

THE KNOWN AND THE UNKNOWN

THE KNOWN AND THE UNKNOWN:
An Exploration of Attitudes Towards
Death, Dying, and Grieving

By
Wendy J. Renault R.N. B.A.

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AUTHOR: Wendy J. Renault, R.N. Mohawk College
B.A. McMaster University

SUPERVISOR: Professor R. Preston

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ABSTRACT

In this thesis, I discuss the notions of the denial and fear of death which are part of the North American attitude. As a contrast, I present Mayan attitudes and feelings towards death, dying, and grieving which tend to be accepting of death as a change, and therefore not as a thing to be afraid of. In this section I present the Mayan "naturalistic" way of looking at death and their feeling of *communitas* during the liminal stage of death. The next section deals with the topic of palliative care as an example of dealing with a difficult process through a comparable *communitas* in dealing with suffering and hope. These two cultural samples demonstrate that people dealing with the dying can learn from other cultures and that our "culture at large" can also benefit through finding out how other people deal with death, dying and grieving (O'Connor 1991).

INTRODUCTION

The topic of this thesis is death, dying, and grieving. In chapter one I discuss North American¹ notions of death, the denial of death and fear of death. Death is unfamiliar and frightening. I illustrate the European background of this with a summary of Aries (1974) as he takes us through the Middle Ages, the Enlightenment, the Elizabethan period, and the present century. For a discussion of the present I also use the psychologist E. Becker (1973) whose book (entitled The Denial of Death) purports to prove that we are born with an innate fear of death which is the driving force for living (what actions we take, and what choices we make). Then I discuss Kalish (1976), Badone (1989), Metcalf (1979), Aiken (1985) Kubler-Ross (1970), Counts and Counts (1991), Ramsden (1991), and Glaser and Strauss (1968, 1965) in order to examine how different cultures deal with death and how the removal of the old and infirm to hospitals and nursing homes has led to and fostered our fears and denials.

Chapter two is a discussion of the Mayan perspective, presented to serve as an example of another way of dealing with death. To the Mayans, death is familiar; it is not pushed to the fringes of the society. This includes my argument that the Mayans have a different way of perceiving the world than we do. At bottom, there is no distinct separation of body/mind/spirit. There is a kind of holism which involves or has added to it, a

¹Although Mexicans consider themselves to be part of North America, for the purposes of this thesis, I take North American culture to refer to the general culture of Canada and the United States. (Mexican culture, on the whole, is very different from either.) I realize that Canada has a unique and special culture, but I feel that the deathways of the two countries are similar enough that I can use experiences and research from both.

"naturalistic"² way of looking at the world. This includes such notions as that death is a normal event which everyone has seen, been intimately touched by, and is not something which can be avoided through wishful thinking or technology. This does not mean that the Mayans do not become sad when someone dies, nor does it mean that death is treated as an everyday event. What it does mean is that death, as a processual event, will take place for everyone, but in it's own time and way.

In chapter three I discuss palliative care as a way which may, as per O'Connor (1991), help us (North American culture) deal with death, dying, and grieving. I give an outline of the history of hospice/palliative care. I follow this, in chapter four, with a discussion of hope. Hope has been found to be central in the maintenance of a positive attitude which is necessary to alleviate despair, hopelessness, and helplessness which typically lead to an unhappy, unloving, unfulfilled, unquiet death, and probably to a lengthy grieving period or even pathological grieving. This feeling of hope can be fostered by a sense of *communitas* (Turner 1969).

I have chosen to write this thesis in everyday language. The reason for this is twofold. I feel that it is important that any of the people who are represented in this work find it accessible and readable. In this way I feel that I am fulfilling my obligation to them which is that they are able to read what I have written, given their contributions to this work. This work contains much emotion, mine and that of others. It would be a disservice to all to remove this tone by employing mediating academic language.

²By "naturalistic" is meant simply a co-existing with nature in a non-combative way, a kind of working with nature versus attempting to master and control it as we (in the "West") characteristically do. This includes aspects of holism in that everything in the universe is seen as a part of the whole, the parts working together to maintain the whole.

CHAPTER ONE

NORTH AMERICAN FEAR AND DENIAL OF DEATH

Historical Perspectives

North Americans are thought to deny and have a fear of death³. These notions have been characterized by Philip Aries (1974) through a view of how death has been treated down through the ages. Aries talks first of "The Tamed Death"; the people of this age were the Knights of the *chansons de geste*, the old romances. Included are such famous names as King Arthur, Tristram and Iseult, Lancelot, and others. They were typically forewarned of their death. When it was sudden such as by plague, death was not to be talked about, it was the exception, and not a "desirable death" (Aries 1974; p1-25). Generally, though, the person "felt their death upon them", or "knew the end was near", and the family, friends and neighbours gathered around in the bedchamber. There were expressions of sorrow over the impending loss, past guilts; pardons were extended, last prayers uttered, and absolution granted. These rituals were orchestrated by the dying person, with no great fanfare or emotive outbursts. Death was "familiar and near". It was held neither in great fear nor awe.

Aries' second historical period is the Middle Ages. He postulates that in this period people become aware of their own death; it becomes part of their personal biography almost as a process of completion of their life. Aries says that "[f]amiliarity with death is a

³This is a generalization about what seems, in the academic and popular literature, to characterize the "culture at large".

form of acceptance of the order of nature..."(Ibid. p 17). Death was not thought of as something to be escaped or glorified (Ibid. p 18), it was merely met with appropriate solemnity. Later in the Middle Ages, an additional dimension was added to the bedchamber of the dying person which made each death personal and individual. Depicted in art and literature, supernatural figures are seen by the dying person. At times the entire life of the person was shown and judged, at other times or places, the Virgin and hosts of angels and/or saints were on one side of the dying person with Satan and demons on the other. This supernatural scene was initially seen as a judgement but later as a test preceding the last Judgement. A good death became one in which one's attitudes at this "test" were right. This gave final meaning to the person's life. Death had become the time of what would later be called self-actualization⁴, that is, a kind of "putting together" of ones' life, history, accomplishments, and a "wrapping up" of relationships.

The eighteenth century is the focus of Aries' third period. It is a time when people become more focused on what Aries calls "Thy Death". Death becomes exalted, dramatized, and thought of as disquieting and greedy (Aries 1974; p 55). One's own death is not as important as the "other's" death, whose memory inspired new cults and high romanticism. Death images beginning in the 16th and becoming more standard by the 18th century take on an erotic nature. Images of death are superimposed on sexual images in art and literature, and sexual analogies are used to talk about death. "Death "rapes" the living" (Ibid. p 56). "Like the sexual act, death was henceforth increasingly thought of as a transgression which tears man from his daily life, from rational society, from his

⁴See, for example, Maslow's works, especially those concerning his formulation of a hierarchy of needs, for example, Coleman's Abnormal Psychology.

monotonous work, in order to make him undergo a paroxysm, plunging him into an irrational, violent, and beautiful world "(Ibid. p 57). Death now was seen as a break or rupture. In the 18th century the demonstration of strong emotion had become normal in the dying person's bedchamber. The very idea of death is what moved people by the 19th century. There was sorrow, but there was a growing intolerance of separation, especially that caused by death. By the 19th century, mourning was called hysterical, emotional expressions were seen as excessive, and the death of the "other"⁵ was feared.

Aries closes with a discussion of notions of death in the present, which he calls "Forbidden Death". This period is characterized by a "hushing-up" (Ibid. p 87) of death, and the suppressing of displays of strong emotion. Death disrupts a "happy" life, whether in truth or not the life is seen as such. Death is ugly and ought to be avoided or at least hidden. This trend is exacerbated by the fact that during the 1930's-50's the majority of people died in hospitals, alone. But, hospitals are also places where one goes to be cured or to fight against death, (Aries 1974; p 88, see also Badone 1989, and Glaser & Strauss 1968). When death occurs, it is in a number of small steps⁶ instead of one great finale. Shows of emotion are not tolerated, emotion is something which happens in private so as not to upset children, or any one else. Doctors and the "hospital team" allow for an acceptable-vs. graceless- death. Glaser and Strauss report the latter category as including such behaviours as screaming, being unceasingly demanding, etc., and the former as being

⁵Other is a person who while not being oneself, is someone close, for example, a lover, mother, etc.

⁶The small steps take place over a lesser or greater period of time, and include things like; loss of physical control, inability to eat or to feed oneself, inability to bathe oneself, increasing difficulty breathing, increased pain, loss of mental acuity, and finally death.

a quiet death which does not result in guilty feeling in the staff members (Glaser and Strauss 1965 & 1968). This has led Gorer to say that death has replaced sex as the taboo subject. "Mourning", he says, "is akin to masturbation-it is done in private and in shame" (reported in Aries 1974; p 90).

In America, embalming grew into a profession whose members took on a new name; funeral directors. People do not hide death, they "dress it up, make it up" (Aries 1974; p 99), and act as if the person is not really dead but "resting". This makes the person not "really dead", or "almost alive". When people "visit" the dead person at the funeral home, the rupture has been blurred. This is comparable to the case of an ill person, when visitors frequently remark on how well he looks, even though he is obviously quite ill. People do the same thing at the funeral home, commenting on how well the person looks, even when the look is often quite unnatural. This conjures up images of life as some kind of performance which is continued even when we die. This notion is examined by Ramsden (1991) in his article Alice in the Afterlife, in which he suggests that death is a pivotal point which can act as a mirror in that what happened before is "turned backwards" afterwards. (If a person, in Ramsden's case Iroquois Indians, had a long period of illness leading up to death, then there was a long period following death, before being considered really dead, when they were in a similarly non-normal state.) Perhaps the feelings of loss of control and anger when someone close to you dies are what has led Ernest Becker, (1973) a psychologist, to think that human beings have an inborn fear of death. It is this fear, he says, which drives us in living and directs all of our "life" choices. Becker reports that "the *idea* of death, the fear of it, haunts the human animal like nothing else; it is a mainspring of human activity - activity designed largely to avoid the fatality of death, to overcome it by

denying in some way that it is the final destiny for man...the fear of death is indeed a universal in the human condition". (Becker 1973; p ix, emphasis mine). This kind of thinking does not allow anyone to have any sense of control over death or even over the idea of death, yet there have been documented cases where people obviously do have some control over their death and their fear of it. One case which comes to mind is that of suicide. Becker does not deal adequately with this as he does not report how suicide can be consistent with his formulation.

