical considerations were maintained throughout this study in a multitude of ways. Before signing the *Participant Release Agreement* (Appendix D), participants were provided with the *Letter to Co-Researchers* (Appendix B) and with an *Informed Consent Form* (Appendix C), all of which clearly informed them of the nature, purpose, requirements, and possible risks of the research project. I, the researcher, was open to discussing the nature and purpose of the study with the participants. Prior to, during, and following the interview, I also answered participant's questions regarding the study. They were encouraged to feel free to withdraw at any time. Participants were identified by pseudonyms in transcriptions, data analysis, and the final dissertation. Any information that the researcher determined might identify a participant was removed or altered. Confidentiality was and will continue to be maintained unless the participant has been fully informed and agrees to release relevant data so that it can be used. Participants had the opportunity to review, confirm, or alter the research data so that it corresponds with their perception of the experience, and they had the opportunity to read the final

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

draft of the dissertation.

The coma work sessions required special ethical consideration and care because of the involvement of physical contact and the possibility of altered states of consciousness. In addition to the above measures, I made extra efforts to ensure the participant's consent, and I tried to watch out for any signs of hesitation. When a rather strong altered state of consciousness was experienced, I temporarily set aside my data collecting duties and made myself available for open discussion and support. Immediately after the coma work session and at the beginning of the follow-up interview, I checked in with the participants about any perceived negative impacts of the coma work.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

CHAPTER 4:

FINDINGS

This chapter describes the findings of the study. Themes that emerged as a result of the meaning condensation are identified and discussed in detail along with illustrative examples of the narratives.

4.01 Findings

Overview

Analyses of interview data on the professional caregiver's experience of the Process-oriented model of working with coma revealed two major categories of themes. These two major themes were further divided into several sub-themes. The first major theme, "the experience of a simulated coma," appeared to divide into two sub-themes: "physical experiences or senses" and "experiences of emotions, feelings, mind-states and/or thoughts". Sometimes participants reported that these experiences were directly or indirectly related to my interventions or my presence during the coma work, and other times they reported that the experiences seemed to happened spontaneously. The second major theme, "the implications of a simulated coma," divided into the sub-themes of "the meaning for professional life" and "the meaning for personal life." It should be noted that these categorizations are meant to serve as approximate guidelines for the convenience of later discussion and are not meant to be mutually exclusive. Categorization was itself an issue, especially with regards to the first theme because the participants' descriptions

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

often seemed to encompass different sub-themes, or they involved attributes that were outside of their usual conceptions of their experience.

Several themes were identified under the above themes, and the overview of the categorization is depicted in *Table 4.1*. Illustrative examples and a more detailed description of themes will follow in the section called *Meaning Structure for the Caregivers' Experience of Coma Work*. This section focuses on the analyses of the data, and it should be noted that I designated myself with the word "sitter" when references were made to me during coma work sessions

Meaning Structure for the Caregivers' Experience of Coma Work

It was the first time simulating a coma for every participant in this study, and many of them reported having unexpected experiences during the coma work sessions. These experiences gave them a sense of amazement as well as insight for their professional and/or personal lives.

Despite the fact that they were not actually in a medical coma, participants reported having unusual physical and non-physical experiences which differed from their usual "waking consciousness." These experiences included: heightened senses in certain parts of the body, absence of senses in other parts of the body, the feeling of becoming a mind or of becoming perception independent of the physical body, and the sense of drifting or "being" without any thoughts. Participants also had unexpected and spontaneous visual images, including a very vivid image of deceased family members standing at bedside.

Many reported experiencing the sitter's presence, touch, and voice as supportive,

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

calming, soothing, and reassuring, and some felt supported by the fact that the sitter was speaking to them at the ear level. Others experienced heightened senses in certain body parts when the sitter physically supported them, and it increased their awareness of the importance and potential of moving those body parts. Some felt vulnerable and as if they had lost control or protection.

Often participants felt a deep sense relaxation and/or detachment. Some felt removed from or less motivated to respond to the outer world, and instead were in a state of just being or of just following their inner experiences, which one person described as "focused wandering." These participants found it more difficult to respond to the outer world than usual, and one reported feeling that she could not "will" her body to move nor speak despite great effort—she felt as if it was not her body. Degrees of connectedness with the sitter varied from detachment to strong desires to reach out and/or communicate verbally. One woman reported that her perception of the sitter's voice and her sense of connectedness to the sitter changed according to whether the sitter was touching her or not.

Simulating a coma and being "on the other side" of their usual relationship roles, appeared to heightened the participants' awareness of their patients. Many of them reflected on and evaluated their usual work styles and began to wonder about their patients' possible inner experiences. They also speculated on how their interventions as caregivers may be experienced from the patient's point of view. Simulating a coma helped to remind the participants that their patients are people with their own unique inner and outer lives. The sitter's interventions had some practical implications for the professional lives of the participants, such as an increased interest in providing a calming

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

environment, talking to patients with a soothing voice, and touching them. The experience also led to attitudinal changes for some. For example, after the coma work sessions, participants actually tried using some of the interventions that they found effective during their own simulated comas.

Table 4.1 Categories and Themes of Experience

I. Unusual Physical and Non-Physical Experiences

1. Physical Experience / Senses
   (1) heightened senses
   (2) spontaneous visual images
   (3) altered perception (sense) of self / body
2. Feeling/ Emotion / Thought / Mind-State
   (1) sense of comfort (calmness, security, reassurance, relaxation)
   (2) sense of vulnerability
   (3) reduced connectedness with the outer world
   (4) connection with the sitter

II. Implications of the Simulated Coma

1. Implications for Professional Life
   (1) enhanced empathic connection with patients
   (2) attitudinal change
   (3) practical implications
2. Implications for Personal Life

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

(1) enhanced reflection on mortality / own possible coma

(2) appreciation for life

(3) enhanced interest in learning about coma

The simulated coma experience also impacted their personal views of coma. Some were reminded of the possibility of themselves becoming medically comatose and felt a sense of associated fear, while another explored the possibility that being in a coma might not be as bad as previously thought. In addition, the experience reminded participants of their own mortality, gave them a sense of urgency to prepare for their death, and provided them with an appreciation for life. The simulated coma experience motivated participants to learn more about coma and/or coma work through discussion, future study, and/or seminars.

Themes

I. Unusual Physical and Non-Physical Experiences

1. Physical Experience / Senses

(1) Heightened senses

Three out of six participants reported the experience of various forms of heightened senses. When they were perceived as occurring physically, the heightened senses were sometimes in relation to specific parts of the bodies, especially the outer limbs. Two of

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

the participants reported that their fingers were more sensitive than usual, and one of the two also experienced heightened sensations in her face. The descriptions of the experiences ranged from acute awareness of body parts to a more subtle "twitchiness." One of the participants felt that her hearing became more acute, which she attributed to the fact that her eyes were closed.

The acute awareness of certain body parts was described either as an independent experience focused on the effected body part, or in comparison with and contrast to other body parts which were perceived as having less or no sensations. An example of the latter description is demonstrated in the following statement made by Wendy:

> I suddenly became more aware of certain parts of my body and less aware of others. I couldn't feel my legs or my feet pretty much, as if it was not part of me. I felt a lot of twitchiness and high sensation in hands and in face.

Such a body experience led to an altered sense of the whole body, and will be discussed in more detail in the section to follow.

Heightened sensations in the body seemed to occur either spontaneously or in relation to the sitter's interventions. For example, when the sitter perceived movement occurring in Jan's body and then supported it verbally and physically, Jan's perception shifted in the following way:

> It was almost as if my sensation was increasing all over my body, that I was supposed to really sort of be aware of my movement and that I could have the potential to do that. It's harder to move, only because you have no purpose to move, and maybe nobody is paying attention, so why bother? But so when you started paying attention to it, it then ... now that I think about it, I think it heightened my

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

awareness to move, and that it would be important to do that.

Another participant reported several different ways that her senses were heightened. She became acutely aware of her pulse when she laid her hands on her stomach, she felt that her fingers were more sensitive, and her had a more acute perception of her hearing. Furthermore, she reported feeling "energy" from the sitter's fingers when they were touching her wrist, and she instinctively felt that the intention of the energy was good and positive and was meant to be calming and soothing.

(2) Spontaneous visual images

Four out of the six participants reported having "inner visual images" while simulating a coma state with their eyes closed. These images ranged from moving patterns of colors to vivid images of people standing around the bed. Dianne saw swirling clouds of colors with very bright pastels drifting across her inner field of vision. Similarly, in each of her eyes, Wendy saw a wing, which then became swirls of moving colors and finally became flashes of colors. For Wendy, this is a common experience that often occurs as she falls asleep, however, this time she experienced it a bit differently. Normally, Wendy would try to tune out the images and colors, but this time my verbal encouragement to "go with it" motivated her to follow the visual experience even further. As she followed the images, they appeared to have their own direction, and then, all of the sudden, she had a flashing image of a playground with a lot of parents and children and swing-sets. She reported the image as unexpected and surprising.

Jan also had a spontaneous and unexpected image appear during the simulated coma work. She suddenly had an image of herself ski-jumping, which she had never done

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

in real life before. David was also surprised by an unexpected image that emerged, and the experience left him with intense emotion. He made an effort to simulate a coma by trying to remember his past experiences in the hospital where he was diagnosed with cancer and by telling himself that he was dying of cancer. While telling himself this, he suddenly had an extremely vivid image of his family and extended relatives standing around his bed and looking at him. It was an intense experience for David, and it made him very uncomfortable because he "saw" family members who were deceased. The vividness of the image led him to reflect on his mortality and on the inner experiences of his seemingly unresponsive patients.

Those who had clear, movie-like images unanimously reported that the experience came totally "out of the blue" and was surprising for them. They were unable to discern the reason why they had had those particular images, although they did try to come up with some "rational" answers. For example, Wendy commented that her image may have been related to a recent conversation with her husband about having a baby, while Jan associated her image with her plan to go skiing the following winter.

(3) Altered perception (sense) of self / body

Five of the participants reported on what may be described as an "altered sense of self," which can involve unusual sensations or awareness regarding the physical body or the sense of self. These experiences are somehow different from usual waking consciousness, and the very quality of the experiences can make it difficult to name them in clear-cut terms—especially since the experiences appeared to defy "normal" delineations of "self" and/or "body".

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Three of the participants reported a distorted sense of self or body. For them, the usual awareness of the whole body was replaced by an unequal distribution or absence of body awareness and/or sensation. An example of an absence of awareness or sensation can be seen in Wendy's description in the preceding section. Similarly, Dianne reported that her awareness was focused on what she was touching with her hands and on her inner visual imagery. She reports that she did not feel very much going on between the two points of her head and eyes.

