DEATH AND ITS IMPLICATIONS
FOR SOCIAL WORK

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# Death and Its Implications for Social Work

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INTRODUCTION

"Neither the sun nor death can be
looked at with a steady eye."
La Rochefoucauld, 1613-1680

One cannot ignore the universality of death. As Donne has said: "No
man is an island... any man's death diminishes me." Which is to say that the
incidence of the event is total and within its dimensions we are all included.
Death has had an uncertain acceptance in our society in recent times;1 few
can contemplate death with equanimity and the capacity to be significantly
helpful to those who are dying can no longer easily be derived from every day
experiences.2

During the last few years there has arisen an expanding awareness of
the need to proffer more effective care to the terminally ill and more
proficient support to the bereaved resulting in widespread efforts both
medical and lay, religious and secular.

Corresponding to this concern there has been a prolific outpouring of
publications and amongst them the subjective experiences of dying and bereave-
ment have been most eloquently portrayed. The Denial of Death by Becker3 and
C.S. Lewis'4 A Grief Observed are contemporary books which are prominently
acclaimed, widely read, and in which the author's dilemma is poignantly
revealed.

Numerous indeed are the books and articles which explore the implications
of death for the individual, for the family, for society and inevitably for the
professional who is working in this area. No aspect of the subject
seems to have been left untouched and the contributions range from the
historical and panoramic to the introspective and anecdotal, and as we shall
explore, there is also a growing body of information which is derived from
controlled and rational studies and the principles of effective care are
steadily evolving. For the purposes of this paper the topic of death will be
confined to an exploration and discussion of the following aspects:

I. An endeavour to fashion a perspective on the process of dying - on
the individual adjusting to his own death as well as the professionals coping
with their feelings about death itself. Some considerations of the historic
context of this in western society and the principal philosophical positions
which have been established are necessary to accomplish this as well as an
enquiry into a theoretical framework in which the individual act of dying
can be helpfully perceived. Some definitions of death will be reviewed and
reference made to the ethical dilemma of euthanasia.

II. Current enterprize in attempting to bring rational and effective
care to the dying is the focus of the second section of this paper which
reviews the emergence of the hospice movement. The philosophy, assumptions
and categories of hospice care are surveyed at some length.

III. Mourning and its manifestations is a topic which has drawn the
attention of many writers since Lindemann published his classic study three
decades ago. Some of these studies will be reviewed and major theoretical
concepts which have emerged from them will be highlighted. That some groups
of survivors tend to be conspicuously at risk has been repeatedly emphasized
and some detailed consideration will make this explicit.

IV. The relevance of individual death and personal bereavement to social work will be the concern of this last section. There is much to suggest that social work, both as an academic discipline and as a professional practice has yet to perceive the challenge in this area. The social worker can make a meaningful contribution to the care of the dying as well as responding to the needs of the bereaved and in many settings these facets of care are congruent though calling for different skills.

I would like to reiterate that in this paper my concern is with dying and bereavement and that by dying I mean that terminal event in which life finally ceases and not some steady process of attrition which has been termed "little dying", and in bereavement I distinguish the particular loss by death of a familiar and necessary person and am not concerned with general loss which is a ubiquitous and recurring experience for everyone.
DEATH - PERSPECTIVE AND MEANING

We have said that death is universal and reaches each one of us in either a timely or untimely fashion and there are no exceptions. It has always been so and few people contend that it will be otherwise. Those who see death as a gateway and propose to explore a future after death are numerous and sometimes learned but can mingle few facts with their speculations and are in any case outside the range of this paper. However, social historians and anthropologists can tell us that different cultures and different generations have allocated very varying significance to the act of dying and the modes of relating to the dead.

A quest for the meaning of death has exercised the minds of thinking men since before written records began to be kept and today there is a profusion of comment such as never before, but it is beyond the scope of this survey to try to assemble even a summary of such deliberations. Nevertheless, we must provide some historical context for the change which has occurred; as to why in fact in the phrase of Ariès:

"Death, so omnipresent in the past that it was familiar would be efaced, would disappear. It would become shameful and forbidden." 7

In his book Western Attitudes Towards Death 8 which is a recapitulation of the lectures he gave at Johns Hopkins University in 1973, Ariès traces the history of changing attitudes towards death in western societies since the Middle Ages. He describes how at the beginning of this period men and women
graduated out of this world in the orderly process of what he terms Tamed Death. Typically, in the literature of the time at least, they were forewarned and did not die without having had time to realize that they were departing. That this attitude lingered on in peasant societies until recently is revealed by the dying murmurs of Tolstoy: "And the mujiks? How do the mujiks die?" They, as Tolstoy recognized knew what was happening. Knowing that his end was approaching, the dying person prepared for death and did so recumbent and in bed. Death was then a ritual organized by the dying person himself who knew its protocol and presided over it in a public ceremony in which there were those present whom he should forgive and those such as the priest who could ensure that he maintain the routines. It was an open ceremony at which it was essential that relatives, neighbours and friends would be present. It was ceremonial but with no great show of emotion and as Solzhenitsyn put it: "They took death calmly .... and they departed easily, as though they were just moving into a new house."9

Private burial was not important and the body was entrusted to the church with little concern for its placement providing it remained within its holy precincts. Public life continued beside these burial grounds for hundred of years and to quote Ariès again:

"The spectacle of the dead, whose bones were always being brought up to the surface of the cemeteries, as was the skull in Hamlet, made no more impression upon the living than did the idea of their own death. They were as familiar with the dead as they were familiarized with the idea of their own death." 10
Ariès then goes on, in a detail we cannot here reproduce, to explain how the intervention of a concept of individual judgement and an expanding desire for personal recognition after death, spread over several hundred years, and later favoured the advent of the fulsome and exaggerated mourning of the Victorian area. This theme is considered by Choran in his book *Death and Western Thought* and in his chapter on: "The Crisis of the Christian View of Death" he reviews the far ranging debate over the centuries about the immortality and resurrection of the body. This is also taken up by Toynbee in his book, *Man's Concern with Death*, in which he states:

"This seventeenth Century change of attitude towards the Christian religion is one of the greatest revolutions that there have been in Western history so far." 12

And again:

"Since the great seventeenth Century revolution in Western man's outlook, the inability to face with equanimity the fact of death - has overtaken, not only many of those Westerners who have lost their belief in the tenets of their ancestral religion, but also some of those who have retained their belief unquestioningly." 13

Both Choran and Ariès echo the statement of Toynee's: "The word death itself has become almost unmentionable in the West." 14

This striking transformation in attitudes towards death was first made explicit by the eminent English sociologist Gorer who in 1956 published an article graphically entitled *The Pornography of Death*, in which he postulated that the more society was liberated from the Victorian constraints
concerning sex, the more it rejected matters which had to do with death. His subsequent book *Death, Grief And Mourning In Contemporary Britain*, published 10 years later amplified this and is a pertinent source for any consideration of the topic. Such classics as Evelyn Waugh's book *The Loved One* and Jessica Mitford's book *The American Way of Death* have underlined this development for a larger public.

Against this background, a new discipline, Thanatology has sprung to life which determines to study the phenomenon of death objectively, to research directly the attitudes of those who are dying and to fashion concepts of how man might best be helped to die with dignity, and his survivors find a meaningful role in which to expend their grief. Perhaps the earliest book to gain recognition and to maintain its significance in this field was *The Meaning Of Death* edited by Feifel and published in 1954. Feifel has continued his research in this area and was joined during the next decade by an expanding flow of contributors of whom Hinton, Fulton, Kastenbaum, Kübler-Ross, Parks, Pattison, Weisman and Shneidman are only some of the principle investigators. At the same time innovation was taking place, particularly in England, in the manner of caring for the dying and here the pioneer work of Cicely Saunders is outstanding.

In the past, Psychiatrists, Psychologists and attending disciplines have for the most part left the implications of death to philosophers. Freud helped to legitimize this neglect when he wrote:
"It is indeed impossible to imagine our own death: and whenever we attempt to do so we can perceive that we are in fact still present as spectators. Hence the psycho-analytic school could venture on the assertion that at bottom no one believes in his own death, or, to put the same thing in another way, that in his unconscious, every one of us is convinced of his own immortality." 20

In fact as Lifton in a critical observation points out: "We cannot for long look at our own nonbeing."21 Becker maintains this as his central theme in his book The Denial of Death22 implicating life as a disordered chaos in which there is no predictability or sense. He holds that to combat this and survive we must construct a mythology of existence which we prefer to esteem as our mature sense of reality. It is perhaps vital to sense our own nonbeing, but it is like the sun and we cannot look at it directly for long.