Other examples of control over the time of death are found throughout Badone's (1989) book about deathways in Brittany entitled The Appointed Hour; and Number Our Days, a book written by Barbara Myerhoff (1978) about elderly Jewish people in California. They both report people talking about death as if it were a natural occurrence, something to plan for, and something which must be celebrated in just the right way.

Many people seem to "hold off" or almost plan their death, or at least the timing in that they wait until an anticipated event has occurred before they die. Belle⁷ was thrilled about the party which would celebrate her one hundredth birthday. Although she had no major physical problems, she had been requesting more and more assistance in getting groceries to her second floor walk-up apartment. Her mental capacities had not diminished at all. She died the day after her birthday party, all those close to her saying that she had waited to die until after the party because it was such an eagerly anticipated event. This is contrary to Becker's notion that the fear of death is a most basic fear which informs all other fears, and is present in everyone - regardless of cultural teaching, and if it seems not

⁷Belle and my Grandmother emigrated from Scotland in the early 1920's, both with small children. I have known Belle since I was very young, and many in my extended family attended her birthday party.

to be present then it is disguised or is sublimated (in terms of defense mechanisms). It (death) is what Becker reports William James calling "the worm at the core of man's pretensions to happiness" (in Becker 1973; p 15). The repression of the fear of death is, according to Becker, a result of successful cultural programming. Once again this theory goes against the grain, both because of reports of the two authors mentioned above, and work done by Kubler-Ross and others about how people can and do accept their own impending death.

Kubler-Ross (1970) was a pioneer in studies relating to death and grief. She talked to a great many dying people in order to understand how they felt so that she would be better able to deal with her dying patients. She presented a set of stages which people go through with an impending (anticipatory) or actual loss. These stages were taken by later scholars to represent the way that grief happens and Kubler-Ross's formulation became a standard characterization of the way that North Americans grieve. This was soon disputed though, by the new generation of "thanatologists" saying that not everyone goes through all of these stages in the prescribed order. The stages proposed by Kubler-Ross, however, can still be useful if they are used as guidelines, and if it is kept in mind that everyone will not "progress" through each stage in the "proper" order. The first stage is denial; one refuses to believe the diagnosis being presented by the doctor, or a person refuses to believe that a loved one has died. Stage two is anger. This anger is frequently expressed as the question "why me?". The anger being felt is typically directed at anyone or anything. The third stage is bargaining, which is usually with the superior being in whom the person believes. Stage four is depression. The sense of loss of a body part, important life functions, a loved one, or the impending loss of oneself leads to a sadness which can be extremely profound. The

fifth and final stage is acceptance. Kubler-Ross says that we should not mistake acceptance for a happy stage. "It is almost void of feelings" (Kubler-Ross 1969; p 113), perhaps similar to the state of detachment described by some of Eastern religions. The person has, according to Kubler-Ross, peace and acceptance.

Aries was perhaps closer to the truth when he says that we reject separation (Aries 1974; p 90-92). This can be demonstrated by current popular documented results of divorce⁸, and socially by the popular songs which lament being the one left behind. Also, he is correct in implicating the fashion of more people dying in hospitals which adds to the repugnance we feel for death. It is the removal of death into an unfamiliar place with its many rules for behaviour which has made the most impact on how we respond to death. In hospitals, only a certain number of family and/or friends may be present; and in some cases even the most important of friends are not permitted to visit (for example, in the various intensive care units). People are permitted to visit only at certain hours, and the hospital staff is definitely in control of the situation. The family, much of the time it seems, are merely tolerated, they are not included in plans being made, nor are they expected to ask too many questions, or discuss possible problems unless initiated by the physician, or his/her delegate. In Badone's (1989; p 46, 48, 328-9) study in Brittany, the local knowledge suggests that hospitals are places where people go to die, people in hospital are alone, and they are often forgotten-especially when the younger members of the family have moved to the bigger cities. Death becomes "something terrifying the more it gets pushed to the edges of society" (Badone 1989, 43). Dying in hospital, alone, probably is

⁸Some of these include the resultant psychological problems experienced by the partner left behind and by children. There is typically much anger, and feelings of loss of control over one's life.

the most fearful possibility to many people. This is also discussed by Metcalf (1979), Kalish (1976), and Aiken (1985).

In North America since the 1950's, along with the increase in the number of people who go to hospitals when they are sick, and therefore an increase in the number of people who die in hospitals (Badone 1989, Kalish 1976, Aiken 1985), there is also an increase in the number of retirement and nursing homes as places where the elderly live because they cannot manage alone or there is no-one to help them at home and they are not welcome (for whatever reason) in their children's homes. As a result, immediate families are not seeing the elderly on a daily basis, and certainly not when they are dying. When death is something which happens far away, with other people, and is dealt with by professionals, it gets pushed more and more to the fringes of society, and becomes that which is unknown which leads people to be more fearful of it (Aries 1974, Metcalf 1979).

Becker, I believe, has missed this historical and sociological perspective and therefore the more complete picture when he limits his theory to simply an atemporal psychological "fact". Many people in the present are into their twenties when someone close to them dies. I think that although we hear constantly through television and radio news of deaths which happen in other countries, or even our own, even in great numbers, it does not mean the same thing, the immediate, emotional drain and intense feelings are not felt in the same way. I remember hearing of the news of the assassination of John F. Kennedy when in grade school. My friend and I were at her house for lunch and were watching the news with her mother. We cried when we heard that he had been shot and again (or still) when they reported his death. We had heard the announcer say that the United States would never be the same, the world had lost a great leader, and that this

was a tragedy beyond belief. The world was in shock, and we were participating.

But the feelings were not the same as what I felt when I heard that my grandfather died. That was hard, my life changed, certain things I had become used to would not happen any more, and I would never see Papa rocking on the front porch again. The feelings were intense at first, but became less so, and the event was not just remembered each year on the anniversary through the media as for famous people, but frequently, while performing mundane tasks or looking through family pictures.

As death gets pushed further to the edges of society, less people, generally speaking, are involved in the care of the dying; that is left to the hospital or nursing home personnel. When the person dies, the role of care-giver is transferred to the funeral director. The funeral director attempts to make the person look like they did when they were healthy, or as close as possible. The ideal is for those viewing the deceased to comment on how "natural" he looks or that she looks like she is sleeping.

There is some discussion in current authors (eg. Aiken 1985; p 8-10 Counts and Counts 1991;p 278) about determination of death - the absence of breathing, absence of heartrate, absence of brainwave activity; all or some of these, and is one physician enough to make these pronouncements or are two needed? They also discuss why our culture has such an antipathy toward death. They usually come up with notions similar to those Aries presents, rejection of separation, unfamiliarity with death, the need to overcome and subdue nature-including death. They also discuss the fears of dying alone and in hospital, and in pain. Dorothy Counts and David Counts in their book on death and grieving (1991) pose the problem within modern society of determining death. Without all of our technology, physical death usually refers to a state of no breathing and no pulses found.

With technology this determination has become much more difficult. It involves brain waves, electrical monitoring, and lately is involving the quality we associate with living. Biomedicine has tended to look at death as an event, a one-time occurrence. There is a "time of death", a specific time, which is a part of the death certificate completed by the physician (this form must legally be completed for everyone, upon death, in this country). Other people look on death as a process. The physical death is only one part of that process, also included are the social death (which can occur separately from physical death), and the life after death. Death in some societies can be years in the completing. "A society's understanding of death mirrors its understanding of life" (Ramsden 1991).

My argument here is that in biomedicine there is no feeling of *communitas*, no intense sharing of strong emotional, binding feeling. People feel isolated, individual to the point of cutting other people off, or being cut off from other people. Death is no longer a family or community event, being directed by or at least including the dying person, it is almost a non-event for these people (but, an event for the hospital staff who may feel that death is a failure), until the person is made up and dressed so as to look like they are "resting" in their best clothes. At this time they are treated as if they were "partially alive" or "not quite dead" (Aries 1974; p 85-107 & Ramsden 1991; p 27-42). This provides a category which we can more easily deal with.

In dealing with death, people feel a sense of loss of power, that is, the ability to influence what happens to oneself (Miller 1987; p 3). They feel out of control, which leads to feelings of hopelessness and is an aspect of learned helplessness. When these feelings are extreme, the individual "gives up" and can die. Perhaps it is something more like this that Becker really means (or should have meant) instead of a terror of death which is

repressed from childhood. Looking at the feelings associated with death in terms of powerlessness means that we can insert some control back into people's lives and therefore empower the person so that they retain their sense of self - they can remain an individual in the middle of all that is happening during the period of their dying. This will be further elaborated on in another chapter of this thesis. But now I will focus on the notion of *communitas* and how it can affect people during the process of dying. *Communitas* is a missing element in typical North American deathways: it is part of what sets the two cultural examples in this thesis apart.

Communitas

I am using as a basis for this discussion, Turner's (1969) formulation of *communitas*⁹. It is as though elements of spontaneous and normative¹⁰ *communitas* have been combined to result in something with loose rules -- more open and flexible patterns of behaviour, along with an openness, desire for honesty, and deep feeling, which characterize Turner's *communitas*. This intense, immediate feeling is what helps the healing to occur. People are together at an intense, sad time; emotions run high, people's lives are changed, sometimes drastically, and an intense, immediate feeling can arise. It is this which I believe helps those most affected by the death to realize what has happened in realistic terms. It also lets those people know that their family and friends are there for them. It is,

⁹ While *communitas*, as a concept in social science, has a long and complex history beginning at least with the work of Max Weber, I am restricting myself to Turner's use of the concept as the one most salient to this discussion.

¹⁰ Spontaneous *communitas* is, in simple terms, defined by Turner as "direct, immediate and total confrontation of human identities", it is deep and "magical". Normative *communitas* describes a "subculture or subgroup which attempts to foster and maintain relationships of spontaneous *communitas* on a more or less continuous basis" (1969, p 45).

as Turner says, "being" along with the "doing" of specific tasks which are undertaken; the practical things like feeding people, washing, dressing, looking after the rest of the family, etc.

In The Ritual Process (1969), Turner discusses the details of what he calls *communitas*. Society is defined by Turner as a system of social positions with units of social structure which include relationships between statuses, roles, and offices (1969, p 131). *Communitas* occurs beyond social structure which Turner defines as

"a more or less distinctive arrangement (of which there may be more than one type) of specialized and mutually dependent institutions and the institutional organizations of positions and/or of actors which they imply, all involved in the natural course of events, as groups of human beings, with given needs and capacities, have interacted with each other (in various types or modes of interactions) and sought to cope with their environment (Turner 1969; p 125-6).