Half of the participants experienced something very different from their usual body awareness. Susan's awareness was limited to sound and touch, and her sense of having a whole body was lost. She described the experience as there being no differentiation between her perceptions and the rest of her self/body, as though she actually became perception itself:

> I was aware of the touch but I wasn't aware of having a whole body. Does that make any sense? I felt like, kind of, everything going on in my mind, and not so much, like, two arms and two legs ... I just felt like I just had my thoughts, like I was just being there, laying here, and being aware of, like I said, the sounds going on around me, and the touch, you know, listening to the voice, but I didn't feel like a differentiation between that and the rest of me ... I was just aware of the feeling of the touch going to my mind and perceiving.

Dianne had a similar experience in which her awareness seemed limited to her eyes and stomach area. She expressed feeling little else in the rest of her body:

> I would say that, really, I wasn't thinking about [the two parts of my body], just kind of drifting and not really having any real thoughts, more of a being. Just kind of drifting on that ... So I felt like I was just being and not thinking.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Difficulty controlling physical movement due to an altered sense of body or self was reported. The difficulty ranged from needing extra help to move their body to total disconnection between the mind and the body. An example of the latter experience is demonstrated in Christy's statement. She had a strong urge to connect and communicate with the sitter, but could not "will" her body to move nor speak despite great efforts:

> I had my whole mind with me here, but I couldn't bring my body to move, or to open my eyes ... I couldn't will my body to move my legs, and when you were touching my wrist, I wanted to hold on to your hand, but I couldn't get my hand to ... it's like my body was so heavy that I couldn't lift it ... The mind was saying, `don't leave me!!' but could not say it, just could not get the words out ... It is like signals weren't connecting somewhere to my body.

Similarly, Susan, who experienced no differentiation between her perceptions and the rest of her self/body, had the feeling of "minimally moving." She reported experiencing no control of her physical movement, and, when she had an itch on her face, she simply could not bring her hands to her face to scratch it.

This altered experience of "self" also seemed to result in an unusual sense of physical boundaries with others. When, during the simulation, I moved Wendy's arms in an effort to support the perceived movement occurring at that moment, Wendy felt as if she were not really sure who was directing the movement, and she later compared it to a "oui-ja board experience." She attributed this experience to the feeling that there was just enough pressure from the sitter's hands and to the movement being slow and gradual.

Half of the participants described experiencing altered states of consciousness or

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

altered physical states after the simulated coma work. These states ranged from mild relaxation or fogginess to a strong sense of disorientation. Dianne told me in the follow-up interview that she had felt "scattered" and unfocused after the coma work, and that she felt as if her body was there but her mind was not. It took her about half an hour to "regroup" herself and to be able to focus on what she was doing. She attributed this sense of disorientation to the extreme difference between the simulated coma state and the mind-state that was required to carry on with her professional tasks.

2. Feeling/ Emotion / Thought / Mind-State

(1) Sense of comfort (calmness, security, reassurance, relaxation)

All of the participants experienced some sense of comfort including calmness, relaxation, security and/or reassurance. These experiences were often described as occurring in connection with the sitter's presence and in connection with the physical and verbal support carried out by the sitter.

Most of the participants responded positively to the sitter's act of pressing lightly on their wrists with the rhythm of their breath. The perceived lightness, softness, or warmth of the touch was calming and reassuring for them, and one participant even described it as therapeutic in nature. Touching the wrist did not significantly impact David, who felt that holding hands was a better way of relating to a person in a coma. Most of the participants referred to the quality of the sitter's voice as calming, soothing, and relaxing, and they felt that it helped to produce a sense of security or to focus them on their inner experience.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

One of the sitter's interventions was to encourage participants verbally by saying things like, "Just follow what you are experiencing." Statements like these were received positively by many of the participants. For some, the fact that the sitter's presence was perceived through their auditory senses was reassuring and reaffirming, while others attributed it to the quality of the sitter's voice. Two of the participants made a point of mentioning that the sitter spoke to them from ear level. For Jan, this aspect left the biggest impression: "I've never had anybody get down laying low and talked to my ear, instead from up above. It was very profound. It felt like you were really with me, instead of at me."

For some participants, their perceived comfort while in the simulated coma went against their prior expectations. For example, before the simulation began David said half-jokingly but definitively that being comatose would be horrible experience. However, in the follow-up interview, he said, "I don't think I ever want to be in that experience, but if I had to go, that will probably be a good place to be, [because] I didn't imagine being in pain or anything. I was as comfortable as I was going to get." Wendy also had an experience that differed from what she had expected, and was surprised to feel that she could stay in the coma forever. Her experience will be discussed further in the category, *Reduced connectedness with outer world.*

(2) Vulnerability

The theme of "vulnerability" was experienced by four of the participants. They reported feeling a loss of privacy, inability to communicate, and loss of control over their movement and their destiny. This vulnerability was present at certain times despite the

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

perceived relaxation and comfort elsewhere in the interview. One participant felt no sense of privacy while lying on her back with the front part of the body open, and she preferred for the sitter's hands to be on her foot because it felt further away and gave her a greater sense of control and less vulnerability. For Dianne, there was an interesting relationship between the sitter's voice and touch:

> Something that was very profound to me is that when you were speaking to me but not touching me, you were more like this disembodied voice that I didn't have a real feel for where you were or who you were, but when you started touching my wrist, that really made a difference as far as the connection, and the feeling of there being an energy there, your presence was more connected to me. And you had taken that [the fingers] away from me very briefly, and I almost felt a little bit panicked, like not knowing quite where you were, what you were doing next.

Dianne went on to say that she felt disturbed and disoriented by her perception of the sitter as a "disembodied voice."

Susan also felt vulnerable during her simulation experience. She felt as if she had no control or protection, and she became newly aware of the ways in which she protects herself while awake. Susan found that, along with the vulnerability, she could also feel a sense of comfort in the sitter's voice and concluded, "I'm OK and comfortable, even though I'm vulnerable right now." This experience encouraged her to think of the possible implications of her care-providing techniques:

> And I told you that you had, like, incredible, like a very soothing voice, and I think that is something that would be beneficial to this type of patients, because it would be scary to be lying there vulnerable and not really have the ability to protect yourself, and I think those are, you know, the aspects that stayed in my mind that kind of make me reevaluate what it is that I do and how I do it.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

The experience of vulnerability also encouraged two other participants to be more aware of their professional care-giving styles, and it encouraged them to try and connect with the vulnerability that a comatose patient may be feeling.

(3) Reduced connectedness with the outer world

Although the participants were not in an actual medical coma, many of them did report a reduced sense of connectedness with outer world, which ranged from the experience of some movement difficulty to the total inability to respond despite great effort. Similarly, the feelings associated with a reduced sense of connectedness ranged from discomfort to pleasure.

For some, the reduced sense of connectedness seemed to be caused by their preconceived notions that coma states are disconnected from everyday life and are without thoughts. However, once the effort to achieve a simulated coma state more or less succeeded, the experience itself seemed to have its own direction for them, and it often caught them by surprise. This sense of unexpectedness is demonstrated in David's experience. In describing the vivid image of his dead relatives standing around him, he commented, "When we started, I was really trying to concentrate and get into the role play, and I really didn't think I could do it, because how could I put myself in comatose? But I *did*! You know, I really did it!" Similarly, as demonstrated in the section of *Altered perception of self,* Christy's intention to respond either verbally or physically to the outer world failed despite her great effort because she felt that the connection between her mind and body was missing.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

For Wendy, disconnectedness was a pleasant and comfortable experience quite contrary to her expectations. The quiet environment of the room and the soothing voice of the sitter helped her to tune out thoughts regarding daily routines and obligations, and helped her to focus in on the deeply relaxed state of her inner experiences and on the present moment. She called what she was experiencing at the moment "focused wandering." Despite Wendy's usual fears regarding the possibility of her own comatose state and of losing connection with her loved ones, she felt that she could stay in that pleasant and comfortable state forever: "This time I honestly didn't care. I thought about me, I wasn't thinking of anybody else. I thought, `OK, this is not about you, this is about *me*.'"

Dianne also felt less awareness of the outer world as time went on, and, as was described in *Altered perception of self / body* section, she had the experience of drifting and "being" without thinking. Her sense of detachment is described in the following statement:

> I was aware that it [the world outside] was there, and that there were things going on, but I didn't really feel a need to be present, a part of that ... I didn't feel left out of it. It felt like this was a separate little world to that, it was there but it didn't really matter it was there, and it didn't matter that I wasn't a part of that.

Dianne reported that while it was fine to be in a detached state at that moment, it was difficult to remain comfortable with it because, as she said, "that's not what we are kind of trained and meant to do. We are supposed to be thinking and doing."

(4) Connection with the sitter

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Most participants referred to the various degrees and forms of connectedness with the sitter in conjunction with the sitter's presence and interventions, and some specified an intimate connection with the sitter. For example, Christy had such a strong sense of connection with the sitter that she wanted to both physically and verbally reach out to her. In the beginning, David felt that the sitter's talking was disruptive and broke his concentration, but, as he relaxed, he began to perceive her voice as soothing and felt reassured that someone was there and that he was not alone.

As mentioned above, when the sitter touched her wrist, Dianne felt the sitter's good and positive intentions and "energy," and she felt more connected to the sitter than before. As reported in the *Vulnerability* section, Dianne noticed that the difference in the levels of connectedness were dependent on whether the sitter was or was not touching her physically while speaking to her.

II. Implications of the Simulated Coma

1. Implications for professional life

As discussed in detail in the following sections, it appears that participants' various coma experiences acted both as a mirror allowing them to reflect on their personal and professional lives, and as the groundwork from which ideas of practical implications emerged.

(1) Enhanced empathy with patients

All of the participants reported that experiencing "the other side" of the caregiver

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

role enhanced their empathy toward comatose people. For some, it was a reminder or re-enforcement of their already existing views, while for others the experience provided them new insights. The empathy that participants felt toward comatose patients was often accompanied by an evaluation of their usual ways of being with and caring for their patients. This led to additional ideas on the practical applications of coma work as well as changes in sitter accompaniment and techniques. This will be discussed further in sections to follow.

First, the simulated coma served as a reminder of their existing beliefs about people in seemingly unresponsive states. For Wendy, it was a reminder to regard the comatose patient as a person who has a life and a family, and who may be totally aware of the outer world. Then the simulation encouraged the participants to evaluate the ways in which they accompany people in seemingly unresponsive states. As described in the above section, Dianne was sensitive to the sitter's "energy," and she felt disturbed when she sensed that the sitter was disconnected from her. This experience brought her to the realization that she may not be one hundred percent present when sitting with comatose people.

Experiencing "the other side" of the relationship also provided participants with the opportunity to reflect on how comatose people may actually experience their presence or interventions. Jan reported that the vulnerability she experienced while being accompanied and while lying on her back and gave her insight into how her patients may feel in similar situations:

Maybe I know why people would want to roll over and be on their side, and not

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

> have to be so open, you know, their faces open or their private parts are all open, and they are vulnerable for people to touch and it might be kind of weird.