How then have human beings sought to reconcile themselves to the fact of inevitable death? No doubt in many various ways and some of the more prominent strategies have been sketched by Toynbee23 whose panoramic view of history has led him to elaborate on this topic. Toynbee specifically mentions:

A. HEDONISM: Making sure of enjoying life before death grabs it away - "let us eat and drink for tomorrow we shall die", as Isaiah puts it.

B. PESSIMISM: To conclude that life is so miserable that death is the minor evil was the outlook of some of the Greeks and Sophocles24 declared:
"It is best of all never to have been born and second best - second by far - if one has made his appearance in this world to go back again as quickly as may be, thither whence one has come." 23

C. ATTEMPTS TO CIRCUMVENT DEATH BY PHYSICAL COUNTER MEASURES:
This of course was carried to extremes in ancient Egypt by mummification and lavish tomb building. This ancient quest for the elixir of immortality has its counterpart in that exaggerated faith in modern science which has led to the optimistic freezing of bodies to await an eventual resuscitation.

D. ATTEMPTS TO CIRCUMVENT DEATH BY WINNING FAME: To live on by commemoration has been a favourite aspiration since before society became literate, but of course seldom accomplished.

E. PUTTING ONE'S TREASURE INTO FUTURE GENERATIONS: As a way of reconciling oneself to the implacable fact of death this has been ubiquitous and constant, that to the present day it is probably a solace to most of us. Lifton 25 points out that this mode of achieving a sense of immortality never remains purely biological but becomes simultaneously bio-social, expressing itself in attachments to one's tribe, organization or nation.

F. THE BELIEF IN THE IMMORTALITY OF THE HUMAN SOUL: This is a facet of most of the religions prominent in the Western world and especially of Christianity. Some believers have in mind the resurrection of the body and some are fortified by a hope of
heaven and touched by forebodings of hell, but the degree to which this is prominent as an inspiration to modern man has undoubtedly declined.

Indeed, it seems that man cannot live without some sense of continuity - without the prospect of some strand to tie him to the future.

During this decade one of the discussions which impinged not only on medicine, but also on theology and students of ethics was: "Should the dying patient be told?" Academically, this debate would seem to have been resolved in favour of sharing the prognosis with the patient in most instances, but practice would seem to be much more complicated, especially as far as hospitals are concerned - and 70% of the population now die in hospitals. Hinton,26 in a well arranged study of dying patients and using compatible controls showed that most patients in fact know that they are dying whether specifically informed or not. On the other hand Kübler-Ross 27 revealed that there is considerable reluctance on the part of physicians and nurses to acknowledge this. Her revelation of the conspiracy of silence involved has had major repercussions, especially in the nursing profession.

Glaser and Strauss28 went on to study the patterns of interaction between hospital staff and patients and concluded that there are specific awareness contexts revolving around the confrontation of patient and hospital staff. They discerned the following types of awareness in these situations and have designated them as follows:
I CLOSED AWARENESS CONTEXT - Here the staff know the patient's prognosis but the patient does not, and the management of communication and activity intended to keep the patient in ignorance is left almost entirely to the nursing staff. The physician focuses on technical aspects of care, keeping visits to a minimum and escaping from intimacy with the patient. There is thus a striking division of labour.

II SUSPICION AWARENESS CONTEXT - Here the dying person suspects the truth but the staff continue to act out the fiction that recovery is expected.

III PRETENCE AWARENESS CONTEXT - In this instance both patient and staff are fully aware of impending death and realize that the other party is also aware but both act as though the patient eventually will get better.

IV OPEN AWARENESS CONTEXT - Here both parties in the situation acknowledge the fact of impending death and are able to discuss it openly. This of course is the optimum context.

Much of the constraint that lies behind these distorted patterns of interaction has been shown to emanate from the personal uncertainties about death which afflict the staff themselves. With this knowledge in mind, more and more institutions are seeking to educate their staff to deal with their own feelings about dying and to be able to facilitate and manage open communication. In consequence also, and increasingly, medical schools and departments of nursing are introducing courses in this area into their curriculum. Social Work has been less prompt to embrace this need.
How then does a person deal with the knowledge of his impending death? This inevitably has been the focus of detailed study and uncertain theorizing and is central to the whole area of thanatology. The concept of a Dying Trajectory to refer to the perceived course of death was developed by Glaser and Strauss\textsuperscript{29} has been elaborated by Pattison\textsuperscript{30} who drew attention to the Living-Dying Interval which can be divided into three clinical phases:

1. An Acute Crisis Phase.

2. A Chronic Living-Dying Phase.

3. A terminal Phase.

\begin{center}
\textbf{THE DYING TRAJECTORY*}
\end{center}

These phases of dying Pattison relates to the four different trajectories outlined by Glaser and Strauss in the following scheme.

*Pattison, M. 31
rapid and the dying process may remain only with the acute phase, in such events as accidents and fulminating illnesses.

II CERTAIN DEATH AT AN UNKNOWN TIME

This refers to the typical trajectory of chronic fatal illness where effort focuses on the maintenance of effective living in an ambiguous and unpredictable time frame.

III UNCERTAIN DEATH BUT A KNOWN TIME WHEN THE QUESTION WILL BE RESOLVED

The significant example of this is intervention for diagnosed cancer where ambiguity lingers on for years.

IV UNCERTAIN DEATH AND AN UNKNOWN TIME WHEN THE QUESTION WILL BE RESOLVED

This is illustrated by certain genetic diseases and Multiple Sclerosis which leave the person groping with a life of ambiguity.

During the chronic living-dying phase the patient has to negotiate a number of fears and their successful resolution represents the rewarding aspects of what can be termed healthy dying. Some of these specific apprehensions as assembled by Pattison\textsuperscript{32} are:

1. Fear of the unknown.
2. Fear of loneliness.
3. Fear of sorrow.
4. Fear of loss of family and friends.
5. Fear of loss of body.
7. Fear of suffering and pain.
8. Fear of regression.
Helping the dying person diffuse the starkness of some of these fears is one of the challenges for the social worker or other therapist who may become involved as will be discussed in the concluding chapter.

Kübler-Ross, especially in her landmark book On Death And Dying has had remarkable impact on the study of the dying process and her theory has been applied, particularly in nursing circles, enthusiastically and even indiscriminately. Drawn largely from observations she made on dying patients in hospital, she enunciated a series of stages which she felt represented the specific course of psychological reactions undertaken by the patient in response to the knowledge of his own demise. This series of stages begins with initial shock and numbness, followed by denial and isolation, succeeded by anger, bargaining and then depression. Having successfully passed through these stages the person ends in a state of acceptance accompanied by hope. A careful reading of her book reveals that there were many instances where these stages were not followed and she did not present her findings as dogmatically as some of her followers have tended to believe.

Investigators of comparable astuteness have taken issue with Kübler-Ross' concept of stages and Weisman, for instance comments:

"Look how difficult it is to isolate a single characteristic, denial, depression, anger and so forth, and make pronouncements about the process...the idea of staging psychosocial episodes is very artificial...patients cope and fail to cope with various problems, and their emotional responses are simply indicators of personal conflict and crises...the concept of psychosocial staging appeals to me, because patients are apt to have social and emotional problems any way...it would be very orderly if psychosocial issues followed as neatly as anatomical and clinical staging seem to do...but there is no well-organized succession of emotional responses that are typical of people facing incipient death."
Shibles carried out a recent evaluation of stages and writes:

"The stages are too procrustean, narrow and fixed, even though they overlap, to adequately account for thoughts, images, perceptual and motor abilities which a person has regarding dying." 35

Schulz and Aderman36 and also Pattison37 concur and it is by now apparent that the process of dying cannot be subsumed within the framework of Kübler-Ross' stages or in any other formula of orderly progression.

When we consider a patient entering the terminal phase of existence we must bear in mind four definitions of death.

1. **SOCIAL DEATH**: This refers to the withdrawal and separation by others from the patient, which in the case of the aged living in nursing homes may mean that they are treated as if they were dead by their families, long before the event occurs.

2. **PSYCHIC DEATH**: Here the person accepts death and reverts into himself. It may happen in an anomalous way before physical morbidity is apparent as in Voodoo deaths or in those who predict their own death and refuse to continue living.39

3. **BIOLOGICAL DEATH**: Here the human entity is no longer in existence and there is no consciousness or awareness even if the heart and lungs are kept functioning with artificial support.
4. PHYSIOLOGICAL DEATH: At this point the vital organs such as lungs, heart and brain no longer function.