So, *communitas* is outside of the social structure as defined, it is "sacred", "holy", "out of the ordinary", because it "transgresses or dissolves the norms that govern structured and institutionalized relationships and is accompanied by experiences of unexpected potency. The process of "levelling" and "stripping"...often appear to flood their subjects with affect" (Turner 1969; p 128). *Communitas* is a "relationship between concrete, historical, idiosyncratic individuals" (Turner 1969; p 131). These individuals are not segmentalized into roles and statuses but confront one another in the manner of Martin Buber's "I" and "Thou", the essences of the people involved. *Communitas* is the direct, immediate, and total confrontation of human identities. It is often speculative and generates imagery and philosophical ideas, and is an essential relationship as in "I and Thou" or "We".

Spontaneous *communitas* appears to flourish best in situations where there is liminality, phases betwixt and between states where social-structural role-playing is

dominant and especially between status equals. Social life can be seen as a series of processes in which the character of one type of process--*communitas*--differs deeply from all of the other processes. Spontaneous *communitas* is something "magical", it carries with it a feeling of power. For my purposes, I will alter this feeling of power or of the magical to be "transcendental" or "spiritual" which have a similar otherworldliness associated with them, but are more suited to this discussion. *Communitas*, in a practical sense when being discussed in conjunction with death in our society, remains something which occurs outside of or beyond the "normal" social structure. When a person is "dying" or caring for a loved one who is dying, regular social obligations and responsibilities do not apply. Usual deadlines are relaxed, work is not attended to in the usual fashion, someone is typically called in to assist with household tasks and child caring responsibilities, and behaviours are forgiven or excused which would usually not be tolerated in our culture.

There is, around death a sense of more and more intense feeling and emotion. At no other time is such an amount of crying called normal, and at no other time are people expected to cry, hug as much, and talk about the one person and their relationship with him or her. Even in an expected death, the actual occurrence is somewhat of a surprise, the feeling is still incredibly intense, and the touching and crying are again markers of the intensity of the emotions. Death is a time of monumental change, for the dying person it, we suppose, means a complete change in all that she has been aware of in living. For the living, a loved person is no longer there. The fact itself takes time to get used to and so does the intense sad and lonely feeling take time to adjust to. During this period of adjustment, a person is in a state apart from the normal structure of society. Different from the examples of spontaneous *communitas* cited by Turner, death involves sad feelings and

loss. That is why I refer to "transcendental" rather than magical to describe the occurrence of *communitas*. I am referring to spontaneous *communitas* because the people experiencing this typically want to "get back to normal", to experience the familiar rules and regulations regarding behaviour (social structure) as the time and the intensity of the feelings and emotions have created such a drain, and "numb" feeling. The aspect of *communitas* I wish to emphasize is that of "not being part of the normal social structure", it is a setting aside, temporarily, of normal relations and behaviour. There is a strengthening of bonds between family members and friends.

The feelings shared between palliative care workers and patients is often due to a special bond (Cassell, address at VON conference in Sept. 1991; Turner's discussions of *communitas*, and personal communication with other palliative care nurses). My suggestion is that when a person is dying, they are in what van Gennep would refer to as a liminal stage. In a liminal stage¹¹, *communitas*¹², as formulated by Turner, quite often occurs. There is an immediacy, and if permitted, an openness and sharing which does not always happen when providing health care to people who are expected to recover. There is normally no place in modern biomedicine for death as an expected outcome; the cure or at least maintenance of life is the goal. The exceptional openness which happens in

¹¹This is considered to be the time in between one state of being or status, and another.

¹²According to Turner (1979) there are three "types" of *communitas*; the first two having been previously discussed are: spontaneous *communitas* which is "direct, immediate and total confrontation of human identities" it is deep, "magical", carries with it a feeling of endless power, a direct relation to another person free from such cultural constructs as reputation, race, gender, caste, etc. Ideological *communitas* is "a set of theoretical concepts which attempt to describe the interactions of spontaneous *communitas*." This can lead to the formulation of utopian models of living. The third is normative *communitas* which is a "perduring social system", a subculture or subgroup which attempts to foster and maintain relationships of spontaneous *communitas* on a more or less continuous basis (Turner, p 45-6).

palliative care situations may be due to the fact that the patient and family/significant others are treated as one unit, all contributing and discussing (rather than the nurse directing care, with the patient obediently following orders), this allows for the possibility of *communitas*. Cure-oriented biomedicine is the characteristic form of care when a person is in the hospital for whatever reason. This is discussed by Glaser and Strauss in both of their books, A Time For Dying (1968) and An Awareness of Dying (1965). The maintenance of control is very important for the patient, especially when the disease, and some side effects, are thought to be completely out of the patient's control. Empowering the patient is one of the components of hope which is essential for the patient not to despair. This is one of the issues that is well dealt with by providing palliative care in the home. In my own experience with a visiting nurse programme, people are typically encouraged to maintain independence, and families are taught to provide care which the patient can no longer provide for themselves. This is elaborated upon in chapter three.

The notion of *communitas* as something which helps bind people together at the major events of life is one which I found useful. At such major events which can also be periods of "passage", there is the opportunity to knit tightly together the people involved. Following van Gennep's initial formulation of the "Rites of Passage" many authors have pointed out the closeness of age groups and others who have gone through certain passages together such as puberty rites, weddings, births, deaths, and the more recent phenomenon of entire communities going through therapy in order to deal with disasters or violent crimes, as seen in the news media.

Conclusions

North Americans' feelings relating to death seem to be, on the whole, characterized by

fear and denial. These feelings have been exacerbated by the pattern of people dying in nursing homes and hospitals, away from their families, in increasing numbers. The result of this pattern is that dying has become an isolating experience, very different from certain past times as described by Aries, when the dying person was surrounded by family and friends. There is little opportunity for a sense of *communitas* to develop between those who are dying and those who are close to them,¹³ especially when those who are dying are in hospitals and nursing homes with the typical restrictions on times and numbers of visitors. This sense of isolation is encouraged by the direction that medicine has taken, namely biomedicine. While we have been provided with a great many "breakthroughs" in biomedicine, we have ignored the body's own healing mechanisms. We have not paid any attention to the lessons of people like the Indian Yogis who can alter their blood pressure, temperature, heart rate, level of consciousness, and influence other bodily systems. We are beginning to see this more in the field of psychoneuroimmunology (See for example, Norman Cousins' book HEAD FIRST: The Biology of Hope). This developing area of medicine, is however, not receiving much applause from many in the health care field, perhaps this is because of it's newness, or simply because it uses the power of the mind instead of the Doctor simply making the sick part better (see also chapters 3-5).

Although people generally realize, at least intellectually, that death will occur, they think of it as a distant happening, something that few of them have seen, or been a part of; for instance having someone in the immediate family die. Most people die at the hospital or nursing home; anywhere but home, it seems. This has lead people to say that

¹³This is meant to demonstrate the case generally, there most certainly are exceptions.

we, as a society, have medicalized death, made death de-personalized to the point of alienation, and have funerary rites, that make death more distant to us, and unknown and therefore frightening.

One alternative in our society is hospice or palliative care. Palliative care is used in dealing with patients who know they are dying (they have an incurable or chronic disease). Opposed to the curative orientation, palliative care aims to assist the whole person, including significant others, to maintain their optimal level of well-being. And *communitas* is an experience which may be useful in dealing with the intensity of feelings associated with the process of death, it can by virtue of intense sharing of feelings, at least make the experience more bearable. The optimum level of well-being for someone who is dying often includes physical deterioration, and results in the death of the person. The idea is that a person can maintain their personal dignity, and feel like a person while in the "dying process".

I will return to elaborate on this theme in chapter three, but first I will present a discussion of the Mayan Indians of Quintana Roo. Their way of dealing with death is different from the typical North American way, but is somewhat akin to the ideals of palliative care in that death is treated as a natural part of life and the people do not therefore experience the kind of fear of death typical of the rest of North American culture.

CHAPTER TWO

THE MAYANS

In this chapter I will give a brief overview of Mayan geography and history in order to provide a location in time and space. I will proceed with a description of present day Mayans and outline an example of a local healing which parallels the expressions of grief and feelings about death in the culture.

Geography and History

The Yucatan Peninsula is at the most southeast part of Mexico, it juts east and then turns north. In the peninsula there are three states; Yucatan, in the north tip of the peninsula; Campeche, on the Gulf of Mexico coast; and Quintana Roo, on the Caribbean side of the peninsula. The largest city is Merida, the capital of Yucatan state. The generally accepted history of the Mayans is, briefly, that the Olmecs were the originators of the present culture (Sharer 1983; p 44-60, Gallenkamp 1987; p 1-20, and Coe 1972; p 46-57) . The Archaic period is dated ca. 6000-2000 B.C., in which permanent village life became standard (Sharer 1983, p 44). The Mayans flourished in the areas presently known as Belize, Guatamala, and highland southern Mexico during the Early and mid-Classic periods, with the height of Yucatec development occurring during the Late Classic period, 600-900 A.D. The Spanish arrived in the Yucatan peninsula in the sixteenth century and began their conquest.

The Spanish missionary de Landa was so appalled with the sacrifices and pagan activities he heard of and saw that he began a "purge". He eventually held an "inquisition"

to root out the "pagan" priests and others upholding the traditional ways; he burned any Mayan books he could find, and generally made the process of conversion to the Roman Catholic religion very painful for the Mayans. Since some of the religious symbols of the Mayans were similar to those of the invaders, the native expressions of religion were maintained to a certain degree. The Mayans continued to practice their own religion while allowing the invaders to believe that they had adopted Roman Catholicism. The cross is one example of this. The Mayan cross symbolizes the *ceiba* tree which is the tree of life, the Roman Catholic cross was therefore a familiar symbol. The cross itself, as an ancient Mayan religious symbol became the central and rallying figure in the War of the Castes (1847).

The Mayans were not completely subdued by conquest, and when their Spanish (Yucatan residents) "masters" armed them to aid in the fight for independence from Mexico in the nineteenth century, the Mayans rose up against the Spanish. This was known as the Caste War of 1847. The Mayans had driven the Spanish out of most of the peninsula, with much help from the British via Belize, and were on the verge of victory just outside of Merida when they disappeared from the battle ground. The winged ant had appeared which was the signal to begin the planting of corn. The old beliefs were still so strong that the signal was obeyed and all the military gains were lost. Many Mayans subsequently retreated into what is now the state of Quintana Roo, where they were left pretty much alone for many years. In these jungles the cult of the Talking Cross was begun. In a small town near the western Caribbean coast the Cross "talked" to the soldiers who continued to fight for Mayan independence. Quintana Roo was then made a territory, but was not permitted to become a Mexican state until 1974.