For Dianne, who often uses her intuition as a guide when working with people in non-responsive states, the simulated coma work enhanced her reflections on and evaluations of her present work, and led her to ask herself the following question: "Even if the person wanted to be touched before [they went into coma], is it OK to touch them now?" She reported that the experience made her think a lot about what residents in seemingly unresponsive states may be experiencing and about the uniqueness of each individual person. Similarly, David became very curious to know what his patients might be experiencing, and he reported that the following questions went through his head during the simulated coma experience:

> What are these guys thinking of when they are dying? Are they not thinking of anything? Can they hear me? What are they thinking when I'm talking to them? ... I thought of residents when I was holding their hands and talking to them. I'd *love* to know what they were thinking when I was doing that.

(2) Practical implications

While reporting their simulated coma experience, most participants mentioned directly or indirectly how the experience held practical implications for their professional lives. As mentioned above, enhanced empathy resulted from various physical and non-physical experiences and served as the ground from which ideas of practical implications emerged. Despite the fact that the participants were not actually in a medical coma, their subjective experiences in the simulation appeared to open them to the

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

possibility that people in seemingly unresponsive states might have similar kinds of experiences. This belief then encouraged them to reflect even further on the different possibilities for accompaniment.

Some participants referred to the practical implications because their experience was relatively pleasant. Because Christy felt that she gained a great deal of insight into what a comatose person may be experiencing, she felt that in the future she would be more inspired to talk to or touch her patients. Jan also had a realization that people in seeming unresponsiveness may actually be able to interact with outer world. She believed that some of the "techniques" used by the sitter in the simulation could also be useful in her professional life. Techniques which she felt would be especially useful to her were talking to the patient at ear level, and using a calming voice. In addition, Jan had the idea to implement these techniques with other patients who are confined to their bed regardless of their level of consciousness.

For Dianne, the practical implications were related to how her feelings corresponded with what the sitter did or did not do. As mentioned above, Dianne was disturbed when the sitter was speaking to her or moving around her without first connecting with her physically. However, her experience of the sitter's presence changed to a more positive one whenever the sitter started to touch her physically. As seen in the following statement, this experience greatly impacted Dianne's consideration of how to accompany people in the future:

> It's stuck with me a lot, how important your touch was to me when you were talking to me, and I think, you know, that will really stay with me for the rest of my time here, you know, to be really conscious of that when working with the residents

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

> ... I think the most impact that this will have is my being mindful of having that connection with somebody and not just moving around and talking, because I felt distressed by that, so it would be my presumption that people need that, to be mindful maybe of keeping some of my garbage out and not having [it] there, because I feel like people can pick up when you are not closely connected.

Dianne also considered the implications of the fact that she and the sitter were new to each other and basically strangers. She felt that it may have contributed to her perceived discomfort:

> And that circumstance can happen here too. We can have somebody move in and you know, die within a day or two. And I'm kind of in the same place. *I'm* the stranger maybe with a disembodied voice getting in their space.

Susan, who works as a nurse in a hospital trauma unit, reported a feeling of relative comfort (despite some occasional feelings of vulnerability) because she perceived the sitter's voice as calming. Susan used to always talk to her patients in a regular tone of voice, but after her simulation experience she expressed her intent to use a softer and more soothing voice in the future. As described in the following section, Susan also experienced some positive feedback when she tried asking a patient some questions and then received what she perceived as responses. Having directly seen a positive response motivated her to apply the technique to her future patients. When asking such questions, Susan intends to be more aware of signals such as blinking of the eyes or moving of the mouth, instead of just focusing on the vital signs.

David was the only participant who felt that there were no practical implications for him. He reported that he planned on continuing with his previous professional style

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

and techniques, and that his main goal as a care provider was still to ensure that his patients are pain-free and comfortable. David's unaffectedness may in part be due to his perceived confidence in his empathic and related style of care giving. David reported that the simulation experience had more of an impact on his personal life than on his professional one, all of which will be discussed in greater detail in a section to follow.

(3) Attitudinal change

As expressed in their follow-up interviews, the simulated coma experience led Susan and Wendy to change the ways in which they provided care to some of their comatose patients. The remaining participants all worked in the AIDS hospice, and no comatose residents had been present there during the time between the initial interviews and the follow-up interviews.

The simulation experience motivated Susan to reevaluate her usual style of care and to make changes to it. Although she did not have the opportunity to care for a person in a deep coma state, she did have one patient who was just coming out of a coma state. This patient appeared to have some awareness but was only minimally responsive and seemed agitated. Prior to the initial interview, Susan would look primarily to vital signs as a guide for trouble-shooting and as a guide for understanding a patient's experience. However, following the initial interview, Susan made efforts to talk to this person and to communicate with him by asking questions and looking for responses. She found her attempts at communication to be very effective. She also tried using a more soothing voice than usual and was excited about the difference her interventions had made. As soon as the follow-up interview began, Susan volunteered to report the following

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

experience:

> Then I would say something like, "I know this is really frustrating for you, you've been in bed for a long time," and he would say "yeah." So his response is, you know, he was very well aware that something wasn't right in his brain and that frustrated him. He was able to express that too, you know, by me verbalizing and saying, "are you frustrated?" and he would say "Yes." So that was kind of different, because I hadn't really come across that before, and maybe that's because I didn't *ask*. Before this, I didn't realize that it *would* be kind of frustrating, or they were at a point where they could realize that their brain wasn't working right ... It just got me thinking of different ways that I can communicate with them better, and you know, like I said, with this patient, it'd be telling him that, "I really need your help. You really need to help me," and he was then in turn willing to do that. It kind of made him a little less agitated and he was helpful.

Susan also made the following comment:

> Before, I guess it would be, with the head injury patients who couldn't talk to me and tell me what was going on, which made me a little nervous, because if something *is* bothering them or something *is* going on, you don't know what it is. Then this kind of made me think that "well, maybe they are trying to tell me what's wrong and maybe I just need to look for those signs in a different sort of ways."

Having experienced "the other side" of the relationship simply served as a reminder for Wendy of her already existing beliefs that coma patients need to be treated as individuals with unique lives. However, she expressed that it is sometimes not easy to remember this in the midst of her challenging working environment, and that the simulation helped her to keep that knowledge close by. She reported that when she worked with a coma patient the day after the initial interview, she reminded herself much more frequently of the fact that he was an individual with a life and family. Wendy then

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

added the following:

> I thought about that scenario, "what if he is totally aware of me and that he is in there?" So I guess it kind of reminded me more to talk to him, and not *about* him, and it's kind of a constant battle when you are in the room, to make sure you are still talking to him and not to his family about him constantly.

An insight that Wendy had during the simulated coma and then reported on in the initial interview was about the environment. She attributed her perceived comfort to the relative quietness of the room in which the interview took place, which then led her to realize how a calming environment may have a crucial impact on a patient's inner world. Wendy told me that, from then on, she planned on trying to regulate the environment in her patients' rooms more. She also reported that the day after the follow-up interview, she actually did try to make the room quieter for a patient who looked irritated and whose heart rate was much higher than it should have been. Before deciding to give him medication or to call the doctor, Wendy first tried turning off the TV, pulling the blinds, turning down the light, and putting on a classical CD. When she returned to the room an hour later, his heart rate was down and he had less perspiration.

Wendy reported yet another incident that took place a day prior to the follow-up interview. While taking staples out of the head of a comatose patient, she noticed that he was wincing, and she described how she reminded herself to talk to him in a soothing way:

> So I was trying to talk to him very soothing, "I know this hurt. I'm sorry. I'm just taking these out ... just a few more ... Almost done ... I know it's irritating." Just kind of reminding yourself to speak really soothing to them, and don't just start

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

> pulling things off of them not talking to them, [but] telling them, you know, like you would anybody else, telling them what you are doing.

2. Implications for personal life

(1) Enhanced reflection on mortality / own possible coma

The simulated coma experience led four out of the six participants to reflect on their own mortality or on their own possible coma states. As mentioned above, the experience for David bore a stronger association with his own mortality than it did with his professional life. To his amazement, many things went through his mind within the short amount of time needed for the simulation. David was struck by the realization that death or a comatose state could happen to him, and this mortality awareness created a sense of urgency in him which led him to prepare for his own death (an issue that he had been postponing). All kinds of thoughts and questions regarding his imagined impending death went through his mind: "Who is going to talk to me?" "Who is going to hold my hands?" "Will I have my wishes met when I'm getting ready to pass on?" "I want to get prepared and have everything in order and I want to do it quickly." "And I want to see people before I die." "I need to get my will changed."

Jan and Dianne reflected on the possibility of becoming comatose but not on their mortality. After the simulation, Dianne reported having feelings of fear associated with the thought of being in a coma, and she described it as follows:

> How horrible it would be, I think, to have the world to be this, right here, and then have all these other things going on around you and maybe, if you remembered what your life was like? How would you think of missing out on that? I thought

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

> about that a lot. I thought about that, you know, that before, but maybe more deeply into that.

Similarly, Jan thought of what it would be like if she were in a coma and of what would happen to her family. She then quickly put the thought aside, as it was too unpleasant for her to hold.

Contrary to the fears of Jan and Dianne, Wendy felt pleasant and comfortable in her detached state during the simulated coma experience. This was somewhat surprising since Wendy usually feared the possibility of becoming comatose and of losing her connection with loved ones. This unexpected experience encouraged her to explore the possibility that a comatose state may not be as bad as she once thought: "If that was what I would have right there with the coma, that's not so bad, I can deal with that. It wasn't a medical coma, but it wasn't as scary as I was thinking."

(2) Appreciation for life

Out of the four participants who reflected on their own mortality or on the possibility of being in a comatose state, two off them referred to what could be called an "appreciation of life" or "recognition of preciousness of the current life."

While Dianne feared the possibility of going into a comatose state, experiencing the simulation also enhanced her appreciation for life, which she described in the following comment:

> [It] made me think how fortunate we are to be able to, you know, move around, and have our lives! ... Makes you appreciate it a little bit more when you stop and think about it. Don't take it for granted as much.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Having had the visual image of his dead-relatives while simulating a coma, David was reminded of his own mortality and experienced a sense of urgency to do what needs to be done while he still has the opportunity. Although David did not talk directly about appreciation of life, it is possible to recognize his intensified sense of the present moment in the following statement:

> It opened my eyes to think about what do I have to do *now* while I'm healthy in case that situation happens? It's not a pleasant thing to think about, but it's reality and something that you have to deal with.

(3) Enhanced interest in learning about coma

For all of the participants, this study was the first time that they had simulated a coma or been accompanied by someone using a Process-oriented approach to coma work. Experiencing the coma work appeared to stimulate a general interest in comatose states as well as in coma work methods. Half of the participants voluntarily came up with ideas for future studies and/or for different approaches to learning about comas.

Dianne, for example, expressed an interest in having the opportunity to observe coma work sessions from the outside. Wendy, who experienced positive physical feedback after calming the environment of an agitated patient, was extremely curious as to whether the experience would have had the same outcome if the room had remained noisy. She then thought of an idea for a future study in which different degrees of noise could act as stimuli to determine if comatose patients' vital signs react correspondingly.