These definitions of death have great relevance in medical/legal matters where it may be important to determine the precise point of death in connection with estate duties, in multiple family deaths and in transplanting donated organs; but also as the premise on which the issue of euthanasia is debated. Euthanasia is of course a very troubled word which to some represents a good death and to others a morally outrageous one. As a term it can mean many things to so many people and to some it comprehends any steps to hasten the dying process, whether actively or simply as a decision not to start or stop treatment so that the dying process can continue. Veatch has endeavoured to clarify the issues by underlining three crucial distinctions:

A. INEVITABLE DYING VERSUS LIFE OF INSUFFICIENT QUALITY

A primary distinction must be made between allowing a person to die who already is inevitably dying and one who could go on living indefinitely but with a quality of life seen as insufficient by the decision-maker. A patient hospitalized with advanced cancer is different from a child with severe congenital malformation, such as spine bifida, who can be maintained alive, but with excruciating limitations.

B. ACTIVE KILLING VERSUS LETTING DIE

The second major distinction is between the decision to actively hasten the death of the dying patient on the one hand and passively letting the patient die on the other. Some, for example Fletcher, have argued that this is a distinction without a difference. In most western countries active
killing is clearly illegal and those accused are usually acquitted on grounds of temporary insanity or on the grounds that the course of death could not be determined. Letting the dying process continue by not starting the treatment is legally acceptable in certain circumstances but the withdrawal of treatment is much more controversial in law.

C. REASONABLE VERSUS UNREASONABLE REFUSALS

Though mainly confined to omission of treatment the issue of who decides, the medical professionals, the family or the patient himself cannot easily be determined. Nor is it easy to discern what constitutes a reasonable sanction. The pertinence of this to improved care for the dying will be mentioned later in connection with the hospice movement.

By contrast one may contemplate the nature of an appropriate death and though there is no consensus about this, it would seem that the criteria set forth by Pattison, and derived from Weisman represents a supportable point of view:

I The person is able to face and resolve the initial crisis of acute anxiety without disintegration.

II The person is able to reconcile the reality of his life as it is to his ego-ideal image of his life as he wanted it to be.

III The person is able to preserve or restore the continuity of his important relationships during the living-dying interval and gradually achieve separation from his loved ones as death approaches.
IV The person is able to reasonably experience the emergence of basic instincts, wishes, and fantasies that lead without undue conflict to gradual withdrawal and the final acceptance of death.

The following chapter on the hospice movement presents us with an opportunity of noting how the quest for appropriate dying may be facilitated.
During the last few years the Hospice Movement has gained considerable momentum, particularly in North America, and the purpose of this chapter will be to look at its development, philosophy, goals and objectives. In doing so, we have to recognize that not only are there individual differences between Hospices, but that although the underlying philosophy of Hospice approach is the same everywhere, the actual development, as well as its goals and objectives, are determined by national and regional health policies, by economics, cultural differences and indeed the needs of a given population. Thus we shall have to examine four distinct models of hospice care, and in doing so, hope to establish that there are valid alternatives and each has advantages and inevitably some shortcomings. We must bear in mind that each model has been inspired and developed as a response to the unique needs of a community in conjunction with the knowledge, expertise and funding available at that time.

The term hospice (derived from the Latin word for guest), dates back to the Middle Ages. Hospices or wayside inns were the resting places for ailing and dying pilgrims and other travelers; and it was Dr. Cicely Saunders who revived the term giving it a new meaning and purpose when, in 1967, she opened the very well known St. Christopher's Hospice. It was soon recognized that St. Christopher's provided a unique and much needed service which hitherto had not been represented within the framework of medical institutions. Since then hospices such as St. Christopher's have been established across Great Britain and the philosophy of hospice care has been promulgated throughout North America. Here, it is worth noting that according to a recent press release the number of hospice programs in the United States had grown during 1977 from 29 to 115 in
thirty-two States, with several more in the planning stages. In Canada, the
development has proceeded much more slowly and according to my own knowledge,
we have up to this point in time established only four hospice programs - in
Halifax, Montreal, Toronto and Winnipeg.

HOSPICE PHILOSOPHY

The underlying philosophy of the Hospice Movement is based on "simple
yet modern care for the dying patients", with a firm commitment to the
QUALITY of life remaining to the dying person and his family; and moreover,
to death and dignity. Krant suggests that dying becomes dignified when the
person himself is in a position of strength in controlling the events in his
environment when he writes:

"To be in control of one's life and death thus implies
having power - the power to prevent unwanted actions
of others." 43

In other words then, hospice approach to care attempts to provide high quality
palliative care when curative and life prolonging goals are no longer appro-
priate. Palliative care implies total care which proffers regard not only for
the medical/physical needs of the patient but is equally attentive to the
psychosocial, spiritual and economic concerns of the dying patient and his
family.

This philosophy of palliative care where the primary focus is on the
dying patient and his family or significant others, represents a radical
departure from traditional medicine with its orientation and commitment
towards investigation, diagnosis, treatment and cure of a disease and where
the inability to cure and prolong life represents failure. This quest for change has come in response to the undoubtedly enormous historical, social and scientific developments of the past 50 years; and although it is not within the scope of this paper to deal with them in detail, it is important for us to put some of the most significant developments into perspective if we are to understand today's growing interest in death and dying (some critics call it the latest fad).

HISTORICAL PERSPECTIVE

Perhaps the most dramatic change for our Western Industrialized Society has to be seen in terms of average life expectancy, which during the last 100 years has increased from around 45 to around 70 years, and whereas half the population used to die before the age of 45, now half lives beyond the age of 70. Infant mortality has decreased enormously and rarely does a woman die in childbirth. Equally have the causes of death changed and whilst in the past, death was relatively quick to follow an illness or accident and generally occurred within the family home, the advances of modern medicine and its technology have enabled us to sustain and prolong life for extended periods, but in a hospital setting. Thus death has ceased to be a central feature in the lives of most people today.

Other dramatic changes have occurred in our social and economic structure and have resulted in major alterations in our family commitments. In some significant ways, responsibility for family members has largely shifted from the private domain to public agencies with the result of still further separating dying and death from the family. As mentioned earlier, it is estimated that today more than 70% of the population in Canada is likely to
Given the current statistics of life-expectancy and mortality in our society as well as the institutionalization of sickness and death, a crucial lack of concern and knowledge among the general population might well be assumed. But this does not excuse the lack of awareness, concerning the needs of terminally ill patients, as displayed by physicians and other allied professions. Thus, very little was published about the needs of dying patients until the Sixties when as previously described Kubler-Ross, Fulton, Feifel, and others became actively and systematically involved in an explanation of the thoughts, feelings and needs of the terminally ill and their families.

This new concern with mortality has created not only an academic specialty - thanatology - but has also been the driving force behind the Hospice Approach to care of the terminally ill.

HOSPICE CARE

As outlined above, hospice is first and foremost a philosophy or concept of care aimed at providing high quality palliative attention for those patients for whom curative and heroic life prolonging treatment procedures are no longer appropriate. So far the following four major types of hospice care have been developed:
1. An independent and separate physical facility, operating in conjunction with a home care team - as for example St. Christopher's Hospice in England and Hillhaven Hospice in Tucson, Arizona.

2. An autonomous Palliative Care Unit operating within a general hospital as exemplified by the Palliative Care Unit at the Royal Victoria Hospital in Montreal, Quebec. This model, too, includes a home care program, as well as a consultation service to the rest of the hospital. A comparable unit was opened in January, 1979 at Toronto Grace Hospital.

3. A community based Home Care Treatment Team, which may have the privilege of following patients into hospital settings. Best known examples of this model are the New Haven Hospice, Connecticut, and the Hospice of Marin, North of San Francisco.

4. A Hospice Team operating as consultants in an acute care hospital. This is the approach taken by the Victoria General Hospital in Halifax.
Clearly there are some distinct advantages to each of these models of care, but it must be remembered that the creation and development of the different models was determined primarily by available resources, both in terms of economical and professional expertise and by national and/or regional health policies. Professional and public interest or the lack of it, have influenced the extent to which a community was prepared to support this new and innovative development. But in spite of the differences in the delivery of care, the four alternatives are based on the same assumptions and share common goals. These underlying assumptions are:

1. That there is a clear-cut time when active treatment aimed at cure and/or prolonging survival is no longer appropriate and a patient can be labeled as dying.

2. That the level of care generally provided for the dying is inadequate.

3. That there is a body of knowledge re: the care of the terminally ill which is best implemented by specialists in this field.