Present Day Mayans

It is for the historical reasons sketched above that the Mayans of Quintana Roo claim that they are the real Mayans, compared to those who remained in thrall to the Spanish in the states of Yucatan and Campeche (personal communication with consultants). They are the ones who maintained their Mayan beliefs by resisting the Spanish and maintain their ways in the land not run by the Spanish. Many of these Mayans continue to view the ruins as sacred places. Sacrifices, of chickens or of special personal items, can still be seen at some of the ruins, but one popular view is that many sacred places have been moved to where there are no tourists, or at least not hordes of them as in Tulum, Chichen Itza, and Uxmal. The ruins are also places where the native¹⁴ people can make a lot of money from the tourists. The native people are of two minds about these money laden tourists. On one hand the tourists do have money, which when traded for goods could provide luxuries which would otherwise be almost impossible to attain, on the other hand, they are crass, disrespectful of the "ruin" as a sacred place, not generous enough, and generally quite loud and rude.

Fieldwork

We camped at Chemuyil, which is a picturesque bay and camping area near Tulum Pueblo (the town). It was in Tulum that I met Carlos¹⁵ who guided me through the Mayan church, a festival of the local patron saint, took John and me on a day of spearfishing, snorkeling, and sightseeing, and repeatedly took us to visit with his family. Carlos and his

¹⁴Native refers to the people native to the area, and is in no way meant to be derogatory.

¹⁵Names of informants have been changed to protect their privacy.

family helped me to understand what they told me about death, grief, and the feelings related to these topics. Ricardo, another consultant who spent time helping me to understand Mayan deathways, is from near Carillo Puerto, the new name for the village where the "talking cross" cult began. Ricardo was working at a local resort, but goes home often to see his family. His family speak Mayan at home, but Ricardo has learned Spanish well (at school), and speaks English fairly well. Ricardo's mother, in keeping with the custom of many rural Mayan women, does not even speak Spanish.

There are currently many expressions of the religious in Quintana Roo. The Roman Catholic church (as a result of the Spanish invaders) certainly continues to be in evidence, but many varieties of Protestant churches have widened the competition for members. In a village of no more than two hundred, at least ten churches will often be evident, including the ornate Roman Catholic church (one of which seems to be in every village) and the Mayan church. It is the Mayan church and the holism of their beliefs that I wish to develop as the context for traditional Mayan views of death.

The Mayan¹⁶ church and the beliefs of the people who consider themselves members form part of the context. The church serves as a community centre and the feasts and celebrations are held there. The Mayan church in Tulum consists of two rooms, a large outer room and a smaller inner room. The large room is where people dance, eat and generally congregate. Shoes are removed just inside the main door. The smaller room contains the religious symbols. There is a chest-high table about four feet long and one

¹⁶The Mayan Church seems to be the result of the cult of the talking cross, and the "old religion" mixed together. The Mayan church is not, I was told by all of my consultants, Roman Catholic, it is Mayan in its beliefs and symbols. See also Faust 1988, page 364.

foot wide a few steps into the room centred side to side. On this table are candles: upon entering the room you light your candle from an already lit one then extinguish the previously lit one by snuffing it out on the underside of the table; it is not blown out. When asked, neither Carlos nor the grandfathers knew why. They told me "that is the way it is done".¹⁷ To the left is a table with wooden bowls, there are drums hanging on the wall and sacks, also on the wall, containing violins. On the wall to the right are huge pots; these are for preparing food for the festivals. The other side of the table is the "altar" upon which sit the "santos". The santos are crosses which are dressed in traditional Mayan garb, some of which is very old. The embroidery work is incredibly detailed and beautiful. This work is repaired by village women when necessary. There are dried vines, herbs, and plants spread out on the altar surrounding the santos. On the right side of the altar there is a large chair covered in herb garlands. We knelt for three minutes at the altar and made the sign of the cross many times. When it was time to depart Carlos motioned me to follow his actions, we backed out of the door so as not to anger the santos by turning our backs on them. Carlos rehearsed my thank-you for the grandfather who had given permission for me to visit the church. The grandfathers are a sort of honour guard for the santos, a duty maintained from the early days of the cult of the Talking Cross. In the church I was aware of the interlinking of the symbols of nature (the herbs), spirituality (the santos), practical reality (the items used to prepare food), combined in such a way as to emphasize the holistic nature of Mayan thinking.

Beyond these external religious expressions, I learned that the Mayans have a different

¹⁷For report of similar experiences see Faust 1988, pages 350 and 362.

basis or beginning point for the way that they see the world than do we (North Americans). The world view of the present-day Mayans is for the most part quite similar to that of the ancient Mayans (Sharer 1983). There is no separation between the supernatural and natural realms.

"All things, animate or inanimate, were imbued with an unseen power. This invisible power was amorphous in the case of the "spirits" inhabiting rocks, trees, or other objects (animism). In other cases this power was embodied in a "deity" in animal like (zoomorphic) or humanlike (anthropomorphic) form. This fusion of the observable and unobservable is best expressed by the Maya concept of *cuxolalob*, the knowledge of that which is both rational and supernatural." (Sharer 1983, p. 459).

The world is seen to be ordered in its usual state, made so by the "sky wanderers", the stars, moon, sun, and planets, who marked the passage of time. Similar to *cuxolalob*, is the notion of holism. I am using this Western term because I do not know an appropriate Mayan one and because holism particularly fits the idea of the unity of mind/body/spirit. This holism is the basis for medicine and for the beliefs surrounding death.

An Example of Holism from Mayan Medicine.¹⁸

In a doctoral thesis based on fieldwork in a small town near the border of Quintana Roo in Campeche (1988), Faust reports the healing of a young girl. The mother had as part of the local tradition taken the girl to the clinic doctor for healing, which had failed. The patient was 11 years old and was having "attacks" which "were episodes of headache with convulsive movements sometimes ending in temporary loss of consciousness" (Faust

¹⁸Examples of fieldwork among the Mayans in the Yucatan are not common. The ones I located did not deal with the subject of death, the following example of healing was the best which I could find to elaborate what I found. But, see I, Rigoberta Menchu for a Native Voice ethnography of the Guatemala Highland Mayans, and Life Under the Tropical Canopy, by E. Kintz, for a political-cultural discussion of Yucatec Mayans.

1988; p 340). The girl's mother then tried some of her own remedies (garnered from her past, her family, and friends and neighbours) which included using alcohol massages, herbal teas, rest and protection from stressful situations. These too proved ineffectual. The girl was then taken to the traditional healer, the *h-men*, who later came to the family's dwelling in order to perform the healing (the *h-men* is a kind of shaman, he is a healer, herb-collector, and at times performs religious ceremonies). Faust reports an increase in the stress in the lives of the women (1988; p 340) which is manifested through hysteria, chronic rashes, and other psychosomatic illnesses; this was reported by the *h-men* and many elderly villagers. The *h-men* deals with these complaints by treating as many in the extended family as possible in a "collective ritual mediated by the symbolism of Maya cosmology" (Faust 1988; p 340). Faust reports that the "curing ceremony, through its use of Maya symbols, accessed and changed both the girl's unconscious symbolic system and that of her extended family, adapting these systems to the surrounding socio-cultural context" (1988; p 342). The *h-men* did this without being verbally explicit regarding the dysfunctional aspects of the family functioning, and without being confrontive. In so doing he was able to alter thoughts and thought patterns which would in turn alter behaviour. The family counselling occurs before and after the specific ceremony or ritual. This counselling includes much information gathering and prescriptions for behaviour change. The gathering of the information is done in a non-threatening way. The *h-men* asks various family members about the family history, the division of the family land, the reasons that family members had for moving away, and about their thoughts on the girl's illness. After collecting all of this information the *h-men* was ready to suggest the behaviour changes which would make family relationships easier on the people involved. In this instance he

suggested a reduction in drinking for the girl's father, along with other recommendations for other family members including the girl herself.

The ceremony itself was carried out in the communal yard of the family. All of the supplies had been gathered previously. In this specific ceremony

"the symbols...emphasize the interdependency of male and female in the flow of generations of human society, within the context of a universe of interdependent dualities: the Upper World and the Lower World, day and night, the dry and wet seasons, east and west, *birth* and *death*, masculinity and femininity. They "place" the individual patient and her family in a conceptual context in which interdependency is constrained by larger systems and incorporated in the natural cycles of a gendered universe" (Faust 1988; p 340, emphasis mine).

The important thing in terms of this example is that the whole healing process was holistic. It included everyone in the family, and took into account what they could realistically do to help the girl. She was reportedly healed, and the family relations were harmonious. This kind of healing "is an integrated, holistic, therapeutic practice. [It is derived from] a long, anonymous tradition of curing based on experience and on a holistic view of the world and the place of human beings--male and female--as pairs in that world" (Faust 1988; p 382). It also includes the notion that life and death are an integral and necessary pair in the Mayan world view. The healing ceremony would have to be repeated twice more before thirteen years passed. This I believe ensures the continued altered thought patterns and behaviours because it is on everyone's mind--a way of reminding them of the changes that will help to maintain the girl's cure. This also keeps strong the individual's sense of belonging; to the family, and to the larger Mayan community, via the use or awareness of the Mayan symbols. "Traditional curing associated with developmental life crises may be seen as a rite of passage for those who encounter

problems with the transition" (Faust 1988; p 383).

It is the problem with the transition of death which seems to be difficult to deal with for North Americans. It is a passage which evokes the strongest of emotions and feelings and is thus a passage which incurs many difficulties for all concerned. In Mayan healing ceremonies, cycles and pairs are concentrated on. The way in which death is accepted as a part of the natural cycle is something which is valuable to the holism of Mayan curing and thought. As we will see, this kind of holism is what is desired by practitioners of palliative care.¹⁹

The above example of a healing ceremony displays the interdependencies of members of a family, and of the symbolism in Mayan life. This is what happens at the time of death. The Mayan symbols are called upon to help restore balance to the survivor's lives. Death is seen as a part of the life/death duality which is an integral aspect of the Mayan world view. Death does not remove a person from the family. The dead are included in ritual and in everyday life, the ancestors were involved in this particular healing through their remains (a lock of hair or an object which belonged to the dead person) (Faust 1988; p 367). These items are typically kept at the family altar or sacred place. The dead are also remembered at specific time intervals following death and every year on All Soul's Day²⁰.