Similarly, Jan showed an interest in discerning differences in outcomes between

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

when coma work is applied to dying people verses when it is applied to people in temporary coma states. Having felt vulnerable because of the position of her body during the simulation, Jan was also curious as to whether she would have different experiences in different body positions (e.g., lying face down or on her side). As the following statement expresses, Jan also hoped to disseminate the learning to other staff members at her work place:

> Well, one of the immediate things I thought of was I would like you to do this to all my nurses, because I think it's really good, I think it's a very interesting way of looking at a comatose person and I know that, I mean, I would *assume* I'm not alone in people not knowing what to do with somebody who's dying, not knowing how to act or how to interact with someone who can't interact with you. I'm *sure* I'm not alone, and I would love to. It's an interesting perspective for me.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

CHAPTER 5:

DISCUSSION

The purpose of this research is to study in depth professional caregivers' experiences of being in a simulated coma while accompanied by a Process-oriented coma work approach. It is also focused on demarcating possible categories of experience, and on exploring the meanings that such experiences may have in related fields. Areas involved in the topic of seemingly non-responsive or minimally responsive states include psychology, thanatology, and the science of nursing. The purpose of the research was also to create a foundation upon which related training and educational programs could grow and become established. The research assumption was that experiencing Process-oriented coma work while simulating a coma state might enhance the caregiver's understanding of and empathy toward deep altered or near death states. The assumption was also that the experience would have significant implications for the paticipants' professional and personal lives.

Despite the short period of time allowed for the coma work sessions, the study suggests that the experience did enhanced caregiver empathy toward patients in comatose or alterd states, and that it significantly impacted their professional and/or personal lives. There were however, other themes that emerged from the participants' experiences that had not been expected prior to the study. After a brief summary of the study, this chapter will discuss in detail the themes which were expected prior to the investigation and those which were unexpected. This chapter will also look into the study's implications for

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

end-of-life care, issues of consciousness and identity, and death education.

5.01 Overview of the Study

In this phenomenological study, six people in helping professions were interviewed to answer the question, "How do professional caregivers of people in seemingly unresponsive states experience process-oriented coma work?" Five women and one man, all of whom were of European-American ethnicity and worked mainly in the field of nursing, were recruited for the present study. The six participants ranged in age from 25 to 59 years, and had various degrees of experience and job descriptions in the field. Two of them worked in a trauma unit in a general hospital, where they provided care to people whose comatose states were primarily caused by brain injuries. The other four participants worked for a local AIDS hospice, and their main encounters with comatose or seemingly unresponsive states usually occurred just before the resident's death. A male person of African-American ethnicity had had the experience of being a family care provider and was interviewed to acquire comparative data.

Participants were asked to simulate a coma state of their choice and went through 10 to 15 minutes of a Process Work approach to working with coma. I was the researcher, and I conducted the coma work sessions in accordance with the beginning coma work methods suggested by A. S. Mindell (1999). The six participants were interviewed immediately after the experience as well as one to three weeks later in order to better understand the lived experience and the meanings that it may have held for them. The outline of the interview was specified in advance, but the sequence and wording of the

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

questions were decided on by the interviewer spontaneously during the course of the interview. I conducted all interviews and coma work sessions, and all interviews were video-taped, recorded by mini-disk player, and later transcribed for analyses.

The steps chosen for data analyses in this study were influenced by the phenomenologically based meaning condensation method applied by Giorgi (1975, 1985) and demonstrated by various researchers including Worthen & McNeill (2002). The essence of the method involved a condensation of the expressed meanings into "natural meaning units" and then explicating their main themes. This method was also combined with the data organization system suggested by Tesch (1990).

5.02 Limitations

This phenomenological investigation focused on describing and identifying some of the possible experiences that professional caregivers of seemingly unresponsive states might have while going through simulated comas and coma work sessions. The investigation also explored the meanings that these experiences held for the participants. It should be noted that the study did not aim for a generalization of the findings. The samples used leaned heavily toward caregivers of European-American ethnicity working in the field of nursing. Although it is important to understand that each person can have unique experiences despite their common backgrounds, it is also important acknowledge that different themes, categories, and commonalities of experience may emerge in a larger sample size with different variants (e.g., ethnic backgrounds, types of relationships with the people they provide care for, categories of professions, and personal histories). In future research, the instructions used to invite participants to begin the coma simulation

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

could clearly direct them to imagine either a seeming unresponsiveness state or a near death coma state. This delineation would differ from the present study which left the imagined state up to the participant, and it could have an effect on the findings.

This study identified significant attitudinal changes in some of the participants, especially those who had the opportunity to care for people with impaired consciousness between the time of the initial interviews and the follow-up interviews. However, a longitudinal study would be required to determine the long-term influences that each participant's experiences may have on their professional and personal lives.

The nature of the coma simulation should also be addressed. No particular protocol was employed in this study in an effort to produce relatively similar experiences among the participants. Instead, participants were simply encouraged to imagine being in their concept of a comatose state, and how the simulation of that state actually unfolded was left up to each participant. While each simulated state was in itself an interesting aspect of the findings, the influences that these subjective and unique choices had on the experiences themselves cannot be distinguished or determined. Future studies could use a more structured simulation program to enhance generalizability of the findings. Another important consideration is that the duration of the simulation experience was approximately 20 minutes or less for most of the participants, while "real" coma states usually extend for longer periods of time. Future studies could implement longer simulations in order to see what such changes might yield. Future studies could also address aspects of simulation experiences that were not reported on by the participants in this study, such as different or altered senses of time.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Another limitation of the study was in its difficulty in distinguishing how much of the participants' experiences were influenced by the coma worker's presence and participation. Due to the nature of coma work, the ways in which the coma worker (or sitter) interacted with each participant was unique. Since sitters are encouraged to follow what is perceived to be happening in the people they are accompanying, and since each simulation was unique, so too was each accompaniment. Although it is not possible to perfectly control the conditions of participants' experiences, studies using float tanks, for example, could minimize external stimulation and help to clarify the issue.

5.03 Summary of Findings

As a result of data analyses, two major themes of experience, "Unusual Physical and Non-Physical Experience" and "Implication of the Simulated Coma," were identified. Two sub-themes were then identified under each major theme, and these four sub-themes were further divided into various themes. Many of the experiences reported by participants crossed over into multiple themes. It was every participant's first time to simulate a coma and to experience a coma work session. All participants reported having had unexpected physical and/or other experiences during the simulation which gave them insight into their professional and/or personal lives.

In the first category of themes, experiences related to various physical, feeling, mind-state, and thought levels were identified. With regard to physical experiences, half of the participants reported various degrees of heightened senses in certain parts of their bodies, as well as heightened sensitivity to the outer world. Sensitivity to the outer world was experienced through external stimuli such as sounds and the sitter's energy, and was

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

reported as occurring either spontaneously or in relation to the sitter's interventions. Four out of the six participants spontaneously had inner visual images ranging from moving patterns of colors to vivid, movie-like images. As was the case with the participant who had a clear image of his dead relatives standing around his death-bed, various visual experiences occurred spontaneously while in simulation and were received with a sense of unexpectedness and surprise. Five participants experienced some form of an altered sense of self/body, which involved unusual awareness or strange sensations regarding their physical being or sense of "self." One of these experiences had a sense of becoming perception itself and of losing the physical body. For this participant, a sense of total disconnection between the mind and the body occurred along with an unusual perception of physical boundaries with others.

On a more non-physical level, all participants reported experiencing a sense of comfort that included calmness, relaxation, security and/or reassurance. This sense of comfort was often reported in connection with the sitter's presence or interventions. Four participants also addressed a sense of vulnerability that they had had while lying down during the simulation. This sense of vulnerability was influential in leading these participants to reflect on their styles of nursing. Despite the fact that the participants were not in an actual medical coma, many reported a reduced sense connectedness with outer world. This disconnection was described as ranging from some difficulty with movement to total inability to respond despite great effort to do so. On the other hand, some participants reported various forms and degrees of connectedness with the sitter in conjunction with her interventions and presence.

These experiences acted as the ground from which the second category of

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

experience emerged. "Implications of the Simulated Coma" is a category that roughly divides into implications for professional lives and those for personal lives. All of the participants reported that experiencing "the other side" of the relationship enhanced their empathy for the seemingly unresponsive people they provide care to. It also encouraged them to reflect on the possible inner worlds of comatose people, and on their own professional styles. Furthermore, most of the participants reflected on the practical implications that their experiences may hold for their professional lives. In their follow-up interviews, two participants, who had the opportunity to provide care to seemingly unresponsive or minimally responsive patients, reported that when they applied some of the newly learned Process-oriented coma work techniques, they found them to be extremely very effective.

The simulated coma experiences also bore personal meanings for many of the participants. Some reacted to the possibility of becoming comatose with a sense of fear, while others (as the result of having an unexpectedly pleasant simulation experience) explored the possibility that a future coma state may not be as fearful as previously thought. The simulations also encouraged participants to reflect on their mortality. One participant felt a strong urgency to prepare for his imminent death, while another experienced appreciation for life.

The ways in which participants experienced the simulated comas and coma work approaches appeared to stimulate their general interest in coma states and coma work methods. Half of the participants voluntarily came up with ideas for future studies and/or different educational approaches to learning more about coma states and work methods.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

5.04 Discussion: Implications and Recommendations

Enhanced Empathy with Altered States and Implications for Professional Lives

In her book, *Coma: A Healing Journey* (1999), A. S. Mindell suggested that it is important for caregivers of people in seemingly non-responsive states to try to put themselves in the position of the comatose person, to try to experience their possible inner states, and to try to feel what it is like to be accompanied by others. The present study illustrates the initial research thesis, and supports the theory that experiencing (as a recipient) the Process-oriented approach to coma work would enhance caregiver empathy and understanding toward people in seemingly unresponsive states. The study also suggests that the experience had an impact on the professional and/or personal lives of the participants. The analyses of the data revealed that, for most of the participants, the experience had a more significant impact on their professional lives than on their personal lives. The experiences also served as a reminder or re-enforcer of already existing views towards people in comatose states, and encouraged participants to reflect on and evaluate their usual styles of care giving and accompaniment and to explore new approaches and techniques.

Two factors seemed to have largely contributed to these changes. One was the fact that participants had to shift their usual standpoints and perspectives from caregivers to comatose recipients, and the other factor was the nature of interventions and how participants experienced them. For all participants, it was their first time experiencing the other side of the relationship. The impact of this experience can be recognized in the following comment made by one of the participants:

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

> I've always been on the other side, of being the care provider of the person who is sitting there, and you know, until you experience that I realize that you don't really understand what that person is feeling or thinking or what's going on in there. So I realize that this is probably really, you know, the tip of the iceberg of what they are experiencing. But very different to have the opportunity to be the person who is the non-responsive person, and just to *be*, was very funny. Because when you are on the other side and sitting with the person, you still have your own thoughts going on and thinking about other things and maybe not one hundred per cent present.