4. That the dying would be willing to change treatment teams and/or institutions at the time they are defined as being beyond active treatment.

5. That the dying are best cared for at home or in special units or institutions which focus specifically on the needs of dying patients.

6. That hospice care is cost effective.

Although all of these assumptions are still very controversial, particularly within the medical and nursing professions, a review of current research literature provides us with a generally favourable position of support for them, though as Kalish points out "a little knowledge may indeed be dangerous". However, it must be stressed here that all the pioneers
of the Hospice Movement are acutely aware of this fact and certainly all the programs mentioned in this paper have established thorough criteria for ongoing evaluation and research in all aspects of palliative care and bereavement follow-up.

The first is perhaps the most controversial of all the assumptions because it raises two crucial questions:

(a) Is there ever a time when active treatment aimed at cure should be discontinued?

(b) Assuming that there is such a moment then, when is it and who decides?

Inherent in the first question are, the problems of diagnosis and prognosis, the element of human error and the danger of missing something in the effort to ease patients out of this world by being too zealous in the attempt to achieve death with dignity. The second question addresses itself to, who decides? Is it society, the physician, the family or the patient? The advocates of hospice care insist that the decision to provide palliative care does not rest with any one person, but rather it is made jointly by the patient's attending physician, the patient himself, his family and the hospice team; furthermore the decision to palliate is not irreversible.
The second assumption regarding inadequate care for dying patients in acute care wards has been repeatedly substantiated by clinical research and does not appear to be a contentious issue even to the critics of palliative care.

The third assumption laying claim to a particular body of knowledge in the care of the terminally ill, is based on the fourfold approach to pain control and has been very well substantiated by research findings. Assumption number four regarding the lack in continuity of care, is questionable at this point. Little systematic research has been done in this area largely because not all patients are equally affected by it. For example, patients tended by a community or hospital based hospice team will experience no change-over in primary physician or caregivers since the hospice team acts as consultant to those professionals and family already caring for the terminally ill. In the case of an inpatient hospice or palliative care unit, there may indeed be a problem with continuity of care, but advocates of this model do encourage family physicians to visit and claim that the improved total care experienced by the patient in this new setting far outweighs any disadvantages brought about by the change-over. They also feel that it presents a problem only to those patients who die very shortly (within the first week) of being transferred to their care. Here we must also remember that the inpatient hospice as well as the palliative care unit, has excellent provision for home care and indeed many of those who are ultimately admitted as inpatients already know many of the staff through being cared for by the home care team, particularly the physician, the social worker and the volunteers.
If we accept the validity of the first assumption, namely that there is a time and place when active or heroic treatment should be relinquished in favour of palliative care, then the fifth assumption presents no dilemma since research has amply substantiated that acute care facilities cannot provide the type of total care needed by the dying patient, nor should we expect them to since, the knowledge, the tools and the training required for investigation - diagnosis and cure differ considerably from the expertise and setting needed to provide palliative care.

The sixth and final assumption is that of cost effectiveness. In view of the ever increasing costs for medical care it is crucial that this assumption be validated if the concept of hospice care is to survive and expand. Studies done on cost effectiveness in England and at the Royal Victoria Hospital in Montreal yielded very favourable results. In terms of manpower costs are relatively high, equal to those of an intensive care unit; on the other hand in terms of technology, that is to say equipment and laboratory tests, etc., the costs are exceedingly low. The final evaluation in Montreal demonstrated a 36 cent per diem saving per patient. Far greater savings however, have accrued through the home care program which has enabled terminally ill patients to either remain at home for much longer periods or if they so wish, to be cared for at home till death occurs. Cost effectiveness becomes an even more important consideration in the initial planning stages of hospice care and in the choice of model to be adopted. A free standing hospice might well be contemplated as being the most appropriate and desirable, particularly in terms of autonomy in administration, but so far no government and few philanthropic organizations have been prepared to meet the costs of
capital expenditures involved. On the other hand a palliative care unit established within a general hospital can utilize all existing facilities whilst establishing its own independent administration. This has been demonstrated by the Palliative Care Unit in Montreal.

Undoubtedly the controversy surrounding these assumptions will continue and can hope to be resolved only through continuous and rigorous evaluations by not only the various professions but the consumers of this innovative approach to health care.

MODELS OF CARE

Having examined the underlying assumptions which have led to the development of hospice care we must now direct our attention to the different models evolved so far, and outlined earlier.

The independent and separate facility, exemplified by St. Christopher's is undoubtedly the most commonly envisaged. Proponents of this model stress the structural advantages, ie: a building designed specifically for the care of the terminally ill and their families, including easy access to outdoor gardens, etc. It is also felt that inherent in this type of facility is a degree of autonomy that cannot be realized in any other model, thus avoiding much of the institutional, interprofessional and political conflict otherwise intruding. Obvious disadvantages can be seen in terms of economics, eg: the high cost of capital expenditure; additional stress experienced by staff due to relative isolation and possible discontinuity of care for patients transferred to such a facility. Some concern is expressed over the possible return of the death houses if the dying process becomes institutionalized.
Another area of concern to the Hospice Movement in the United States where universal medical coverage has not yet been implemented and where minimum standards for health care vary greatly, is the possibility of private enterprise establishing hospices as franchised operations. It is for this reason that the National Hospice Association was formed earlier this year in Washington, D.C. Their aim is to set national standards for accreditation training, supervision and evaluation of hospices.

The second model of care is a palliative care unit located in a general hospital as is the case at the Royal Victoria Hospital, Montreal, or one that is integrated into a long term or chronic care facility, as demonstrated by St. Boniface's Hospital in Winnipeg. It does not have to contend with professional isolation and can more readily reduce the problem of discontinuity in care by becoming involved with the patient and his family at an earlier point of his illness. On the other hand, hospital politics are complicated and tenacious, and maintaining the unit's autonomy within the larger setting can be exceedingly difficult. Also the high staff to patient ratio necessary for good palliative care tends to create envy and discontentment among the hospital staff at large. The integration of the terminally ill with the long term or chronically ill patients has been very successful at St. Christopher's Hospice over the past three years, but some English hospices report that staff tend to favour the chronically ill while neglecting the dying patients. And lastly, while such a unit has the potential to be cost effective as has been proven in Montreal, the mere physical obstacles of existing hospital buildings present an enormous challenge in the creation of a relaxed and homelike atmosphere so vital for the dying patient and his family.
Next is the community based Hospice Team. This model was pioneered in the United States and originally conceived as an interim program while awaiting government or foundation grants for building purposes. Community support for this model whose primary thrust is on home care treatment has been considerable. Perhaps this is due to the assumption that people prefer to die at home, as is claimed or it could be that this program represents a viable alternative for many families in the United States for whom the cost of hospitalization is prohibitively high. In this model the Team, on call 24 hours a day, 7 days a week, acts primarily as consultants and co-ordinators; they do not become the primary physician and caregivers. Some of these hospice teams, most notably New Haven Hospice and Marin Hospice have developed most effective links with existing community services, eg: public health nurses, homemaker services, general hospitals and physicians in the area, so that high quality palliative care which is also relatively inexpensive, is actually achieved. Some of these hospice teams are free to follow their patients to hospital if or when this becomes necessary - but always as consultants. In terms of costs, this model has some decided advantages, but it has limited scope regarding the population it serves, primarily because it demands that there be a primary caregiver. This stipulation precludes a large proportion of elderly and single people as well as families who for a variety of reasons are unable to take on this demanding role. In addition, there are many communities which do not yet have the medical and/or social support services necessary for this kind of program to work effectively.

Lastly there is the hospice team operating within a general hospital. Little is known about its effectiveness so far. Clearly it is the least expensive service, but the friction created by territorial overlap may be
considerable, unless the authority of such a team is undisputed. Moreover, patient and family cared for by this program would likely have to conform to the many hospital rules and restrictions, if for no other reason than to safeguard the needs of the acute care patients.

Hospice is a concept and philosophy of timely importance, but the discussion of the four models developed so far, shows, I hope, that no one program can fulfill the multiple needs of the terminally ill, their families and the requirements of the professional staff within the confines of our present socio-economic structure. In an effort to come closer to the ideal of palliative care, an International Work Group on Death, Dying and Bereavement was formed three years ago. This group has delineated a set of assumptions and principles covering the overall philosophy, the patient, his family and the staff, in order to assist both existing and developing programs and above all to set some universal standards.