The feeling that I am left with is that the Mayans tend to have what I call a naturalistic (as defined earlier) way of looking at life including major events and mundane

¹⁹I would expect that periods of *communitas* occur among Mayans at the liminal stage of death, but did not personally attend a wake or death.

²⁰For a similar celebration see Badone's (1989; p 164) report of *Toussant* in Brittany.

day-to-day existence. This is not to say that they are in any way "simple", or unsophisticated, or unable to be incredibly subtle. It means that they tend to "take things as they come", they tend to work with nature instead of attempting to overcome it, they tend not to make a great deal of control - that is, they don't feel our need to be in charge of everything possible. They are more easy going and Taoist²¹ in the way they interact with their world. It is a kind of acceptance, without the feeling of "giving up" or "fatalism" which we usually attach to the word acceptance. The environment is not something to be tamed or taken over, it is something you learn the natural rhythms of and work with. This does not seem to result in feelings of powerlessness as it does in Westerners, but encourages a sense of cooperation and connection with the environment.

The people with whom I spoke reported that people are free to express their grief in whatever way is appropriate to them. Family and friends are there for support, but individuals are not told to stop crying, or to cry more loudly, etc. In some of the traditional villages, especially in the homes of older (or very poor) people, the dead person is buried under the house, which may or may not be abandoned later because of the presence of the ghost. It may be the "soul" before it goes to heaven that people are afraid of, or it may represent a soul that cannot get to heaven. Most people, though, are buried in the local cemetery. Carlos and Ricardo both told me that the soul goes to heaven (if the person has led a "good", tranquil life), even though they maintained that there is a unity in thinking of the person, mind/body/spirit, as a whole. I did not get to the bottom of the philosophy of this question, which would be an excellent topic for further research.

²¹I refer here to a sense of Taoism in which people act according to their nature, ie. having their nature work in conjunction with the rest of nature (see Chuang-tzu 1981).

When someone dies, the body is washed in a traditional Mayan tub, and laid out, preferably in traditional clothing. Family and friends look a lot at the face of the person so that how they look will remain imprinted on the memory. A wake continues all night and involves a lot of eating and drinking, and gambling for the men. Sweets and breads are primarily for the women, and there is chocolate for everyone. The amounts of these items depend on the person's wealth. The body is buried within three days. In three days the soul goes to heaven. At intervals of one week, three weeks, seven weeks, and every November 1, a meal is eaten in memory of the dead. November 1 is All Soul's Day, or Day of the Dead. It is an important day for all Mayans; they prepare a meal and go to the cemetery to eat and celebrate²², and to remember their dead. This is very similar to Badone's discussion of *Toussant* in Brittany (Badone 1989).

Although a show of emotion is not consciously encouraged or discouraged, cultural expectations or ideals are that each person hopes to "get the feeling out" so that he is tranquil in his heart. Being tranquil also helps to prevent "problems in the head" from occurring which would necessitate a visit to the "psychology doctor". It is important to maintain a sense of tranquillity. This is a daily thing, not just reserved for special occurrences. After three days the soul goes to heaven (I was unable to clarify how much of this is Roman Catholic teaching, as the ancient Mayans had an elaborate scheme of rings or layers of heaven and an underworld). Suicide is considered to be a negative thing, the soul of a suicide victim does not go to heaven in modern day beliefs, but in Landa's time suicides by hanging went directly to heaven along with warriors killed in battle and women

²²The celebration is the meal, companionship and remembering the dead.

who died in childbirth (Landa 1978; p 58).

The notions described above are somewhat different than what Bishop de Landa described shortly after conquest. He writes that the Mayans have an almost unreasonable fear (terror) of death:

"[T]his they showed in that in all their services the rendered to their gods were for no other end than that they should give them health and life and their subsistence. But when it came time to die, it was a thing to see what were the grief and lamentations they displayed for their deceased, and the sadness they felt...it was the devil that had taken them off, because they thought all ills came from him, especially death (de Landa, p 56-57).

This belief was again reported by Gallenkamp in 1987, using Landa as a source. Judging by what people told me, and the rich belief in a peaceful afterlife for most people, my suspicion is that Landa did not have the whole story. I would suspect that the fears may proceed along the lines of the following scenario: the "soul" may remain for a period of days in the village or home thereby posing a possible threat to the family and other mourners. The "lost" soul causes fear and requires wailing and lamentation to aid it in it's travel to heaven. These notions are similar to those of the Eastern Cree as described by S. Preston and R. Preston (1991; p 135-156).

Conclusions

The contemporary Mayans seem to have a holistic way of looking at medicine and this carries over into the way that they deal with death. The present day Mayans of the Yucatan peninsula have a rich culture which ought to be further explored. There are many areas of study available; ethnobotany, native medicine, deathways, connections with the ancient Maya culture, language, coping with the changes brought on by tourism, the entry of Mexico into trading agreements with the rest of North America, and the status of being

"Indian" in class conscious Mexico. The evidence I use for calling the medical system holistic is the example from Faust. I have expanded this to include deathways based on discussions with people about death and their feelings about it. Contrary to what some people had warned me about, people were not at all hesitant to talk about death. It is not a taboo subject, nor is it one which people are so afraid of that they will not mention the subject. On the contrary, people were interested in knowing why I thought the topic was interesting, and what I thought I might do with the information.

CHAPTER THREE

PALLIATIVE CARE

An Historical Perspective of Hospice/Palliative Care.

Palliative Care is a relatively new area in modern health care. It is also called hospice care. Both of these terms refer to a philosophy or an approach as opposed to a discipline or specialty area (Brockopp 1967; p 18-23). The modern hospice movement began in the 1960's when Cicely Saunders founded St. Christopher's Hospice in London. She had been a nurse who became a social worker and then a medical doctor. She furthered her education in order to be able to deal with more aspects associated with caring for the dying (Abel 1986; p 71-85 & Lev 1986; p 241-243). The hospice movement spread throughout England and North America during the 1970's and 1980's so that at present there are a number of ways of providing hospice/palliative care. There are self-contained inpatient facilities, hospital-based free-standing units (a separate building only for palliative care), programs in general hospitals, home-care programs sponsored by insurance companies or governments, and autonomous community-based organizations.

The philosophy of palliative care involves the skilled and at least adequate control of physical and emotional distress; social support and bereavement counselling, and recognition of the spiritual needs of the patients and their families (Doyle 1986; p 5-7). Following through with this approach involves such things as supporting the patient regarding his/her beliefs and wishes, for example praying with a patient even though you do not believe in the prayer, or even believe in God in the same way in which the patient

does. It also involves being able to effectively deal with symptom control, primarily to allow the patient to be alert and as pain-free as possible while living until the end of her life. Palliative care, then deals with the mind/body/spirit systems of the person, the family and/or significant others, as a whole, and grief and bereavement. It is in this sense, holistic.

The Palliative Care Team with which I work was formed in 1982 after a year of deliberations and studies. In October of 1991, an average of 350 visits were made weekly to patients who range in age from young children to people in their nineties. There are twelve full- and permanent part- time nurses, and six relief nurses. The former are responsible for regular visits to patients in seven geographical areas in the region, and the relief nurses fill in when the district nurse is ill, on days off, overloaded, or on holidays. The functions of the team include "the provision of personal care to terminally ill [patients], assessment and treatment of pain and other symptoms, assessment of coping skills of the patient and family and the referral to other community services, emotional support and counselling to patients, families, and significant others, assessment for bereavement risks and referral to appropriate services for bereavement follow up in the case of the high risk bereaver²³" (personal communication with the supervisor of the Palliative Care Team).

The selection for Palliative Care Nurses is somewhat different than for other specialties in nursing. The original proposals for nurse selection where I work included specific questions and criteria. Nurses "should not have experienced significant losses for the year prior, (ie. separation, divorce or death), but they should have experienced death in the past so that the meaning of life and death has become integrated as part of their

²³This is someone who grieves intensely, and/or for an extended period of time, the grief does not diminish.

values and personality" (personal communication with [the same] supervisor of Palliative Care Team). The nurse should also have in place a stable set of spiritual beliefs in order to help in dealing with death and loss on an ongoing basis. One other necessary thing is an adequate system of support and various outlets for feelings. The supervisor interviewing nurses for the Palliative Care Team has a list of items which were determined by the founding supervisor (of the Palliative Care Team) to be important, these include asking questions about the following: 1) reasons for applying to the team, 2) what rewards, satisfactions do you expect, 3) expected stressors, 4) personal strengths, 5) areas of weakness or limitations, 6) experiences of past loss and death, 7) outside supports, 8) how losses and stress are dealt with, 9) predilection to become overinvolved with patients or families, 10) can this be recognized and dealt with, 11) do you tend to make decisions for the patient, 12) can you let the patient be responsible for decisions, outcomes, 13) do you struggle with trying to "be all things to all people"?, and 14) how was/is this dealt with? Any questions or concerns about the team are discussed (personal communication with the supervisor of the Palliative Care Team). The nurses go through an orientation program which for the first two years was taught by the original supervisor for the team, and now is taught by various team members. The inservices²⁴ include such topics as pain and symptom control, dealing with loss and grief for the patient, family, and the nurse, and bereavement. Team meetings were originally held weekly, but presently are held monthly. Team business is discussed as well as new products and case presentations, especially

²⁴An inservice is a teaching period which is held for the staff most usually on the work premises, and is typically considered to be a part of the work routine so that staff members are paid for their attendance time.

about complex or difficult patients. The team meeting is also used to provide support for each other. The nurses attempt to meet informally during the day, for lunch or coffee break.

The role of the palliative care visiting nurse is a complex one. The nurse can explain the treatments that the patient may experience. The nurse may be required to provide personal care, nutritional counselling, suggestions to the patient and family members about how to do various things (medical treatments, providing comfort, etc.) for the patient, emotional support, guidance on how things may proceed, and whatever else is needed to ensure that the patient is maintained at the optimum level of comfort possible. This care includes discussing what to do when it looks as if the person is no longer breathing²⁵. The family must decide when to institute, if necessary, an order from the doctor not to attempt to resuscitate the patient. Other services, such as homemaking or social work, must be introduced to the home as the patient and the family require and will permit. It is of utmost importance to remember that any health care professional is a visitor in the home, and the patient and the family have the right to any information pertaining to the patient and her care.