Current approaches to comatose states other than standard medical procedures are geared toward either stimulating patients (e.g., Lewinn, 1985) or sitting quietly and peacefully with them (e.g., De Hennezel, 1997). In contrast, Process Work holds the view that people in a coma may be having important inner experiences, and it provides a coma work approach that allows the helper/sitter to follow the unique processes of each comatose person. Most aspects of Process-oriented coma work were new to the participants in this study. The combination of experiencing both the recipient perspective and the Process-oriented approach to coma work appears to have laid the foundation for an enhanced understanding of patients' inner worlds and for the acquisition of new ideas for professional approaches.

Researchers of near-death studies have used simulation to explore its effect on individuals' mental attitudes toward death, and they have found at least some short-term positive effects (Quekelberghe, Gobel & Hertweck, 1995). While the present study did not specifically focus on attitudinal changes toward death, the findings did suggest the there were benefits associated with having had the simulated coma experiences. After having these immersive experiences and the corresponding reactions and feeling

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

responses, participants felt that people in seemingly unresponsive states may have similar experiences to the ones that they had had during the simulation.

Two participants who provided care to patients in minimally responsive states between the time of the initial interviews and the follow-up interviews showed significant attitudinal changes in their styles of care. For example, one of them had previously depended on vital signs to "guess" at a patient's condition, but after her initial interview and simulation, she tried asking a patient questions with the intention to communicate, and, much to her surprise, she had some success in doing so. While it is promising to observe that only 15 to 20 minutes of simulation and coma work can lead to significant attitudinal changes, further research is required. For example, a detailed investigation into the different aspects of changes (e.g., degrees of impact, contributors, and duration) may prove significant.

Personal Meaning

The issue of comatose or unresponsive states is relevant to the topic of death for a couple of reasons: coma often occurs near the last stage of dying, and coma itself can look similar to death (as discussed in Chapter 2, Review of the Literature). The seeming unresponsiveness of the comatose state may give others the impression that the person they used to know is gone—that the everyday identity of that person is dead. One of the background interests for this study was whether going through a simulated coma would heighten a person's awareness regarding life and death. Of particular interest were two aspects associated with death and dying. The first is that facing death is known to serve as an impetus for bringing awareness to mortality, and it is also known to enhance

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

appreciation for life (e.g., De Hennezel, 1997; Levine, 1982). The second aspect is the appreciation of near-death states, which, contrary to most expectations, are often pleasant and even blissful, and generally help to reduce fears of death (e.g., Ring, 1984).

With regard to the first aspect, one of the six participants reported sensing a strong urgency to live life fully and to prepare for death, while another participant expressed an enhanced appreciation for life. The former participant was the only one in the study who specifically tried to imagine being in a near-death comatose state. For him, a spontaneous and clear image emerged of his dead relatives surrounding him at his deathbed, and the image made the whole experience very real and intense for him. His subsequent urgency may have been partially due to the fact that he was diagnosed with cancer five years prior, and, for this reason, the concepts of death and mortality may be more in his foreground. The participant who experienced an enhanced appreciation of life also expressed that working with the dying frequently made her reflect on her own mortality and spirituality.

In the Literature Review, I discussed in detail the tendency of modern industrialized societies to marginalize death, as well as the significant way that death awareness relates to living life more fully. In this culture, those who choose to work in the field of terminal care (like the participants in this study) already have more awareness of death than most people. This study suggests that even for such people, the experience of putting themselves in the shoes of the dying is relatively new. It also suggests that such experiences can significantly impact and/or renew a person's views and attitudes toward their lives. Both of the above mentioned participants had had relatively intense experiences during the coma simulations and were left with strong impressions. This study provided them with the opportunity to deeply role-play the one who is comatose or

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

dying, and it appeared that the experience led them to a new awareness of their own mortality and appreciation of life. For example, before the coma simulation, the participant who had been diagnosed with cancer reported that he felt relatively satisfied with the way he had lived his life since the diagnosis ("I feel like I've had a pretty good life, I've traveled, ... but I think it's enough"). However, after the coma simulation, his tone changed to one of urgency ("I'm not ready to go yet, no, no ,no! I haven't visited the East, I haven't visited south America ...").

With regard to the second aspect (i.e., recognition of the value of near death or death states), researchers of Near-Death-Experiences (NDEs) have shown that altered states of consciousness during NDEs have a strong, long-lasting, positive effect on individuals (Flynn, 1982; Noyes, 1980). In the present study, many participants reported unusual mind-states and a sense of detachment from the outer world, but only one participant spoke directly of her diminished fear of the possibility of becoming comatose. Contrary to her expectations and usual fears regarding the possibility of her own comatose state, this participant felt a detached and pleasant mind-state while simulating a coma. However, we cannot apply this example to the topic of death because she was only focused on a comatose state. This narrow focus was probably owed to the fact that instructions were not given to specifically imagine near death comatose states, and also to the fact that she works in a trauma unit where many comatose states do not lead to death. Similar future research may instruct participants to specifically simulate near death comatose states, and to study the correlations between the various impacts on individuals. Another participant who experienced detachment felt no discomfort about her separation from the outer world while in the simulation, and she described the experience as "just

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

being." However, in retrospect, she did become uncomfortable about the experience because it was so different from her usual way of existing in the world. Such discrepancies are interesting and will be discussed in more detail in one of the following sections.

In conclusion, a simulated coma experience may heighten awareness of or appreciation toward death, life, and/or deep altered states, depending on the types of experiences that occur during simulation, and/or the degree of readiness a person has for that level of awareness.

If such a short period of coma simulation can influence a person's attitudes toward life and death, then it is possible that a much more significant impact could occur from an extended period of medical coma or actual death experience. Past studies have shown that people who have had near death experiences often demonstrate significant changes in their views of life and death, including an increased appreciation of life and a decreased fear of death (e.g., Ring, 1884). In addition, accounts from people who have returned from comatose states illustrate that blissful experiences often occur within a coma and frequently lead to attitudinal changes regarding death. Blakely (1990), who had been in a coma for nine days before she woke up, demonstrates the significant impact that the experience had for her with the following words:

> I felt radically altered by my nine-day sleep, a passionate psychological journey that uncovered old, unextinguished yearnings. After awakening on March 31, I gradually discovered that the life planned by the woman I had been no longer fit the woman I'd become ... The coma was far harder on the people who loved me, who spent nine days wishing me back into existence, than it was for me, captured by fantastic hallucinations and visions (pp. 261-262).

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Despite the non-medical nature of the experience, a simulated coma can sometimes have similar experiences and qualities to those of a medical coma or near-death state. All too often, we put off facing death and try to live fully until death or serious illness are imminent, and only then are we forced to acknowledge our mortality. The findings of the present research point to the possible value of the simulated coma experience, not only for professional training, but also for death education of the general population and enhancement of life and death awareness. Several factors, including the simulation exercise instructions and participant levels of readiness, should be taken into consideration when considering this training or educational method.

Simulated Coma and Altered States of Consciousness

One aspect of the present study that particularly stands out is that, despite merely role-playing comatose states, almost all of the participants had sensations and experiences that were outside of their usual delineation of "self." They experienced such things as acute hearing, unequally distributed sensations in the body, awareness of the sitter's "energy", and altered perception of body and/or self. Especially interesting were people's altered perceptions of their body and/or self, which were reported by five of the six participants. As discussed in the previous chapter, some participants felt an absence of sensation in certain body parts, or felt as if they had lost their sense of a whole body and were "becoming a mind or perception itself without a body . . . drifting on the sense of being." An altered sense of physical boundaries with others was reported by one participant, and she used the analogy of a "Ouija board experience" to describe it.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Another participant reported a sense of disconnection between her mind and body and felt an inability to respond physically or verbally despite great effort.

The term, "altered states of consciousness," refers to any alteration from an "ordinary" state of consciousness in which a person is able to function reasonably well. Although the procedure of the present study did not intend to limit people's state of consciousness in particular ways, most of the participants had experiences that appeared to fulfill the criteria employed to identify altered states of consciousness (Glicksohn 1991, 1993-94). These criteria include: direct references to experiences as "drifting" and "floating", reports of alterations in thought, changes in body perception, and altered visual or auditory perceptions. Researchers of altered states of consciousness have suggested that virtual reality could be used as a research tool for studying subjective experiences because of its immersive nature (Glicksohn and Avnon, 1997; Tart, 1990). In the present study, it is possible that the combination of participants' efforts to relax or tune out what was going on around them, together with the sitter's mode of accompaniment (e.g., tone of voice, joining of breath, rhythmic touch of the wrist, and encouragement to follow various perceptions) produced conditions in which altered states of consciousness were readily induced. When altered states did occur, they appear to have added to the immersive quality of the experience, and to have contributed to the learning that the participants gained. In other words, it gave participants the impression that they were experiencing inner states very different from their usual waking states. It also appeared to have made them feel, even if just for a moment, that they were truly in the virtually reality of a coma or dying state.

As mentioned in the Literature Review, Van Quekelberghe, Gobel, and Hertweck

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

(1995), in their report on a NDE simulation experiment, showed that special hypnotic techniques and well-designed dissociation training are able to produce experiences similar to "real NDE," and can lead to positive changes in consciousness. Their procedure to induce such states involved structured simulation programs that included 10 -15 minutes of relaxation. These programs were based on the principles of autogenic training and other efforts to induce components of NDEs, such as out-of-body experiences, tunnel experiences, and light experiences. The present study suggests that it is possible to achieve simulated experiences that involve altered states of consciousness and are enough to create impacts on participants' personal and professional lives without such structured programs. However, future studies may choose to develop and incorporate a program that employs similar techniques as those used in the above NDE simulation study.

Coma In Us

It is interesting to note that some of the participants' experiences bore similarities to experiences reported by people who regained consciousness after having been in a medically diagnosed coma. For example, Gimenez (1992) reported a very similar experience to Dianne's. She described that her sense of hearing became more acute than usual, and that she was able to feel the quality of the sitter's energy. Like Dianne, Gimenez reported the ability to feel the emotional vibrations from his wife, and that his sense of hearing became acute. Studies of the experiences of people who went into seemingly unconscious states show that some of them felt the quality of the sitter's energy (Lawrence, 1998). Similarly, accounts by people who were in a medical coma and then regained consciousness describe the sensation of becoming a thought or perception

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

without the ability to respond. After her nine-day coma, Blakely (1990) described her inner experience as follows:

> I heard and felt him, but couldn't speak or touch in return ... in the benevolent atmosphere of my dream I felt more curiosity than alarm, if I could claim any feelings at all.... Physically, I felt no attachment to my body.... Yet having shed my body, I still seemed to *be* here, a kind of dispossessed spirit floating through time. I existed only as thought, although it didn't seem to be exactly my thought. This mind I was in worked in a far more detached, intuitive, unconscious way. I knew the meaning of a sound or touch, but didn't pass through any of my usual, fitful, emotional turns on the way to that knowledge. I was thinking without having to rely on the temperamental machinery of my brain. It was completely unlabored thought, thought unbound by feelings. (p. 52)

This recollection is in accordance with the view of A. P. Mindell (1994) who believes that coma does not necessarily equal unconsciousness, but instead may be considered the deepest and most extreme form of altered states of consciousness. As discussed in the previous section, altered states are readily accessible to people who are not in medical comas, and the states can be accessed in a relatively short period of time.