COMPONENTS OF CARE

As already mentioned palliative care implies total care of the dying patient and with a focus not on death but on the quality of life remaining. To achieve this goal, a fourfold approach to the control of pain has been developed. Fourfold because the origin of pain may be physical, psychological, social or spiritual and most frequently is a combination of all or any of these. This is best illustrated by the Hospice Pain Model.
In the words of Dr. T.S. West of St. Christopher's Hospice:

"The task of the skilled clinician in alleviating pain is to tease out through careful observation and examination of the patient specifically which of the four components of pain are present, active, in what combination, and to what degree. Once the combination has been determined, then the appropriate combination of intervention strategies can be initiated." 52
During this initial assessment the patient's social-cultural response to pain as well as his own autoplasti process are considered so that the necessary pain control measures can be tailored to the individual patient's needs. The goal of this fourfold approach is to keep the patient pain-free, comfortable and mentally, fully alert.

Whilst the scope of this paper does not allow a detailed description of the use of medication in the management of chronic pain, the basic principles of this approach developed by C. Saunders should be outlined and include the following:

1. The successful management of the patient's pain is both an art and a science.
2. The concept of addiction does not apply in the care of the terminally ill patient.
3. There is a need for great flexibility in both the variety of drugs used and in their dosage levels. 53

Recognizing that physical pain, especially in the terminally ill patient, is closely linked to psychological pain, eg: depression, anxiety, and insomnia, as well as to social pain, defined by the level and intensity of discomfort in interpersonal relationships, palliative care pays close attention to these non-medical pain factors. Depression, anxiety and insomnia are seen as normal grief reactions in coping with approaching death, and are treated primarily within a therapeutic milieu of concern and genuine caring thus reducing the need for medication. Family, friends and even pets are encouraged to spend time with the dying patient to facilitate social interaction and to avoid the terrifying sense of isolation and abandonment commonly experienced by the terminally ill in our institutions.
Spiritual pain is not easily defined, especially as it relates to death and will vary greatly depending on the patient's racial, cultural and religious background. Although the various hospice models put great emphasis on the spiritual needs of dying patients, the literature says little on how to respond to those needs outside our judeo-christian heritage. Since most hospice programs have been initiated and indeed partially funded by christian organizations there is the inherent danger the staff might seek death bed conversions to a particular denomination. This is well recognized by administration and precautions are implemented.

In addition to the abovementioned components of care, every hospice program attempts to provide a bereavement follow-up service. Bereavement is seen as a crisis period and as will be discussed in the next chapter, early intervention is recognized as good preventative medicine. The intensity of this follow-up service varies and is determined largely by the potential risk of impairment to health and psycho-social adjustment of the bereaved. Whenever possible this service is provided by someone who knew the patient before his death, and as a rule continues for a year.

THE HOSPICE TEAM

Realizing that the needs of the dying patient and his family are multidimensional, complex, demanding and indeed very stressful to the primary caregivers, hospice care requires an interdisciplinary team, implying the integration of all available resources - including the patient and his family, rather than a multidisciplinary team approach where the different professionals co-exist in relative peace with minimum input from patient and family, as examplified in our traditional medical settings.
The creation of such a team needs time and careful selection as well as ongoing components of support and nurturing and the recognition that not all health care professionals are suited to undertake this task.

The key person on the hospice or palliative care team is the physician. This is imperative because only the physician has the very specialized knowledge regarding pain and symptom control, and perhaps because the dying patient's greatest fear is in feeling abandoned by his doctor when nothing more can be done. This is not to imply that the physician necessarily heads the team in a hierarchical sense, but rather that he is available 24 hours a day, 7 days a week, like other members of the team. In addition, the team consists of nurses, medical social workers, physiotherapists, volunteers, chaplain, psychiatrist and to reiterate once more, the dying patient and his immediate family.

This chapter has been an attempt to provide an overview of the Hospice Movement, discussed the underlying philosophy and assumptions upon which the hospice concept has been built and analyzed the major models developed so far. As stated in the beginning of this discussion, there is no one ideal hospice model and any community planning to improve the care of its terminally ill members, must carefully consider present legislation, available financial resources, existing professional expertise and the actual needs as perceived by the dying and their families.

In contrast to prevailing approaches we have here a concept of health care which encourages active participation, based on informed consent from the patient and his family, at all stages of the treatment plan. This degree
of participation in the decision making process is central to all hospice programs, and if we employ Sherry Arnstein's model of "A Ladder of Citizen Participation" we can readily see the high degree of involvement in the decision making process accorded to the dying patient and his family.

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And perhaps the greatest challenge for professionals in this field is to create and maintain this degree of power and partnership and thereby sustaining the patient's dignity until death.

From my own readings and observations, hospice care in England has become a reality and a viable option for most patients, regardless of their socio-economic, racial or religious background. In the United States it is at this point in time a dream come true only for those who can afford to pay and those who are sponsored by reason of a religious affiliation.
For Canadians, in spite of universal medical coverage, it is neither a reality nor a dream coming true but seemingly a matter of geographical proximity to one of the very few palliative care programs implemented so far.

Perhaps a society will come to be judged on its respect for human life by the way it cares for its dying, honours its dead and shares each other's grief.
As already indicated, it is not the intention of this paper to explore the significance of general loss which is a recurring experience but of the particular loss by death of a familiar and necessary person. Such separation by death is a certain exposure for each of us in the content of a lifetime and an awareness of the experience of others in their losses, a not infrequent occasion. We are made to realize then that grief, the reaction to a parting by death is one of the most profound of all human experiences, full of turbulence and pain. The distress of bereavement may readily supercede all other considerations and as Brabantio puts it:

"For my particular grief is of so floodgate and o'erbearing nature, that it engluts and swallows other sorrows, And it is still itself."

(Othello, 1.iii)

We may rightly expect that a plight so ubiquitous and so full of anguish has drawn the compelling attention of the greatest writers, both in fiction and biography, from the ancient world and onwards. The Bible portrays the epic grieving of David in contemplating the death of Jonathan; and Euripides describes distorted grief in the Bacchae - both describing reactions with which we can empathize today. Others have conveyed exquisitely the nature and course of their own grief and when empowered by a sensitive and reflective mind their observations can deeply move and instruct us. A noteworthy example is C.S. Lewis in A Grief Observed of which further mention will be made.
It is perhaps surprising then, in view of the universality of the event, the intensity of the emotions involved and the contributions of literature to the theme, that grief has only recently become the subject of controlled research and the behaviour of the bereaved studied in a systematic way. This is not to say however, that its significance has been obscure and Freud for instance drew inspiration from his enquiries into bereavement and forwarded some of his more salient insights into the dynamics of human behaviour in his classic *Mourning and Melancholia*.  

The publication which first made an impact on the medical literature and offered a predictable commentary on the nature of grieving came out in 1944 and was entitled *The Symptomatology and Management of Acute Grief*. It was written by Erich Lindemann, Professor of Psychiatry at Harvard University, who, drawn into concern for wartime bereavement, became particularly involved in studying the reactions of survivors of a disastrous night club fire in the city of Boston. In this classic article he describes the elements in the picture of normal grief which he had discerned and designated the nature of aberrant grief reactions which may occur. His findings have not always been supported by other studies but his perceptions continue to represent the reference point for most subsequent enquirers. It is therefore necessary to review his theory of grief in detail.

Lindemann drew his conclusions after observing 101 patients, who included besides the survivors already mentioned, some patients who lost a relative during the course of treatment, relatives of patients who died in hospital and relatives of members of the armed forces. As a result of his investigation, Lindemann established the following points:
1. Acute grief is a definite syndrome in which psychological and somatic symptoms are manifest.

2. The occurrence of this syndrome may be immediate or delayed, or it may be exaggerated, or it may be apparently absent.

3. Distorted pictures may appear in place of the typical manifestation.

4. These distorted occurrences may be successfully transformed into a normal grief reaction which then resolves itself, if suitable intervention becomes available.

It is important to expand further on what is constituted by normal grief and its pathological variations.

Symptomatology of Normal Grief and its Course

Lindemann maintained that the behaviour of people suffering from acute grief was quite uniform and drew attention to the common experience of having sensations of physical distress which occur in waves and last from 20 minutes to one hour at a time. These become conspicuous after the initial shock of learning of a loss has passed and as they tend to be precipitated by recollections and the visits of sympathizers and are highly unpleasant, visitors and references to the deceased tend to be avoided. The striking components of this experience are a conspicuous tendency to sighing respiration, an overwhelming complaint of lack of strength and exhaustion and significant interference with digestion.
Moreover there are some cognitive alterations in that there is commonly a slight sense of unreality and an intense preoccupation with the image of the deceased, which may become disturbing to the degree that the sufferer fears approaching insanity.