The following examples are some indication of what palliative care is in reality. They are meant to provide insight into that reality for the reader, all are experiences which I have had as a palliative care nurse.

²⁵The family doctor is typically the person to be called, she will come to the home and fill out the required certificate of death, then the funeral home is notified, they deal with the person's body. The visiting nurse is often called first in order to help with or perform the other necessary calls, and to provide support.

Example Number One

Mrs. Ayer²⁶ has been looking after her husband for just over six months. She gives him regular dosages of his painkilling medication through a small needle which remains in place as long as possible (it usually needs to be changed every one to three weeks). Mrs. Ayer has someone to help during the night; they help Mr. Ayer with his personal care which allows Mrs. Ayer to sleep. She hasn't been out of the house for more than an hour at a time since her husband became ill. She feels that looking after her husband is the "normal" thing to do and it is an expression of her love for him. Mrs. Ayer has told me that she would not want him in the hospital as he might not get his medication on time (to control the pain, which has been severe and difficult to control in this case), he would probably get bedsores which would add to his general discomfort, and he would be in an atmosphere she considers not conducive to feeling the best that he can; and he would be surrounded by strangers. And, she would not be able to be with him any time of the day or night. Mr. Ayer is thankful that his wife feels this way. In this case it is very important for Mrs. Ayer to maintain control of the situation. She lets the nurse know how many needles to prepare until the next nursing visit. She asks for advice on how to do things with which she is unfamiliar, although there are not many personal care nursing practices with which she is unfamiliar. The nurses provide support and feedback to Mrs. Ayer during the visit. She feels free to call the office to request that a nurse make an extra, unscheduled visit, if there is a problem with the needles or if there is something of which she is unsure. Both Mr. and Mrs. Ayer are in control of Mr. Ayer's care. They report feeling that this is a very

²⁶These are real patients and families whom I have visited as a nurse. The names have been changed to ensure privacy and confidentiality.

special time which they are sharing.

Example Number Two

While working one day in mid-October, I received a phone call from my office asking if I could go to see a patient. The regular nurse was temporarily unavailable and I knew the patient. His wife had called the office in distress, but due to her heavy accent, and broken English, there was a problem with communication. I went to the house, in about half an hour from the wife's call. When I got there, Mrs Switzer said that Mr. Switzer was "maybe unconscious" like the other time when he was in a diabetic coma. I went to see him and knew, as soon as I looked at him down the hallway, that he had died. The doctor had been called by the homemaker who was in the kitchen with Mrs. Switzer. When Mrs. Switzer asked me if she should call the ambulance, I suggested waiting for the doctor, and the daughter, who had also been called. There was a "no code"²⁷ on Mr. Switzer so that calling the ambulance would have resulted in a resuscitation attempt, especially as Mr. Switzer had just passed away. The daughter arrived and I met her in the driveway and explained what I had found (no pulse, no breathing) and went inside with her. She immediately went into her father's room, and stayed a few minutes. When she returned, she told her mother that he had died. They went into the bedroom and talked. It had been decided by the family in the past month not to resuscitate, and that he would probably die

²⁷This refers to a written Doctor's order not to resuscitate a patient. This order is arrived at through discussion with the patient, and usually family. In the hospital when a patient stops breathing and has a "no code", the staff will call the doctor to pronounce the patient dead and he/she will notify the morgue. In the home there are some differences, most of the time when the patient stops breathing, the family call the nurse and the Doctor, and the same pattern as above is followed. But if anyone, for any reason calls 911, they will attempt to resuscitate even with a signed Doctor's order for "no code". This response is their mandate, there is a committee (in this region) working on changing this so that "no code" orders will be followed in patient's homes.

soon. They cried and talked alone and looked at Mr. Switzer. When they returned to the kitchen, the homemaker had begun to prepare coffee. This was supplemented by cookies and we all sat around the kitchen table to wait for the doctor to make the announcement "official". The regular nurse called and Mrs. Switzer requested that she come over, they had worked together for six months and had quite a strong bond. We all talked about Mr. Switzer and told our stories of our time with him. Mrs. Switzer told us how her husband had died the way he wanted to; at home, and in his sleep. There was a feeling of intimacy between us, and a feeling that time was temporarily suspended. This was momentarily interrupted when the doctor came. He made his official announcement, but seemed not to be completely at ease. It seemed to me that Mrs. Switzer needed to hear that her husband was dead from the "proper" source, but that she was disappointed in him for taking so long to arrive (two hours from the time of the first call to his office). The feeling of sharing included how the nurses had helped Mr. and Mrs. Switzer through the past six months. There was much hugging and holding of hands, these were expressions of closeness, I felt. When I was leaving, Mrs. Switzer hugged me again, cried a bit, and said thank you for providing nursing for her husband and that I was like a daughter to them because I cared so much. The evidence of this to her was my "special care" for Mr. Switzer by making sure he was shaved and clean and in fresh clothing when I visited. Mr. Switzer looked very peaceful when I saw him last. I thought to myself at the time, "perhaps the euphemisms we use to describe the dead are not all wrong". Mr. Switzer certainly looked like he was sleeping which is perhaps a part of our ideal of a good death, which includes peacefulness. This was an example of a "good" death, the kind which nurses hope for their patients.

Example Number Three

There are times when palliative care, for a variety of reasons is not carried through as the care givers would wish. I recall trying to phone my first patient one Saturday morning. Three times there was no answer. I really do not know why I did this, but I called his daughter when there was no answer (this is not an atypical occurrence). She said that her husband had just left to go to her father's apartment, and that she would meet me in the parking lot. We went up to the apartment together, she was crying a little, and the knot in my stomach would not go away. When she opened the apartment door, I saw her husband on the phone, he gestured me to the bedroom, and by hearing what he was saying, I knew that he had called an ambulance. The patient was obviously dead. Hearing the sirens in the street, I had to determine the daughter's wishes regarding resuscitation. She said she didn't want that. Then the ambulance attendants and police were there. Later, the detective arrived. It was a very stressful time. About two hours after I arrived the coroner came and made his pronouncement. I remained with the daughter and her husband till the people from the funeral home came and took the patient away. What I think was interesting was that through her crying, and distress, the daughter made coffee for everyone. I think this is interesting as it seems to be a ritual to prepare food²⁸, and share it, even though suffering intense feelings of grief and loss. It was an experience in which I felt a sense of intimacy with people I had never met, sharing experiences about someone I had not met. They told me about him, the course of the cancer, and how they thought it had progressed so fast. The thing that struck me was the intensity of emotion I

²⁸There is typically food at a wake as well. There is a room at most funeral homes where coffee and cookies are available, and there is often a gathering at a designated home after a funeral.

felt. Upon reflection, it may have had to do with the fact that she was only two years older than myself, and had just lost her father. I began to think of what it would be like to lose my father. The important thing here is the intimacy and immediacy of emotions which is another example of the experience of what I think can be called *communitas*. Although it turned out to be acceptable, this experience could have been more positive if the family had been involved more. In this case that would have been difficult, Mr. Richard's condition deteriorated rapidly, and he resisted the nurse's desire to involve the family. In a case like this the patient's wishes must be honoured even at the expense of feelings of exclusion of family members.

The above family situation would seem alien to the Mayas, where everyone in the family would know what was happening, even if the family functioning was not optimal. The Mayans would have the family gather around to be with the person who is ill.

Example Number Four

Another instance of the plans and attempts of the palliative care-givers failing was a patient whom we looked after a couple of years ago. Mrs. Britnal was in her early 70's when I met her. She was one of the few patients I had the feeling that I would rather not visit. This was not because of an unclean environment or violent/abusive behaviour, but because she was rather commanding and imperious in her attitude; this attitude was toward everyone, the nurses, her husband, her daughters, and her friend who came from "the old country" to help. It took a while for us (the nurses) to understand that she was quite fearful. She was a devoted Roman Catholic and had worked in various countries as a missionary, and might therefore be thought to have the traditional religious view that God will "take me when He decides", and "I'll be going to heaven to be with God". Her priest

spent a lot of time with her. He would read to her, talk with her, and she would report how much more secure she felt when he was there. Mrs. Britnal, was however, hard on the nurses. She would be extremely particular about how, where, and in what order to do the necessary procedures. Her manner was not polite most of the time, which when added to her brusque attitude led us to believe that she was very frightened. The strain on the nurse-patient relationship was exacerbated because open talk about her fear was not occurring. Generally, any pain or nausea she felt was controlled as quickly as possible. The nurses felt that it was unfortunate for Mrs. Britnal and her family that they were unable to work out what was happening to her. I do not mean that she ought to be serenely accepting, but that feelings and perhaps unresolved difficulties needed to be dealt with. Mrs. Britnal became quite animated when discussing things of interest to her other than to do with her illness. She was feeling what Judith Miller would identify as loss of control, and feelings of hopelessness (1989; p 3). These two factors seemed at odds with her religiousness, which perhaps let the problem escalate. It was not only Mrs. Britnal who felt hopeless, the nurses did as well because we felt we could do much more to help her feel some degree of contentment, but were not permitted to do so. These feelings led to frustration in the nurse which is one reason that it is imperative for palliative care personnel to have special training in the area, and a system of support to maintain equilibrium.

Considering the last example, we see that the possibility for unresolved feelings can easily become a reality, even when there is time to work out these difficulties if the person so chooses. Rabbi Kushner (presentation at Mohawk College November 11, 1991 in connection with Bereavement Week) reminds us that if someone needs denial or any other defense mechanism, then that should not be forcibly removed. One can be

supportive but it is not appropriate to force the person get on with their mourning, anticipatory or actual. These feelings are often exacerbated with the occurrence of a sudden, unexpected death.

Expected versus Unexpected Death

There is a difference between an expected death and an unexpected one in that the former allows for advance planning and a "tying up of loose ends", while the latter typically leaves the feeling of things unfinished and incomplete. With an unexpected death, good-byes are not properly said, arguments are often left unresolved, and other affairs are often in disarray. Rabbi Kushner (1981) suggests that in our culture we have a need to explain events which occur to people, even when the most viable option appears to be to blame the person (blaming the victim, Kushner 1981; p.39). With sudden death, the prominent feelings are usually strong disbelief and anger which ranges in intensity according to circumstance and the individual. An example of extreme anger is what is described by Rosaldo in writing about his wife's death.