The inner worlds of the medically comatose are varied, just as the experiences of those who go through coma simulations are. It is important to note that accounts of inner states while in a coma can only be obtained from those who were able to regain consciousness. Little is known about the inner worlds of people who never regain consciousness or whose degree of brain damage is very severe. However, the present study suggests that the mere effort and act of simulating a coma can provide people with vivid experiences similar to those reported by people who have regained consciousness after comatose states.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Exploring the medical or scientific explanations of these similarities is beyond the scope of this study. The interest here lies instead in the similarities' implications for society's marginalization of impaired consciousness. As discussed in the Literature Review, people's interactions with those who are in seemingly unresponsive states greatly depend on their existing views of coma states and impaired consciousness. For example, although recent studies have indicated the possibility that a number of people with medically diagnosed comas or persistent vegetative states have some kind of awareness (e.g., Menon et al., 1998; Schiff et al., 2002), the medical view still largely equates coma with unconsciousness. In addition, people generally tend to regard comatose states as being incomprehensible and very far away from "ordinary" states. As a result, caregivers often avoid direct contact with people in deeply altered or seemingly unresponsive states of consciousness, or they relate to them as if they were at equal levels of consciousness. Some caregivers and medical practitioners try to pull people out of unresponsive states at all cost, and believe that such states are meaningless and somehow "wrong." However, studies do suggest that at least some of those who have regained consciousness reported that their comatose experience was not as foreign to them as perhaps expected, but was instead just over the threshold of their so-called "normal" consciousness. A. P. Mindell (1994) suggests that the states generally recognized as comatose may simply be on a continuum of different levels of consciousness and/or awareness, and that most of us vacillate on this continuum to varying degrees throughout the day. This study has demonstrated that the mere intent to imagine into the inner world of a coma can be enough to provide people with a glimpse into such experiences.

The view that comatose states may not be that far from our ordinary consciousness

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

is a radical perspective. It suggests, metaphorically, those who are identified as "normal" may in fact also have a part in them that is somehow "comatose." As discussed in the Literature Review, Process Work theory addresses the tendency of individuals and groups to stay in one position or role with which they are closely identified in a given moment (e.g., "*I* am the caregiver, and *they* are the comatose"). While a person may wonder about the experience of the other side, they usually reflect on it from their identified perspectives, and it rarely occurs to them to actually "go to the other side" and immerse themselves in the other role. Similarly, all of the participants in this study claimed that they had never before attempted to play a coma role. Findings that suggest at least some awareness in seeming unresponsive states brings comatose people bit closer on the continuum to those who are seen as medically "healthy." Similarly, medically healthy people's efforts to simulate inner comatose states might bring them closer on the continuum to the inner workings of comatose states. Simulating the other side is a radical act which might allow people to find in themselves the part of them that they project onto others. This could result in a reduction of distance between the mainstream (healthy) and the marginalized (comatose, seriously ill, or dying) positions in the society. While further research is necessary to determine the generalizability of the findings, the experience of being on the other side (at least for the participants in this study) was received with surprise and amazement, and it provided them with fresh insights into their professional and personal lives.

The terms "caregiver" and "helper" reflect society's positional attitude toward people who are in dying or seeming unresponsiveness states. These terms imply the rank difference that exists between the two roles: one person is the giver and the other is the

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

receiver. Considering the ways in which the participants in this study learned from their simulated coma experiences, these terms might be too one-sided. In other words, those who are in the identified roles of the dying or comatose also offer valuable teachings to those who are in mainstream roles in society. For example, one of the teachings people in seeming unconscious states may offer is the wisdom of "being" as opposed to "doing."

Who Is There?

The descriptions of the participants' inner experiences are also interesting when explored from the perspective of Buddhism. Levine (1982), a Buddhist practitioner and author of multiple literatures on death and dying, explains that the fundamental principle of Buddhist teaching is about the true nature (Buddha nature), and that the source of suffering comes from the illusion of identifying ourselves with our physical bodies. Levine suggests various meditation exercises, and invites his readers to practice being in touch with their True Self and with the sense of being one.

The verbal expressions used by some of the participants to describe their subjective experiences touch upon the question of "who is actually having the experience?" Although all of the participants used the subjective pronoun "I" in their descriptions, the quality or level of the experience seemed to shift between, for example, the one who was feeling the comfort of being touched by the sitter, the one who was just "being," and the one who was reporting the experience in the interview. All of these different experiences were reported by the same "I." Dianne reported having drifted on the sense of just "being," and, because of the very nature of that experience, she was not judgmental about it while experiencing it. However, she became uncomfortable about it in retrospect

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

because, as she said, "that's not what we are kind of trained and meant to do. We are supposed to be thinking and doing." In this case, the latter "I" (the one thinking and doing) objectifies the former "I" (the one drifting and being), and the discomfort that arises in retrospect is apparently due to difference between the two.

Similarly, Christy, who reported feeling detached from her body, struggled to find the words to explain the experience of not feeling her body and yet "knowing" that the sitter's touch was there. Susan somehow simultaneously felt vulnerable and as if she had become perception itself. Did the same "I" experience both feelings or was she alternately identifying with different standpoints? The author of *Wake Me When It's Over* (Blakely 1990), described her experience as follows: "I existed only as thought, although it didn't seem to be exactly my thought. This mind I was in worked in a far more detached, intuitive, unconscious way." In this statement, Blakely seems to refer to a state of being different from her usual waking consciousness, and she also appears to be struggling a bit to find the appropriate language to convey this unfamiliar sense of self.

As Levine (1982) explains, typical human beings tend to cling to the illusion of having been born, and they identify themselves with their mortal body. From this perspective, the experience of "not being a body" may open avenues to what Buddhism would call the "true nature." The findings of the present study suggest that role-playing a comatose state may have inadvertently served as an opportunity for some participants to experientially glimpse into a Buddhist state—namely the state achieved through meditation. The findings also suggest that a simulated coma experience may have similar values to those in Buddhist meditation practice.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Implications for Family Caregivers

One participant in this study had been a caregiver to his dying partner, who went into coma at the last stage of her life. He was chosen in order to broaden the range of perspectives explored in this study. Some of the experiences that he had during the coma work session were similar to those reported by the professional caregivers (e.g., the sense of comfort associated with the sitter's interventions). However, there was also a fundamental difference between him and the six participants: he had a personal and intimate relationship with the comatose person. The mere idea of participating in this study motivated him to reflect on the last minutes of their lives together, and it motivated him to write about it and share it with others for the first time since the death of his wife. This participant described his experience as touching.

What stood out most with this particular participant was that the physical contact of the coma work held a different meaning for him than it did for the other participants. At the time of the simulation, his wife had already been dead for a year, and he was not with a new partner. He reported that the sitter's touch was significant to him, that it left him with a strong impression, and that he experienced the touch as something very pleasant. He also said that the touch reminded him of his longing for the physical contact and connection he had had with his deceased partner:

> It's not very often that I get touched. And when it happens, it is significant.... It was a reminder of what it felt like, that that could be something that I could have on regular basis if I wanted. If I had or regained a partner, that type of touch would be more frequent and pleasing.

A great deal of the interview time was also spent reflecting on and sharing memories

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

about his wife.

This finding suggests that, in a study of this kind, it is important to consider the issues of grief and mourning of family caregivers. This is true not only for the bereaved but also for practicing caregivers, who frequently feel that they have lost the relationship they are used to and may be grieving even if their family member is still alive. Practitioners considering incorporating aspects of coma work into family care giving should be aware of the implications that such a practice may have. Coma work interventions such as touching the wrist or talking closely to the ear are somewhat intimate in nature, and may stimulate strong emotions or remind participants of the intimacy that they are missing. As was the case with the above-mentioned participant, there is a possibility that such sessions will partially turn into grief counseling. It is advisable that helpers who wish to incorporate coma work into family caregiver education be equipped with therapeutic knowledge and skills in case such situations occur.

Implications for Education

As already discussed, despite limited simulation time and the absence of actual medical comatose states, the study somehow provided participants with opportunities to have "unusual" experiences, some of which appeared similar those reported by people who were once medically comatose. There was a general sense of surprise, curiosity, and excitement amongst all of the participants with regards to their simulation experiences and the coma work methods used. For the participants in this study, the experience impacted their professional and/or personal lives, and for some it significantly changed

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

their care providing techniques with patients.

The findings of this study connect with emerging research findings that address the possible discrepancy between seeming unresponsiveness and the possible inner experiences of comatose patients (e.g., Kotchoubey et al., 2002). Lawrence (1998) states that "there was considerable inconsistency . . . between the subjects' descriptions of when they were unconscious and the perceptions of the caregivers" (p. 5). The present study indicates the value of incorporating simulated coma experiences into the training of health care practitioners and/or family caregivers. Doing so may provide people with first-hand views of the inner worlds of those in seeming unconscious states, and it may bring caregivers and patients closer together. Consider Dianne's comment:

> [It was different to simulate coma] because I've always been on the other side, of being the care provider of the person who is sitting there, and you know, until you experience that I realize that you don't really understand what that person is feeling or thinking or what's going on in there. So I realize that this is probably really, you know, the tip of the iceberg of what they are experiencing. But very different to have the opportunity to be the person who is the non-responsive person, and just to *be*, was very funny. Because when you are on the other side and sitting with the person, you still have our own thoughts going on and thinking about other things and maybe not one hundred percent present.

David, who had a vivid image of himself in his death-bed, was faced with a sense of mortality during the coma work session and commented:

> What amazed me is just in that short amount of time that I was in bed, all those different things went through my mind... I think had I not been in that bed today, I would never think of those things, you know.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Incidentally, David was the only participant who specifically chose to imagine and simulate a near death coma. Although further research is needed, these findings imply that the simulated coma experience may be useful in death education for the general public. Used for this purpose, it may be appropriate to give participants specific instructions to imagine being in a near death comatose state.

Furthermore, the simulation experiences stimulated participant interest in learning more about such themes as consciousness, unconsciousness, coma, death, and dying. In fact, during the interviews, many participants wanted to exchange views on these themes or wanted further education on coma work methods. As described in the previous chapter, the present study resulted in an educational seminar at the AIDS hospice where four of the participants work. The seminar received good feedback and helped open doors for further discussion with others in the field.