Strong feelings of guilt form as a major preoccupation for the bereaved who accuse themselves of negligence and exaggerate minor omissions.

Often there is a disturbing loss of warmth in relating to other people and with it a tendency to be irritable and plagued by persistent anger.

Although there is usually a pressure of speech and a pervasive restlessness, a bereaved person typically shows a distressful lack of capacity to initiate and to maintain organized patterns of activity.

These five features namely, the physical distress, the preoccupation with the image of the deceased, the sensations of guilt, the hostile reactions and loss of patterns of conduct, are considered by Lindemann to be, in his phrase, *Pathognomonic*. He mentions a further characteristic which is not invariable and which borders on the pathological and that is the tendency to take on the traits of the dead person.

It is Lindemann's concept that these features of a grief reaction are universal and normal and are resolved as the person accomplishes what he terms *grief work*. This consists of liberating oneself from the bondage of the deceased, re-adjusting to the environment from which the deceased is missing and forming new and appropriate relationships. Grief work is not automatic
and unimpeded and is obstructed for many who try to avoid the intense but inevitable distress which is connected with the grief experience and try to circumvent the expression of emotion which is needed. Intervention consists of sharing in this grief work and promoting its occurrence and this can usually be accomplished effectively.

Morbid Grief Reactions

As mentioned above, grief work does not always progress to an effective level of resolution and Lindemann draws attention to the various abnormal reactions which may emerge. Of these, the most easily discernable and most frequently encountered is delay and postponement. If bereavement overtakes a person who is immersed in other tasks of supreme importance or required to maintain the morale of others, little or no reaction may occur for weeks or even longer. This is initially adaptive but sometimes years may pass before a further loss precipitates the unresolved grief or it may occur at the time of anniversary or when the bereaved reaches the age of the person who died.

Certain reactions, distorted in their content may take the place of normal grief and in mild form may show as an alteration of a person's conduct during the period of delayed grief. In his article Lindemann classified them as follows:

1. Overactivity without a sense of loss and accompanied by a sense of well-being and a devotion to activities formerly carried out by the deceased.
2. Acquiring symptoms which were displayed by the deceased during his last illness.

3. The occurrence of a medical disease, certain psychosomatic conditions such as ulcerative colitis, rheumatoid arthritis and asthma predominating.

4. Alteration in approaches to friends and relatives with apathy and irritability and avoidance conspicuous.

5. Aggressive hostility towards particular people, especially doctors involved in the care of the deceased.

6. Concealment and suppression of emotion and conduct, even to resembling a catatonic picture.

7. A persistent disruption of the course of social interaction and though wakeful and restless showing lack of decision and initiative.

8. Persistent self punitive behaviour by detrimental activities and without awareness of feelings of guilt.

9. The emergence of an outright agitated depression, often with a suicidal potential.
This summarizes Lindemann's propositions regarding grief with an additional comment on anticipatory grief which will be discussed later and although modified by other researchers, his work remains seminal for all clinical discussions of the topic.

Although many authors on the topic of grief have assumed Lindemann's exposition to be valid and ubiquitous and have elaborated their discussions on this assumption, there are a number of significant contributions from researchers whose findings emphasize other features of bereavement and some research providing conclusions which are at variance with those of Lindemann. An example of the latter is the work of Clayton, Desmarais and Winokur\(^5\) who studied the symptoms of grief in a group of people who were selected by means other than their consulting a physician and were considered to represent a normal reaction to bereavement. They found that those symptoms of somatic distress which Lindemann emphasized occurred in only 36% of their subjects and that none described them as being as intense or prolonged as he had indicated. Their conclusion was that in normal bereavement there are only three symptoms - depressed mood, sleep disturbance and crying, which were experienced by more than one half of their subjects.
Lindemann drew attention to anticipatory grief as a phenomenon occurring during significant separation and in the light of potential death and this aspect has been elaborated on particularly by Robert Fulton, a sociologist and Director of the Centre for Death Education and Research at the University of Minnesota. Fulton draws a distinction between high grief potential death and low grief potential death. He defines the former as being occasioned by the sudden incidental death of a man or a woman upon whom others depend for their physical and/or psychological well-being and the consequence of such a death is that it will usually precipitate the kind of reactions which (as we have just described) Lindemann has characterized as normal grief. In low grief death in which a prolonged illness is involved or an old person is afflicted, there is according to Fulton, less grief experienced, because the bereaved has undertaken a period of anticipated grief before the death occurs. Fulton identifies four stages in the process of anticipatory grief and outlines them as:

1. Depression.
2. Hightened concern for the ill person.
3. Rehearsal of the death.
4. An attempt to adjust to the consequences of the death.

As stressful events are less obnoxious to the extent that they are predictable, appropriate coping mechanisms can be more effectively mustered and by preparing for the anticipated death, the period after death becomes more controllable for the bereaved person. Death is perceived as less mysterious and hence less frightening. There is not a universal acceptance of this point of view and Glick argues that the pre-death response should not be characterized as a grieving process. What is clear, however, is that an anticipatory
reaction does occur and may have a detrimental effect on the relationship with the person whose death is surmised and a leukemia patient in an unexpectedly long remission or a soldier returning intact from war may be unfortunately compelled to deal with a spouse or parent in whose world they are no longer counted as alive. A number of examples of this kind are quoted in the literature.

That certain kinds of illnesses notably asthma and ulcerative colitis occur with some prominence among bereaved people was emphasized by Lindemann and Cobb and later Engel reviewed this tendency in more detailed studies. But there is also much to indicate that especially amongst the widowed there is an increased mortality rate which reaches its peak during the first year of bereavement. Young for instance found an increase in the death rate among 4,486 widowers over the age of 54, of almost 40% during the first six months of bereavement. A well publicized study by Rees and Lutkins based on a semi-rural community in Wales showed that 4.8% of the close relatives of those residents who died during the five year period, themselves died within one year of bereavement compared with only 0.7% of a comparable group of non-bereaved people of the same age living in the same area. Widows and widowers seem particularly vulnerable. Other studies confirm this trend and what has become apparent is that a large proportion of the increased mortality is attributable to heart disease. The literary connotation of the heart as a site of grief ("Bind up the broken hearted" - Isaiah) has drawn the attention of various commentators. The physiological connection however, remains obscure.
The cause of this increased mortality in surviving spouses has in fact been much debated but not satisfactorily explained, though five relevant hypotheses have been advanced.66 They are:

1. That the finding is an artificial one because healthy survivors remarry quickly and return into the married population, while those who are ill tend to remain widowed and are so classified. However, Young's study already mentioned, points to a high mortality during the first six months, before remarriage is likely to have taken place.

2. That there was a mutual choice of poor risk mates might explain the phenomenon, but no studies have been found to support this.

3. A common unfavourable environment has also been proposed, but the fact that couples rarely die, of the same disease, does not substantiate this.

4. The desolation effect hypothesis supposes that the low morale of the bereaved results in direct physiological changes with a lowered resistance to disease and alterations in accordance with the stress syndrome of Selye. The plausibility of this is appealing but it still awaits confirmation.
5. Self neglect and high risk behaviour may be a consequence of the death of a spouse who formerly was instrumental in guiding or protecting the bereaved.

What is evident then is that the recently bereaved are a group at special risk, even of their life, and more understanding of this phenomenon is needed so that the modes of successful intervention may be determined. Moreover, there is an added risk of suicide amongst the bereaved and many authors have quoted their subjects as having expressed a desire for death during the process of their grief, and in the stage of accentuated loneliness in which it may culminate.

In the overall adjustment to bereavement there are two other factors apart from grief which have to be contended with, and these are: Stigma and Deprivation. By stigma is meant the change in attitude which takes place in society when a person dies and this is most relevant to widows. In some societies this is extreme and the taboo on bereaved people is quite explicit. Cochrane mentions a local example:

"Among the Shuswap of British Columbia widows and widowers in mourning are secluded and forbidden to touch their own bodies; the cups and cooking vessels which they use may be used by no one else.... No hunter comes near such mourners for their presence is unlucky." 68

There is much to suggest that whilst we do not abjure widows, we continue to pityingly avoid them. As Gorer states:
"Mourning is treated as if it were a weakness, a self indulgence, a reprehensible bad habit instead of a psychological necessity." 69

Deprivation implicates the absence of a necessary person as opposed to loss of that person and whereas grief is the reaction to loss, loneliness is reaction to deprivation. (Bowlby has extensively discussed the evolution of attachment behaviour and the lack of a close attachment to another person may give rise to strong subjective feelings of insecurity and danger.) Loss and deprivation are bound together, perhaps inseparably and one can postulate that the reaction to loss will be greatest shortly after a significant death has occurred and will then decline giving way to the reaction to deprivation.