The rage of grief as described by Rosaldo (1989) is something with which I am not personally familiar. I have seen and felt anger from those with incurable diseases, and sadness, hurt, and anger in those left behind, but not this kind of rage. It seems clear from what Rosaldo says that rage is what the Llongot are taught to associate with grief - I do not think that this is a cross-cultural constant. This leads me to suggest that the way we deal with death and grief is taught to us by our culture, which influences us greatly. As with all learned things, there is the possibility of change. Rosaldo says that ethnographies that "eliminate intense emotions not only distort their descriptions but also remove potentially key variables from their explanations" (1989; p 12). With an expected death, there is the

possibility that the intensity of emotion will be dissipated over the time of the progression of the illness. The intense emotions begin with diagnosis and are begun to be dealt with soon after, this process is called anticipatory grieving.

The "how could you abandon me?" or "why did you leave me" type questions discussed by Rosaldo (1989; p 9), although not confined to our culture, is by no means universal. Kushner (1981) suggests that "why" questions are not helpful as much as they are a cry of pain, he suggests rather that we ask questions such as "What can I do now?" The Mayans respond in a slightly different way. They begin with the idea that death is a part of life, it is a part of the cycle; death is an expected outcome, to ask why would not make sense. This is what some people in palliative care try to demonstrate. Death has become, for our society and our biomedical orientation to medicine, a failure, a negative end/outcome, a *wrong* thing; when in fact it is a natural occurrence. This does not mean life is hopeless, nor does it necessarily lead to nihilism; it does mean that life can be lived to the fullest and thoroughly enjoyed and rejoiced in by the survivors when it is over. This in no way negates the extreme sadness and agony of loss by those survivors.

Rosaldo talks of various rituals of bereavement; for example, Llongot headhunting, and Nyakyusa war dances. The ritual which I see North Americans performing is two-fold: the public ritual is the funeral home scene which involves many people, and provides a release for those not intimately but still involved. The more private ritual aspect involves, among other things, much talking about the deceased; recalling memories, food preferences, favourite sayings and typical gestures. Talking about the deceased person seems to allay some of the intensity of emotion. The corresponding occurrence in an unexpected or accidental death is to do something positive. The example which comes to

mind is the mother whose teenager was killed by a drunk driver originating the Mothers Against Drunk Driving organisation.

Investigators who "equate death with funerary ritual assume that rituals store encapsulated wisdom as if it were a microcosm of its encompassing cultural macrocosm" (Rosaldo 1989; p 15). Events around death happen out of the routine, or out of the normal social structures of the people involved. This is the place of spontaneous *communitas*. "Rituals serve as vehicles for processes that occur both before and after the period of their performance...Ritual and bereavement should not be collapsed into one another because they neither fully encapsulate nor fully explain one another" (Rosaldo 1989: 20).

"One theme is that the ethos of a society, the central cluster of values that directs its members how to live their lives, will also likely tell them how to die their death" (Counts and Counts 1991: 4). In this way guidelines are available for those who are dying and for those who are facing the death of others. O'Connor (1991; p 253-276) suggests that the strengths that we (North Americans) display in living, we will also show in dying. Preston and Preston (1991; p 135-156) report that among the Cree a person should meet death as they meet life - with equanimity, competence, reticence, and self-reliance. Wellenkamp (1991; p 113-134), who worked among the Toraja, reports a kind of resignation about death which is reminiscent of the Mayan way of thinking about death.

"The facts of life and death are neutral. We, by our responses give suffering either a positive or a negative meaning. Illnesses, accidents, human tragedies kill people. But they do not necessarily kill life or faith. If the death and suffering of someone we love makes us bitter, jealous, against all religion, and incapable of happiness, we turn the person who died into one of the "devils martyrs." If suffering and death in someone close to us brings us to explore the limits of our capacity for strength and love and

cheerfulness, if it leads us to discover sources of consolation we never knew before, then we make the person into a witness for the affirmation of life rather than its rejection." (Kushner 1981: 138).

There is a concept which seems to be widely spread which is that a death is "good" or "bad". "Those whose dying takes them through the full transition from life to death - have a good death" (Counts and Counts 1990: 6). When someone dies at an unexpected time or place their life is thought to be incomplete; there is a rupture. This is a "bad" death.

Counts and Counts define grief as the internally felt emotions, and mourning as the outward expression of these emotions. Most cultures tolerate a wide range of responses to death; some are extremely ritualized like the Balinese people of the South Pacific as described by Geertz, and there are some cultures where much more impulsive behaviours are the norm. Each society "must respond to, control, channel or transform the emotional storm that death unleashes" (Ibid: 17).

In our own culture a number of people have suggested that maintaining a sense of self-worth and of being able to in some way affect one's own future is important to the way in which people respond to death. I will turn now to a discussion of hope and control as concerns the maintaining of dignity with death.

CHAPTER FOUR

HOPE AND CONTROL: Hope, Communitas and Palliative Care Relating to a Holistic Perspective

This discussion is one that emerges from a central issue in health care. The issue is one of control. Who has it, how to maintain it, and what it means. Typically control is held by the health care professional. This is typified by not sharing information, scheduling tests and appointments without checking with the patient that the time is acceptable, a patronizing manner, a "do what I tell you" approach, and much more. It is difficult but not impossible for a patient to maintain control, I will deal with this possibility in the present section. Having control means, in a health care situation, being in charge of what is happening. Nurses feel that this is important when working in a hospital ward. The worst example of this is the "Big Nurse"²⁹ in One Flew Over The Cuckoo's Nest. In a more moderate situation this is not a completely undesirable thing. There are certain schedules which dealing with a large number of people requires. For example, when there are thirty-five or forty people to serve lunch to, and three people to do so, special requests for re-heating and special placement of items are not always feasible, although most nurses wish they had the time to do these little things for patients. The meaning of control is very different for the patient. When control is maintained, compliance with treatment is greater and the patient is usually more content, leading to a generalized feeling of well-being.

²⁹She would punish patients by taking away privileges if she were disobeyed. The movie is set in a state hospital for the mentally ill. It was made in the 1970's.

When control is removed from the patient, a sense of loss can be felt which often is followed by lethargy, giving in, depression, and giving up. When this happens for an extended period, death can ensue.

Hope is discussed by Eric Cassell along with suffering. "Physicians' failure to understand the nature of suffering can result in medical intervention that (though technically adequate) not only fails to relieve suffering but becomes a source of suffering itself" (Cassell 1982: 639). The alleviating of suffering includes the promoting of hope. Cassell distinguishes between types of hope. One kind of hope is what he call "hangman's hope", there are no alternatives; either the thing will happen or you will be saved just in the nick of time. The other kind of hope involves a "little bit of luck". There are alternatives and degrees. Hopelessness means, for Cassell, despair and loss of all purpose. When someone experiences hopelessness he has lost his central purpose, which is to *be* and to *realize* ourselves. Cassell elaborated this point by saying that this means having a reason for being, a feeling that life is not purposeless nor useless. When the focus is on specific body parts or functioning there can only be adequate care. But when the whole person is not the focus of care then the sick person as a person is not looked at. It is the psychological and spiritual aspects of the person which usually are neglected in providing care, and it is these aspects which can provide the maintenance of hope. When competent care is delivered and symptoms are controlled, then the person can use her energy to restore purpose. For this to happen Cassell says that there must be an "intense connection" between the patient and the care giver. This is not talked about in the literature except to be romanticized, but it is a common therapeutic, rewarding experience. It sometimes is ignored because of embarrassment or discomfort, but if fostered can lead to a special kind

of bonding. This bonding can lead to an openness and "soul to soul" sharing which is very similar to what Turner calls *communitas*. Although Turner does not use health care examples, they fit well into his notions of *communitas*. Cassell reports that this kind of feeling doesn't have professional sanction, perhaps because it is not "objective" nor "scientific". This intimacy, which I am calling *communitas*, is a special sharing, it is one reason which the nurses I work with give for continuing to work in palliative care, and why they feel so rewarded in their work.

These notions resonate with the example cited earlier of the Mayan traditional healer and the ritual to cure the young girl of her problems. The Mayan healer talked with the whole extended family to discover the social relations and then encouraged everyone to be a part of the cure. This happened because different relatives were given specific tasks to perform in relation to the girl's recovery, and they all were expected to be present for the proper number of follow-up performances of the ritual.

Even though experiences of *communitas* may not be a part of scientifically based nursing practice, they inspire and maintain hope for the patient and/or family members. For example, I saw a patient during the evening most of one week. She looked as if she was in the last stages of dying (her physical symptoms showed this, and she was drifting in and, mostly, out of consciousness). Her husband was looking after her with the help of their two daughters. He talked to me more each evening about how he was feeling sad that she was dying and how lonely he was beginning to feel. We talked together about his concerns, and one evening he went to the bedroom and brought back a lovely picture of her. He had tears in his eyes and said to me, "We've been married over sixty years. She's always been there to hold my hand and to talk to. I've always been right by her side. Now

she's dying. What am I going to do?" With tears in my eyes and strong emotions, I hugged him. He cried for a while. When I left, the emotions were still very strong inside of me. My next patient was about a half hour drive away and I cried the whole way. While I was driving and crying I thought of what I would say to a policeman if he stopped me, "I'm a nurse and this man's feelings hit me so hard I can't stop crying" and similar messages went through my mind. I wondered why I felt so affected. The man's feelings were so intense, and I had been getting to know him, and that resulted in the intense feelings I felt for him, and with the deep emotion he was feeling.

This is an example of the soul to soul openness Cassell is talking about and is also the kind of *communitas* I regard as so valuable. It is this *communitas* which allows a person to know that there is another person who shares his pain, and sense of loss, and therefore reinforces his worth as a human being. This is a powerful feeling. It is not lessened for me by writing it or having other people read it. Although I am talking about it, removed from the situation, it has not lost the import, while at the same time the intensity has dulled. This is fortunate, I believe, because to carry emotions that intense for many different situations would quickly lead to emotional overload. But, once again, because the intensity has lessened, the importance attached to the feeling has not. I can still hear his voice and see this man's face - especially his eyes. The pain he was feeling can still make tears come to my eyes. The pain was at least partially alleviated for this man by my listening and by sharing hugs.

The point of this and the examples cited previously is that I as a nurse have feelings which I share with patients and their families which I have labelled as "communitas". This takes into account the dealing with families in the period preceding imminent dying

through to the period shortly after the actual death. There are ritual behaviours which attend to these periods, they are dependent on the family and their past behaviour patterns.³⁰ Some people are very aware of the impending death and will lay down with or sit with their loved one and hold their hand. They may not be sure of the exact moment of death, but they know that they were with the person, providing support and love for the transition which was taking place.