The act of simulating a comatose state has significance, not only for the personal and professional lives of caregivers, but also for the various possibilities and implications of death education programs for the general public. Simulations can bring awareness to issues of marginalization, and, in our present society, the mainstream tends to isolate or ignore people in comatose and/or impaired states of consciousness. The present study suggests that the simulation of coma states, when accompanied by Process-oriented coma work methods, can provide people with the opportunity to glimpse into the world of the other side. It can shake up people's usual sense of their identity, create empathetic understanding towards different levels of consciousness, and help the two worlds to come a little closer together.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

GLOSSARY

Altered states of consciousness. A term referring to a state of consciousness which is different from ordinary waking consciousness. A person in altered states of consciousness may experience alterations in thought, body perception, and visual or auditory perception. Altered states of consciousness are experienced, for example, through the use of drugs and/or alcohol, when a person is tired or sleepy, moved by emotion, and/or in meditation.

Bereavement. A term that identifies the feelings associated with the loss of a person or thing that was greatly valued or loved.

Coma. A term used medically to describe a state of unarousable, neurobehavioral unresponsiveness. The patient does not have a sleep-awake pattern but may respond to painful stimulation by subcortical reflex pattern responses. The definition and treatment of coma is a controversial issue that requires multiple levels of medical and philosophical discussions.

Coma work. A Process Work approach to working with individuals in minimally responsive and/or non-responsive states. Coma workers are encouraged to relate to individuals in ways that adapt to their unique altered states, and they believe that the individuals are going through meaningful inner experiences. Coma work may involve techniques of matching breathing rates, noticing subtle "signals" (e.g., movements,

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

gestures, and sounds), and encouraging awareness through verbal and physical support.

Grief. An emotional reaction to loss.

Mourning. A term indicating the process of coping with grief and loss. It is an internal and private process as well as an external and public process.

Process-oriented psychology (Process Work). A cross-disciplinary approach of working with individuals and groups which was originally developed in the 1970s by Dr. Arnold Mindell, a former Jungian analyst. Process Work believes that the solution to a problem is contained within the disturbance itself, and it provides a practical framework through which individuals, couples, families and groups can connect with greater awareness and creativity. Its areas of application include personal challenges, physical symptoms, relationship problems, group conflicts, world issues, and work with the comatose and dying.

Thanatology. The study of death and dying.

Vegetative State. A condition in which sleep-awake cycles and some reflexes return after a comatose state. Recent studies suggest that old definitions of vegetative states are no longer accurate because diagnosis was based on levels of responsiveness that were assumed to indicate the presence or absence of consciousness.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

REFERENCES

Albom, M. (1997). *Tuesdays with Morrie*. New York: Doubleday.

Andrews, K., Murphy, L., Munday, R., & Littlewood, C. (1996). Misdiagnosis of the vegetative state: Retrospective study in a rehabilitation unit. *British Medical Journal, 313*, 13-16.

Ariès, P. (1981). *The hour of our death*. (H. Weaver, Trans.) New York: Knopf.

Barley, N. (1995). *Grave matters: A lively history of death around the world.* New York: Henry Holt & Company.

Bauby, J. D. (1997). *The diving bell and the butterfly*. New York: Alfred A. Knopf.

Becker, E. (1973). *The Denial of Death.* New York: Free Press.

Bertman, S. L. (1974). Death education in the face of a taboo. In E. A. Grollman (Ed.), *Concerning death: A practical guide for the living* (pp. 333-61). Boston: Beacon.

Blakely, M. (1990). *Wake me when it's over: A journey to the edge and back.* New York: Times Books.

Bonenfant, R. J. (2001). A child's encounter with the devil: An unusual near-death experience with both blissful and frightening elements. *Journal of Near-Death Studies, 20*(2), 87-100.

Byock, I. (1997). *Dying well: The prospect for growth at the end of life.* New York: Riverhead Books.

Calhoun, L. G., & Tedeschi, R. G. (2001). Posttraumatic growth: The positive lessons of loss. In R. Neimeyer (Ed.), *Meaning reconstruction & the experience of loss.*

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Washington, DC: American Psychologist Association.

Callanan, M., & Kelley, P. (1992). *Final gifts: Understanding the special awareness, needs and communication of the dying.* New York: Bantam Books.

Childs, N. L., Mercer W. N., & Childs, H. W. (1993). Accuracy in the diagnosis of persistent vegetative state. *Neurology, 43,* 1465.

Cieurzo & Keitel (1999). Ethics in qualitative research. In M. Kopala & L. Suzuki (Eds.), *Using Qualitative methods in psychology* (pp. 63-75). Thousand Oaks, CA: Sage Publications.

Clayman, C. B. (Ed.). (1989). *The American Medical Association encyclopedia of medicine*. New York: Random House.

Corr, C., Corr, D., & Nabe, C. (Eds.). (2000). *Death and dying, life and living* (3rd ed). Belmont, CA: Wadsworth.

Counts, D. R., & Counts, D. A. (Eds.). (1991). *Coping with the final tragedy*. Amityville, New York: Baywood Publishing Company.

Creswell, J. W. (1994). *Research design: qualitative and quantitative approaches.* Thousand Oaks, CA: Sage publications.

Crick, F. (1994). *The astonishing hypothesis.* London: Routledge & Kegan Paul.

Danforth, L. M. (1982). *The death rituals of rural Greece.* Princeton, NJ: Princeton University Press.

De Hennezel, M. (1997). *Intimate death: How the dying teach us how to live.* New York: Alfred A. Knopf.

Denzin & Lincoln (1994). Part V: The art of interpretation, evaluation, and presentation. In *Handbook of qualitative research* (pp. 479-483). Thousand Oaks, CA: Sage

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Feifel, H. (Ed.). (1959). *The meaning of death.* New York: McGraw-Hill.

Feifel, H. (1963). Death. In N. L. Farberow (Ed.). *Taboo topics* (pp. 8-21). New York: Atherton.

Flynn, C. P. (1982). Meanings and implications of NDE transformations: Some preliminary findings and implications, *Anabiosis, 2,* 3-14.

Frantz, T. T., Farrell, M. M., & Trolley, B. C. (2001). Positive outcomes of losing a loved one. In R. Neimeyer (Ed.), *Meaning Reconstruction & the experience of loss* (pp. 191-209). Washington, D.C.: American Psychological Association.

Gibson, A. S. (1996). Frightening near-death experiences. *Journal of Near-Death Studies, 15*(2), 141.

Gimenez, R. (1992). A metaphysical journey in a comatose state. *Clinical Nurse Specialist 6*(4), 191-194.

Giorgi, A. (Ed.). (1985). *Phenomenology and psychological research.* Pittsburgh, PA: Duquesne University Press.

Giorgi, A. (1989). One type of analysis of descriptive data: Procedures involved in following a scientific phenomenological method. *Methods, 1,* 39-61.

Giorgi, A., Fischer, C., & Murray, E. (1975). *Duquesne studies in phenomenological psychology, 2.* Pittsburgh: Duquesne University Press.

Glicksohn, J. (1991). The induction of an altered state of consciousness as a function of sensory environment and experience seeking. *Personality and Individual Differences, 12*(10), 1057-1066.

Glicksohn, J. (1993-94). Rating the incidence of an altered state of consciousness as a function of the rater's own absorption score. *Imagination, Cognition and Personality,*

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

13(3), 225-228.

Glicksohn J. & Avnon, M. (1997-98). Explorations in virtual reality: absorption, cognition and altered state of consciousness. *Imagination, Cognition and Personality, 17*(2), 141-151.

Goldman, A. (1989). Interpretation psychologized. *Mind and Language, 4,* 161-185. Reprinted in M. Davies & T. Stone (Eds.). (1995). *Folk psychology: The theory of mind debate.* Oxford: Blackwell Publishers

Goodbread, J. (1997). *The dreambody toolkit: A practical introduction to the philosophy, goals and practice of Process-Oriented Psychology.* Portland, OR: Lao Tse Press.

Gordon, R. M. (1986). Folk psychology as simulation. *Mind and Language, 1,* 158-171. Reprinted in M. Davies, & T. Stone (Eds.). (1995). *Folk psychology: The theory of mind debate.* Oxford: Blackwell Publishers

Gorer, G. (1965). The pornography of death. In G. Gorer. *Death, grief, and mourning* (pp. 192-99). Garden City, NY: Doubleday.

Harris, P. (1989). *Children and emotion.* Oxford: Blackwell Publishers.

Heal, J. (1998). Understanding other minds from the inside. In A. O'Hear (Ed.). *Current issues in philosophy of mind* (pp. 83-99). Cambridge, MA: Cambridge University Press.

Husserl, E. (1931). *Ideas.* (W. R. Boyce Gibson, Trans.). London: George Allen & University.

Husserl, E. (1970). *Logical investigations, 1.* (J. N. Findlay, Trans.). New York: Humanities Press.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Irish, D. P., Lundquist, K. F., & Nelson, V. J. (Eds.). (1993). *Ethnic variations in dying, death, and grief: Diversity in universality.* Washington, DC: Taylor & Francis.

Ivan, L. P., & Ventureyra, E. G. (1982). Coma and the evolution of brain resuscitation in coma. In L.P. Ivan & Bruce D.A. (Eds). *Coma:Physiopathology, diagnosis and management* (pp.3-15). Springfield, IL: Charles C. Thomas.

Jones, R. (1980). Religious symbolism in Limbu death-by-violence. In R. A. Kalish (Ed.). *Death and dying: Views from many cultures* (pp. 25-33). Farmingdale, New York: Baywood Publishing Company.

Kant, I. (1953). *Critique of pure reason* (N. K. Smith, Trans.). London: Macmillan.

Kastenbaum, R. (1972). On the future of death: Some images and options. *Omega, 3,* 306-318.

Kockelmans, J. J. (Ed.). (1967). *Phenomenology.* Garden City, NY: Doubleday.

Kotchoubey, B., Lang, S., Bostanov, V., & Birbaumer, N. (2002) Is there a mind? Electrophysiology of unconscious patients. *News Physiological Science, 17,* 38-42.

Kübler-Ross, E. (1969). *On death and dying.* New York: Macmillan.

Kvale, S. (1996). *Inter views: An introduction to qualitative research interviewing.* Thousand Oaks, London, New Delhi: Sage publications.

Lawrence, M. (1998) *In a world of their own: Experiencing unconsciousness.* Westport, CT: Praeger.

Levine, S. (1982). *Who dies? : An investigation into conscious living and dying.* New York: Doubleday.

LeWinn, E. (1985). *Coma Arousal.* New York: Doubleday.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry.* Beverly Hills, CA: Sage.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

May, R. (1983). *The discovery of being: Writing in existential psychology.* New York & London: W. W. Norton & Company.

Maxwell, J. A. (1996). *Qualitative research design: An interactive approach.* Thousand Oaks, CA: Sage Publications.

Menon, D. K., Owen, A. M., William, E. J., Minhas, P. S., Allen, C. M., Boniface, S. J. (1998). Cortical processing in the vegetative state. *Lancet, 352,* 200.

Merleau-Ponty (1962). *Phenomenology of perception* (C. Smith, Trans.). Boston: Routledge & Kegan Paul.

Merrick, E. (1999). An exploration of quality in qualitative research: Are "reliability" and "validity" relevant? In M. Kopala & L. A. Suzuki (Eds.). *Using qualitative methods in psychology* (pp.25-36). Thousand Oaks: CA: Sage.