All observers of grief have recognized that it is not a state of perpetuated depression but is an occurrence of acute and episodic pìnings. Parks describes a pang of grief as being:

"an episode of severe anxiety and of psychological pain. At such a time the lost person is strongly missed and the survivor sobs or cries aloud for him." 71

He points out that such episodes begin within a few hours or days of bereavement and reach a peak of intensity within five to fourteen days. Initially they occur spontaneously but later need the reminder of a photograph or a meeting or a discovery to precipitate them. In his book on bereavement, Parks, who has had close contact with Bowlby discusses the significance and purposefulness of this experience which is apparently such a useless and unpleasant emotion. He argues that this pining is the subjective and emotional component of the
urge to search for a lost object. Ethnologists have shown how powerful is the impulse to search for a lost mate amongst many species of social animals. Lorenz\textsuperscript{72} has given a classic description of the effects of separating a greylag goose from his mate. Bowlby has written:

"Members of lower species protest at the loss of a loved object and do all in their power to seek and recover it; hostility externally directed is frequent; withdrawal, rejection of a potential new object, apathy and restlessness are the rule." \textsuperscript{73}

Parks reviews many examples amongst the bereaved widows he studied, where searching was quite manifest but the majority were not consciously aware of their need to search. He contends that much of the aimless behaviour to which Lindemann drew attention really has the specific aim of finding the one who has gone. Preoccupied with thoughts of the lost person bereaved people develop a perceptual set for that person and commonly mis-identify the bereaved person's face in public places or hear his familiar voice in a setting where it would formerly be an every day occurrence.

As Parks discusses it, these traumatic episodes of pining constitute an initial phase of the task of successfully re-adjusting to the loss of the beloved person. This endeavour was termed \textit{grief work} by Freud who cast it in the energy models of his libido theory and subsequent authors have adopted his term but often have not found his theory very helpful. Even so there is an ongoing quest to more fully understand the process of grief work and one contribution in this direction is again that of Parks who specified the following components:
1. There is a preoccupation with thoughts of the lost person which may be considered to be derived from the urge to search for that person.

2. There is a painful repetitious recollection of the experience of loss which is needful for the loss to be fully accepted as irrevocable.

3. There is an attempt to make sense of the loss; to either fit it into one's assumptive world or to modify one's assumptions about the world to accommodate it.

As Parks puts it:

"Attempts to make sense of what has happened would seem to be one way of restoring what is lost by fitting its absence into some super-ordinate pattern." 74

A firm philosophical point of view or a clear religious faith may facilitate this.

Kavanaugh, a psychologist and ex-priest and the perceptive author of Facing Death, mentions the feelings of relief that characterize the emergence from the process of grieving for as he says:

"All brands of human love can be gentle tyrants, mixing the pressures of love's demands with ample rewards." 75
He also discusses the struggle that may take place to avoid a sense of guilt that such relief is possible.

Although the terms, *grief* and *bereavement*, are readily used in conjunction and sometimes interchangeably, there is good reason for offering some differentiation between them. Distinction is not in fact regularly made in the literature and confusion is not always avoided, but it is not being pedantic to endeavour to separate out their respective implications. This is made clear by Fulton in his article *The Sociology of Death* in which he states:

"Grief has to be understood then, not only in terms of the inner dynamics of the survivors, but also in a situational sense - in terms of the concept of social role.

"So too with bereavement. Whilst grief is the subjective emotional response to loss bereavement has a sociological denotation. It has to do with status and role. It has to do with the fact that a loss has been experienced, although it may not be felt subjectively or emotionally. A survivor may not experience the death in Lindemann's classical sense; nevertheless, he has suffered the loss of someone with whom he was related or connected in different ways." 76

Thus we have to recognize that in helping or in bringing sustenance to a survivor it is not necessarily the inner misery caused by the trauma of loss with which we have to deal but also the task of re-establishing identity, function and social role. Not all survivors have to deal with these issues to any profound degree and not all the bereaved require professional intervention to facilitate their mourning; nor is the manpower available to offer it on such a scale if it were. The intention then of this discussion is to acknowledge that some survivors will be specially vulnerable to disturbance and dislocation, and to comprehend the strategies and timing of intervention.
Often, today, the death of an elderly relative will occasion only a limited acknowledgement and such a death is termed by Fulton as *Low-Grief-Death*. The point is significant because numerically the kind of death that most families experience today is of one of its elderly members. (Two-thirds of those dying in this country at the present time are over the age of 65.)

It is not that regard has been dissipated but rather that over time the family has made an adjustment to the potential loss. Moreover, dispersal of family members in our society, often over extensive distances, promotes a preliminary disengagement. The point at issue is not that the elderly do not give rise to intense mourning in those who survive them, and for the spouse this is especially true, but that there is a trend for their deaths to have less impact on their extended family.

Here, it is appropriate to consider the factors which can be supposed to influence the outcome of bereavement. Unfortunately, although many such factors have been postulated, there is no consensus from the research as to which are the most predictable in a given situation. However, I would like to review the three clusters of particularly relevant determinants as outlined by Parks. He writes about:

1. **Antecedent Factors**
   - past experiences of the loss of significant persons.
   - past mental illness, especially depression.
   - quality of the relationship with the deceased, especially the strength and security of attachment and the intensity of ambivalence.
1. Continued
   - mode of death, eg: its timeliness and the preparation for bereavement being important.
   - life crises prior to bereavement.

2. Concurrent Factors
   - personality of the griever, and in particular their proneness to grief in previous encounters with death and their tendency to an inhibition of feelings are particularly relevant.
   - socio-economic status.
   - religion as reflected in degree of faith and rituals subscribed to.
   - cultural and familial factors influencing the expression of grief.

3. Subsequent Factors
   - social support or isolation.
   - secondary stresses.
   - quality of options which emerge.

All of the above deserve elaboration which the scale of this paper does not permit, but when we consider those who might be deemed to be at special risk and for whom some prospect of identification might be possible, I find the following groups emerge:
I Those survivors who were not afforded a sufficient preparation time for the loss.

II Parents bereaved by the death of a child.

III Close survivors of suicide.

IV Hidden mourners.

V Those individuals whose prior experience of unresolved loss makes them particularly vulnerable to a close bereavement.

VI Caregivers who are continually in contact with patients in their terminal illness.

GROUP I

That anticipatory grief may accompany a terminal illness - or pre-empt the fatal outcome - has been discussed as it was outlined by Lindemann and amplified by other contributors. On the other hand, that sudden unexpected bereavements are a likely source of pathological grief has been demonstrated a number of times, Shand\textsuperscript{79} and Volkan\textsuperscript{80} and more recently by Parks\textsuperscript{81}

In this study, Parks and his colleagues followed up the course of adjustment of 68 recently bereaved men and women in the Boston area. They received a perceptive interview at 3 weeks, 6 weeks and 13 months after bereavement and most of them were re-interviewed 1, 2 and 3 years after that. A group of 24 of the respondents who had had less than 2 weeks warning that their spouse's condition was likely to prove fatal, or had less than 3 days warning that death was imminent was differentiated as the Short-Preparation group. Their outcome was compared with the remaining 46 respondents whose period of preparation for bereavement had been longer and who were called the Long-Preparation group.
Using a variety of indices of emotional state, health and behaviour, the outcome for these subjects was rated and it was shown that adjustment was much poorer for the short-preparation group. For example, at the 4 year follow-up only one of the short-preparation group had remarried, compared to 11 in the other group; 81% had financial problems and 73% were having difficulties in performing their job, compared with 29% and 34% in the other group. It was shown also that the process of grieving took a very different course in the short-preparation group who became much more emotionally disturbed and anxious and impelled to express feelings of guilt and self reproach.

It would seem from this study, as the author points out, that spouses who do not have the opportunity which is provided by a period of anticipation of death to make restitution for the deficiencies in the relationship, and who are caught by the magnitude of abrupt change without it being mitigated by gradual realization, are at risk of complicated grieving and curtailed post-bereavement adjustment.

The studies of Rees and Lutkins and of Young as discussed above have a significant implication along these lines.