Along with Cassell, other authors report that "communitas" is not an accepted mode of professional behaviour (Gray-Toft 1986; p 27-38 and Thompson 1985; p 233-242). A lot of this literature goes back to Glaser and Strauss, A Time for Dying (1968) and Awareness of Dying (1965). They point out that the differences in how nurses react to dying patients depends of the type of nursing and the specific ward sentiment. Nurses oriented to the biomedical/curative model of treatment are going to react differently to death than do palliative-oriented nurses. The sentiment on the ward is going to make a difference as well. Death on a maternity ward will have a more negative effect than death in an ICU (Glaser and Strauss 1968: 41-6, 121-2, 127-8, 133). This has to do with what typically happens on each unit. A maternity ward is geared to welcoming new lives and the staff generally have a more difficult time dealing with death than an ICU where life comes to an end more frequently and the staff often do not get to know their patients well. I will now turn to a discussion of palliative care in particular.

Palliative care nurses are trained to provide comfort, alleviate suffering, maintain hope (the kind of hope talked about by Cassell-- the general kind), allow for spiritual

³⁰These rituals include the preparation and sharing of food and the sharing of memories and stories involving the deceased.

expression and satisfaction, and to realize that they are helping to provide a safe, comfortable environment in which the person can die. Part of palliative care is that the patient is not the only person being ministered to; the whole family/significant others are a part of the basic unit of care. All of these things mean that the nurse (and other professionals) cannot maintain the distance that we were taught to maintain in nursing school³¹. There must be a more intimate sharing and involvement. The nurse has to be able to comfortably talk about death with the person who is dying and must be able to talk about death and bereavement to the ones who are left.

Palliative care therefore allows the circle of people close to the dying person to be a part of the dying, in physical presence and in emotional "closure", that is, the people have a chance to say goodbye and to satisfactorily end their relationships. With the focus that is particular to nurses with a palliative orientation, a feeling of *communitas* then is likely to occur. The nurse visits the patient at home with increasing frequency and usually gets to know the person and the family very well as he is providing personal care and discussing intimate things to do with feelings and what is usually considered to be a highly individual matter, death.

One day last November, I heard a discussion on the radio about a hospice for AIDS patients in Toronto. The speaker, who was a care provider, said that each death was difficult because each time someone he had gotten to know had died, a part of him died as well. I think that we can turn around that kind of thinking to something like; yes there is

³¹In nursing school I was told, along with the rest of my class, that we were not to get emotionally involved with any patient. A good nurse does not let feelings intrude on the "professional" relationship she/he maintains with his patients.

an emptiness for a period of time, but part of the survivor has not died; instead, a part (memories) of the deceased has been left with the survivor, in the memories and shared experiences with the deceased are added to who she is. By this I mean memories of shared experiences, and of the person herself are added to the person who is left. This is certainly not the immediate feeling, but can occur over time, and is perhaps what we can learn from the Mayan example cited previously; when the death occurs amidst a feeling of *communitas*, and guilt is not the emotion left over, I think that positive feelings are possible. We may also realize that death is not an unnatural event in each life cycle. Palliative Care allows the possibility for the doctor, as part of the health care team, to accept death as an acceptable outcome which results in more positive feelings about death generally.

I will now turn to a discussion about how this relates to the general North American culture.

CHAPTER FIVE

A CULTURAL DISCUSSION

The above Mayan and Palliative care examples can serve as a counterpoint to the attitudes characteristically found in North American culture. Marcus and Fischer (1986) talk of "[a]nthropology [as being] not the mindless collection of the exotic, but the use of cultural richness for self-reflection and self-growth" (Marcus and Fischer, 1986: ix). They are reinforcing what I quoted O'Connor as suggesting at the beginning of this thesis, that we can learn more accepting and "naturalistic" ways of dealing with, and thinking about, death from other cultures (and I would add, from various aspects of our own culture). Both the Mayans and Palliative Care workers in a general sense have an idea of death as a part of the normal life cycle. Certainly it is not considered part of "normalcy" for people to die before they have gone through the other cycles of life, and have not achieved their full potential, but there are only averages for life spans; some are longer and others are shorter. The way in which we as North Americans deal with death is, I believe, a result of social teaching and learning. It is possible to adjust this. Death could be looked upon as the final stage of growth, instead of as the ultimate in annihilation.

Judith Miller (1987) has been previously cited. She has done a great deal of work in the area of working with people with chronic illness. I will extrapolate her material so as to be applicable to working with people with terminal illness. As in most works on illness, Kleinman's (1980) distinction between disease and illness is one way of looking at the situation. Disease, as defined by Kleinman, "refers to a malfunctioning of biological and/or

psychological processes". Illness "refers to the psychosocial experience and meaning of perceived disease" (Kleinman; 1980 p.72). It is disease which affects individuals, while illness involves the wider circle of family, friends, and perhaps even communities. There are other ways of looking at the problem, one is Susan Sontag's discussion of disease/illness metaphors. She is concerned that the metaphor can do more damage than the actual disease, the examples she uses are T.B. and cancer (Sontag: 1978). The one thing which is most important is that the patient is no longer just the person who has the physical illness. The "patient", I would define as "the patient unit", which includes: the person who is ill, the disease³², the significant others, and the environment. The environment includes the shelter, important (to the people involved) items; pets, plants, and other things. The significant others include family, close friends, and other important people (eg. priest, rabbi, etc.). The person with the illness refers not only to the physical manifestations, but also the person's history, what the illness means to them, what the impending death means to them, how they see themselves with the illness, and many more aspects.

One of the reasons that home programmes for palliative care are becoming more popular is that they allow the person to remain in their own, familiar surroundings. When all else seems to be slipping from one's control this is very often quite comforting. Miller reports that people maintain hope much better when they feel that they are still in control, or at least have some control. This is especially so when it comes to being home, choosing when and what to eat, when to have one's personal care attended to, and when to have

³²A disease like cancer, AIDS, or MS is often seen as an entity in itself, affecting or even a part of the person, but distinct from their essence as a person.

people close by.

Although hospitals are becoming less rigid in this regard, they still have quite a long way to go. This may have to do in part with the curative orientation relegating such things as visitors and psycho-social well-being to a much less important role in the person getting better. Miller states that the most important thing for a person with chronic illness is to maintain hope. This is the same kind of hope that was talked about in regards to Cassell previously. Miller says that hope is a "determinant of survival" and "doesn't exist in social isolation" (these quotes are from the keynote speech given by Dr. Miller at a VON seminar Hamilton Sept. 18, 1991). The opposite of hope is hopelessness. This "most painful emotion" results in despair which can in itself result in death.

The reason that hope is important when someone is dying is that hope allows for the person to be able to say good-bye. It also allows the survivors to be able to carry on in the face of death and afterward. Hope is important to the maintenance and resolution of meaningful relationships, lightheartedness, serenity, and spiritual strength. It also allows for daily aims/goals to be realistic and for uplifting memories to be permitted and encouraged. All of this requires nurses in particular to become closer and more involved with their patients which in turn leads to *communitas*. When the death occurs, the event can be seen as a mirror (Ramsden 1991;p 27-42 . The time preceding and after the death is filled with the same kind of reminiscing and memory creating and perpetuating.

In summary, the past three chapters have dealt with what Palliative Care is, and have presented some examples of my experiences working as a Palliative Care nurse. In palliative care, the preserving of one's dignity and comfort are ultimate aims as contrasted to biomedicine where the ultimate aim is to preserve life even at the expense of comfort

(freedom from pain), and dignity. The aims of palliative care are achieved in many ways, but of the utmost importance is the feeling of intimacy which is not discouraged. In my experience, the building of *communitas* led to more satisfying memories when the person dies, and typically create a more positive atmosphere for those who are dying. An important aspect of palliative care is that of hope. Hope is a generalized feeling which can be fostered in people to alleviate the opposite feelings of hopelessness and despair. Hope empowers people to maintain their sense of self and worth even while dying and allows the person to live up until death. Hope also allows the family/significant others to deal with their impending loss with similar positive feelings. I must point out that none of these things of which I speak will prevent the sadness felt when a loved one dies, nor are they meant to. There is however, a difference in a death being a positive experience, memories of the person sad but filled with love; and a negative experience where the "loved one's" name is not mentioned without feelings of guilt or despair. With the spread of diseases like AIDS, and cancer, more people are being exposed, as in earlier times, to loved ones dying at home, and at an earlier age. One must see "the tragedy in the context of a whole life, keeping one's eye and mind on what has enriched you and not only on what you have lost" (Kushner 1981; p 139). The feelings described above will become more prevalent, and hopefully more people will feel that the rewards of palliative care are worth the difference in the way of providing health care.

CONCLUDING REMARKS

Although the study of death is no longer novel, nor is the comparison of different culture's deathways, I think that using an aspect of our own culture in order to explore alternatives is somewhat new. I have presented a brief overview of the results of preliminary field work in the Yucatan to this end, as well as my experiences as a palliative care nurse. In discussing Mayan attitudes (as another culture) towards death and grieving with palliative care (an aspect of our own culture) attitudes towards death and grieving, I am making an attempt to follow through with John O'Connor's suggestion that anthropologists studying death should use their information to more pragmatic ends, that is, to help people learn to deal with death so that its effects are not so overwhelming and negative. In presenting a historical perspective of thoughts and feelings related to death in our own culture I set the stage to begin to think both culturally and comparatively about how these notions might be altered.

Palliative care, in its present form, has been around for about twenty years, and with the prevalence of more virulent diseases, for example, cancer and AIDS, more people are becoming aware of the need to "do something". It is not only the hospital workers any more who see suffering and death. As in earlier times and other places, death is returning to a place within the family boundaries. Families and significant others are looking after people who are very sick. They are learning to care, and in doing so are experiencing, perhaps, the rewards of such intensive work. One of these rewards results from the experience of *communitas*. The feeling which results from this is one of hope and a connection with another person that is not easily achievable in many other situations.

More work is needed in this area to further the goals suggested by O'Connor (1991; p

253-276). They are, I think, reasonable goals. The kind of holism practised by the Mayans is not so different than that of other Native American cultures, and is similar to the philosophy of palliative care. But in our culture, palliative care occupies a unique position. It is a part of the "medical system" but it does not operate under the same philosophy as the rest of biomedicine. There are other such specialties, which although edging away from biomedicine remain within that basic philosophy; for example, chronic care. Palliative care holds the elements required for a humanistic, caring, knowledgable way of providing health care.

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