Mindell, A. S. (1995). *Metaskills: The spiritual art of therapy.* Tempe, AZ: New Falcon Publications.

Mindell, A. S. (1999). *Coma, a healing journey: A guide for family, friends and helpers.* Portland, OR: Lao Tse Press.

Mindell, A. P. (1987). *The dreambody in relationship.* New York & London: Penguin.

Mindell, A. P. (1988). *City shadows: Psychological interventions in psychiatry.* New York & London: Penguin/Arkana.

Mindell, A. P. (1992). *Riding the horse backwards: Process Work in theory and practice.* New York & London: Penguin/Arkana.

Mindell, A. P. (1994). *Coma: The dreambody near death.* New York & London: Penguin/Arkana. Reprint of *Coma: Key to awakening.* (1988). Boulder, CO: Shambhala.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Mindell, A. P. (1997). *Sitting in the fire: Large group transformation through diversity and conflict.* Portland, OR: Lao Tse Press.

Moody, R. (1975). *Life after life.* New York: Bantam Books.

Moustakas, C. (1990). *Heuristic Research: Design, Methodology, and Applications.* Newbury Park: Sage Publications.

Moustakas, C. (1994). *Phenomenological research methods.* Thousand Oaks, CA: Sage Publications.

Multi-Society Task Force on PVS (1994). Medical aspects of the persistent vegetative state. *The New England Journal of Medicine,* 330-1449.

Neaman, J. S., & Silver, C. G. (1983). *Kind words: A thesaurus of euphemisms.* New York: Facts On File Publications.

Neimeyer, R. (Ed.). (2001). *Meaning reconstruction & the experience of loss.* Washington, DC: American Psychological Association.

Neimeyer, R. & Fortner, B. (1997). In S. Strack (Ed.). *Death attitudes in contemporary perspective* (pp. 3-56). Northvale, NJ: Jason Aronson.

Noyes, R. (1980). Attitude change following near-death experiences. *Psychiatry, 43,* 234-242.

Patton, M. Q. (2002). *Qualitative Research & Evaluation methods* (3rd ed). Thousand Oaks, London, New Delhi: Sage Publications.

Pine, V. R. (1977). A socio-historical portrait of death education. *Death Education, 1,* 57-84.

Pine, V. R. (1986). The age of maturity for death education: A socio-historical portrait of the era 1976-1985. *Death Studies, 10,* 209-31.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Plato (1945). *The Republic* (F. M. Cornford, Trans.). London, New York: Oxford University Press.

Plum, F. & Posner, J. B. (1980). *The diagnosis of stupor and coma* (3rd ed). Contemporary Neurology Series 19, Philadelphia: F. A. Davis.

Rando,T. A. (1984). *Grief, dying, and death: Clinical interventions for caregivers.* Champaign, IL: Research Press.

Rando, T. A. (1993). *Treatment of complicated mourning.* Champaign, IL: Research Press.

Reiss, G. (2004). *Vital loving: A guide book for couples and families.* Eugene, OR: Changing Worlds Publications.

Ring. K. (1984). *Heading toward Omega:In search of the meaning of the near-death experience.* New York: William Morrow and Company.

Rinpoche, S. (1993). *The Tibetan book of living and dying.* New York: Harper Collins Publishers.

Schiff, N. D., Ribary, U., Moreno, D. R., Beattie, B., Kronberg, E., Blasberg, R., Giacino, J., McCagg, C., Fins, J., Llinás, R., Plum, F. (2002). Residual cerebral activity and behavioural fragments can remain in the persistently vegetative brain. *Brain, 125,* 1210-1234.

Shepard, R. N. (1984). Ecological constraints on internal representation: Resonant kinematics of perceiving, imagining, thinking, and dreaming. *Psychological Review, 91*(4), 417-447.

Smith, R. (1998) *Lessons from the dying.* Boston, MA: Wisdom Publications.

Tart, C. T. (1969). *Altered states of consciousness.* New York: Wiley.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Tart, C. T. (1990). Multiple personality, altered states and virtual reality: The world simulation process approach. *Dissociation, 3*(4), 222-233.

Tesch, R. (1990). *Qualitative research: Analysis types and software tools.* New York: The Falmer Press.

Twycross, R. G. (1995). *Introducing palliative care.* New York: Radcliffe Medical Press.

Van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy.* London, Ontario, Canada: State University of New York Press.

Van Quelelberghe, R., Goebel, P., & Hertweck, E. (1995). Simulation of near-death and out-of-body experiences under hypnosis. *Imagination, cognition, and personality, 14,* (2), 151-164.

Velmans, M. (2002). How could conscious experiences affect brains? *Journal of consciousness studies, 9,* 3-29.

Webster J. & Kristjanson L. J. (2002). "But isn't it depressing?" The vitality of palliative care. *Journal of Palliative Care, 18* (1), 15-24.

Wellenkamp, J. (1991). Fallen leaves: Death and grieving in Toraja. In D. R. Counts & D. A. Counts (Eds.), *Coping with the final tragedy.* Amityville, New York: Baywood Publishing Company.

Worden, J. W. (1976). *Personal death awareness.* Englewood Cliffs, NJ: Prentice-Hall

Worden, J. W. (1991). *Grief counseling and grief therapy: A handbook for the mental health practitioner.* New York: Springer.

Worthen, V. E. & McNeill, B. W. (2002). A phenomenological investigation of "good" supervision events. In S. B. Merriam. *Qualitative research in practice: Examples for discussion & analysis.* San Francisco: Jessey-Bass.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Yates, J. (1985). The content of awareness is a model of the world. *Psychological Review, 92,* 249-284.

Young, G. B., Ropper A. H., & Bolton, C. F. (Eds.). (1998). *Coma and impaired consciousness: A clinical perspective.* New York: McGraw-Hill.

Zaleski, C. (1987). *Otherworld journeys: Accounts of near-death experience in medieval and modern times.* New York: Oxford University Press.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

APPENDIX A.

LOOKING FOR PARTICIPANTS IN DOCTORAL RESEARCH ON

"COMA WORK"

Are you currently giving care to a person in minimally responsive or non-responsive state such as coma, either professionally or as a family member? I am a clinical psychologist in private practice in Japan and a doctoral candidate in psychology in the United States, who is currently conducting for my thesis a research on a modality of working with comatose or minimally responsive states, called **Process Oriented Coma Work**. I am looking for family and professional caregivers who would be interested in participating in my research.

Coma work has been developed by Dr. Arnold Mindell (author of *Coma: Key to Awakening*), Dr. Amy Mindell (author of *Coma, a healing journey: A guide for family, friends and helpers.*), and their associates. It is a special method to accompany people in seemingly unresponsive states by pacing breathing, being aware of the minimal body signals, and following the feedback of the person.

For my research, I am interested in studying how caregivers of the people who are in such states themselves experience the Coma Work, and the meaning the experience holds for them. Your research participation will include experience of a Coma Work session, and pre- and post-interviews. Your total participation time will be approximately 2 to 2.5 hours. The results of the study will be shared with you, and your identity will be held strictly confidential.

I am conducting this research in the hopes that it will contribute to our understanding of the ways to accompany people in coma, or seemingly non-responsive states. I am aware that you already have so much on your plate in giving care to your loved ones or your patients, but I am hoping that this project will be an enjoyable experience from which we can learn together. If you are interested in participation, or have any questions, please contact me at (phone number) or (email address).

Thank you very much for your attention, Hitomi Sakamoto

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

APPENDIX B.

Date _____
Dear _____

Thank you for your interest in my dissertation research on the experience of Process Oriented method for coma. I value the unique contribution that you can make to my study and I am excited about the possibility of your participation in it. The purpose of this letter is to reiterate some of the things we have already discussed and to secure your signature on the participation-release form and the informed consent form that you will find attached.

I am conducting this research as part of my Ph.D. program in Interdisciplinary Studies in Psychology at Union Institute & University. The research mode I am using is a qualitative one through which I am seeking comprehensive depictions or descriptions of your experience. In this way, I hope to illuminate or answer my questions: ``How do caregivers of people in a seemingly unresponsive state experience the Process Work model of working with coma, and what meaning does it hold for them?" Through your participation as a co-researcher, I hope to understand the nature of Process Work model of coma work as it reveals itself in your experience. Information about this research project will enhance understanding of the application of such model in working with people in minimally responsive and non-responsive states.

Following a brief interview in which you will be asked about yourself and your current situation, you will go through a short course of Process Work model of coma work facilitated by myself. Following the session, you will be interviewed on your experience of the coma work. The interviews and the session will both be videotaped and tape recorded. I am seeking vivid, accurate, and comprehensive portrayals of what these experiences were like for you including your thoughts and feelings. I will also be contacting you approximately a week later for a follow-up interview. Your involvement will require about 120 – 180 minutes of your time. After the research is completed, I will forward a summary of my findings and the implications of those findings to you by mail.

I am not aware of any risks involved in participation in this project. I hope that it will be an enjoyable experience from which we can learn together. You will be identified by initials and not by your name. All responses will be confidential and your name will not be used in any report regarding this research. You are free to decline to participate or to withdraw at any time.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

I value your participation and thank you for the commitment of time, energy, and effort. If you have any further questions before signing the release form or if there is a problem with the date and time of our meeting, I can be reached at 503-227-2154.

With warm regards,

Hitomi Sakamoto

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

APPENDIX C.

Informed Consent Form

I, _____ , consent to participate in the study of "The qualitative study in Process Oriented Psychology model of working with coma: the caregivers' experiences", conducted by Hitomi Sakamoto. I understand that I may refuse to participate or withdraw from this study at any time. I understand that all responses will be confidential. I understand that I may direct questions about this project to Hitomi Sakamoto.

_____ _____

Signature Date

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

APPENDIX D.

Participant Release Agreement

I, _____ , consent to participate in the study of ``The qualitative study in Process Oriented Psychology model of working with coma: the caregivers' experiences", conducted by Hitomi Sakamoto. I understand the purpose and nature of this study and I am participating voluntarily. I grant permission for the data to be used in the process of completing a Ph.D. degree, including a dissertation and any other future publication. I understand that a brief synopsis of each participant, including myself, will be used and will include the following information: initials, age, sex, ethnic background, occupation, and any other pertinent information that will help the reader come to know and recall each participant. I grant permission for the above personal information to be used.

I agree to meet at the mutually agreed upon location and times for an initial interview of 1 to 2 hours. If necessary, I will be available at a mutually agreed upon time and place for an additional 1 hour interview. I also grant permission to video and tape recording of the interview(s).

_____ _____

Research Participant / Date Primary Researcher/ Date

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

APPENDIX E.

No.

INFORMATION SHEET

Name	sex	ethnicity	age

Occupation

Address	City	State	Zipcode

Phone	email address

* What is (was) your relationship to the person you are (were) giving care to?

* How long have you been (were you) taking care of the person?

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.