Parks' study has been mentioned at length because it so forcefully reveals a group of survivors whose prospect for adjustment is poor and who may be identified in the community and for whom intervention might be planned.
GROUP II

In our generation, with small families and an infant mortality rate no longer devastating, the death of a child is a singular and traumatic event. That such bereaved parents are at exceptional risk was high-lighted by a study carried out by the Department of Paediatrics at the University of Western Ontario and reported in 1978. Fifteen families were contacted and interviewed some months after they had lost a child to cancer; this revealed vast disruption and pathology. Twelve of the couples had either separated or divorced since that death, and there appeared to be an exceptional degree of isolation and guilt amongst these parents. Although this study is exceptional in presenting such a bleak outcome in parental adjustment, there are numerous reports of serious complications engendered in the family by a child's death.

In his article Reaction of the Family to the Fatal Illness of a Child, Wiener confirms the vulnerability of parents to this stress with their propensity to strong guilt feelings, and he attempts to discern some of the features of marriages at particular risk.

Whilst a detailed consideration of the mourning behaviour of children is not appropriate here, it should nevertheless be affirmed that children - even at a very young age - do grieve and that their comprehension of death and their mode of grief varies with the age of the child. A young child's apparent indifference to the news of a personal bereavement is often adaptive and the initial denial permits him to reimmerse in familiar activities and consider the loss within its protection. To be able to duly express his emotional distress and to deal with possible guilt which may have arisen in
his fantasies is important to facilitate, as is the necessity to provide him with surrogate parenting if this has been disrupted.

GROUP III

A special group of mourners whose distress is intense and who should be more fully identified are those whom Shneidman designates in these words:

"In the case of suicide the largest public health problem is neither the prevention of suicide nor the management of suicide attempts but the alleviation of the effects of stress in the survivor-victims of suicidal deaths, whose lives are forever changed and who, over a period of years, number in the millions." 86

Welu87 in his article Pathological Bereavement. A Plan for its Prevention draws attention to the complete insufficiency of available Mental Health Services in dealing with these problems and underscores the self-destructive urges of these survivors. He advocates that there should be a group of caregivers who would be in touch with the bereaved within 48 hours to commence a therapeutic relationship. Welu, supported by Stone,88 supposes that the most effective professional would be a clergyman because as he says:

"If clergymen are employed as caregivers, a new group of professionals or para-professionals would not have to be created; furthermore, there would be almost no expense involved in recruiting the clergy to perform a service they have already dedicated themselves to." 89

This registers as expediency and though recommendations for immediate contact and intimate support are very appropriate, it would seem to me in our secular society there are distinct disadvantages in employing clergy in an
unfamiliar role and in ambiguous circumstances (until quite recently the church in fact refused burial to suicides!) I would maintain that a social worker has a better general preparation for such therapeutic work and greater credibility.

GROUP IV

There is a group of survivors who are not discussed in the professional journals though more widely represented in creative literature and whom we may surmise are not few in number in our contemporary society. I am referring to those whose relationship to the deceased was close, intimate and personally meaningful, but where competing commitments made the relationship socially illicit and necessarily covert. The love-relationship was concealed and so perhaps must be the corresponding grief. I would like to call them the Hidden Mourners.

The benefit of a ritualized, public expression of mourning is well recognized, yet this opportunity is denied them and hence they may be at particular risk. What is happening to them? A perusal of therapeutic case histories in the literature seems to suggest that they tend to enter treatment for reactive depression and often have somatic accompaniments in accordance with Lindemann's perspective of pathological mourning. Moreover, personal communication from both clergymen and psychiatrists confirms my assumptions. It is worth considering that an anonymous society to aid such griever would be a beneficial endeavour, but I know of no enterprise of this kind.
GROUP V

We have acknowledged previously that there are a variety of personal factors which help determine the outcome of grief and may lead to a pathological course. However, the implication for the individual is likely to be idiosyncratic and unpredictable except to someone who has an intimate and perhaps objective understanding of this person.

Prevention is therefore not easily planned except for those whose predisposition has already become manifest. Lily Pincus, the distinguished British Social Worker, in her book *Death and the Family*, which she wrote in the aftermath of a personal bereavement successfully resolved, discusses a number of case studies in which previous irrational responses to loss and abandonment, often in childhood, are revived to complicate subsequent grief. This gives rise to the supposition that amongst those on the case load of a line worker will be some whose previous experience with loss has become apparent, though not a cause for intervention, and who become bereaved within the period of contact with the worker. Their need for therapeutic support should be clearly recognized by the professional involved.

GROUP VI

The last group to be specifically mentioned is those caregivers who are exposed to the dying in the nature of their regular employment and who experience continuous deprivation. Fulton amplifies this in discussing the phenomena of the *surrogate griever* where the role of mourning is taken over by the professional caregiving staff because the relatives of the deceased have completed their grief work in anticipation. Two studies in particular support this view, that of Natterson and Knutson and the study of Binger.
The staff of a Palliative Care Unit or Hospice, Intensive Care Unit or Extended Care Unit and the Cancer Institute are known to be subject to considerable stress and this is discussed by Vachon\textsuperscript{95} in her article Motivation and Stress Experienced by Staff Working with the Terminally Ill. In emphasizing the need for an adequate support system in such settings, she gives attention to the role of a visiting consultant and the scope for a suitably trained social worker in this context is quite evident.

In this chapter I have sought to explicate the general features and dynamics of the grieving process as discussed by some of the principle authors on this topic and have endeavoured to draw a personal perspective on those at special risk in their bereavement and will go on to review strategies of intervention in the context of social work. However, I would like to conclude with a reminder of the intensely personal experience of grief in its maximum impact. This was expressed poignantly by C.S. Lewis, immediately following the death of his wife:

"No one ever told me that grief felt so like fear. I am not afraid, but the sensation is like being afraid. The same fluttering in the stomach, the same restlessness, the yawning. I keep on swallowing...It is hard to have patience with people who say "There is no death" or "Death does not matter". There is death. And whatever is matters. And whatever happens has consequences, and it and they are irrevocable and irreversible. You might as well say that birth doesn't matter. I look up at the night sky. Is anything more certain than that in all those vast times and spaces, if I were allowed to search them, I should nowhere find her face, her voice, her touch? She died. She is dead. Is the word so difficult to learn..."
"I cannot talk to the children about her. The moment I try there appears on their faces neither grief, nor love, nor fear, nor pity, but the most fatal of all non-conductors, embarrassment. They look as if I were committing an indecency. They are longing for me to stop. I felt just the same after my mother's death when my father mentioned her. I can't blame them. It's the way they are. It isn't only the boys either. An odd by-product of my loss is that I'm aware of being an embarrassment to everyone I meet. At work, at the club, in the street, I see people, as they approach me, trying to make up their minds whether they'll "say something about it" or not. I hate it if they do, and if they don't...Perhaps the bereaved ought to be isolated in special settlements like lepers."
IV
IMPLICATIONS FOR SOCIAL WORK

Where, then, does the social worker stand with regard to death and dying, grief and mourning, and what might be an appropriate commitment for a social worker in this area?

Although there is no comprehensive survey manifest in the literature which adequately reveals the scope of social work involvement in this field, I have attempted to delineate a number of significant contributions which social work may be able to make. Before doing so it is timely to contemplate this observation from Ginsberg, who is himself Head of a School of Social Work, and who writes:

"Learning to accept and to deal with irreversible problems such as death and finding ways to make sad and difficult situations less so are essential in services to the dying and their families. For that reason it may be that most current social work problem-solving strategies do not fully lend themselves to this problem, although death and dying are among the most common phenomena with which professional social workers must deal.

"It may also be true that social workers, like other health professionals, are psychologically set in a manner that makes it difficult for them to deal with the problems of death and dying, and they may be psychologically less adequately prepared for such problems than other professionals are. Social work may be the most optimistic and future-oriented of the human service professions. Social workers seem to believe that improvement is possible, no matter how pervasive a problem might be; the notion that certain problems have always existed and will continue to exist is not acceptable." 97
I consider the admonition of Ginsberg as perturbing and accurate. In fact I would recommend that the foremost priority should be in an effort to orient the members of the profession to the problems of dying and bereavement and to equip them with suitable skills and knowledge to make effective intervention possible. As he points out, there are certain primary assumptions within the basic credence of North American social work which tend to make it reach for radical solutions and want to change situations rather than to adapt to the inevitable. Death however does not submit to such aspirations!

Moreover, social work is not alone in this contemporary avoidance of death in the current taboo on this topic and a change of attitude is a necessary preparation for effective function. As Gary Lloyd, Head of Social Work in Houston, Texas, has pointed out:

"Social Workers are as apt as anyone else to be influenced by culture bound attitudes toward expression of grief and expressing grief themselves. ...Helping bereaved persons express grief and reduce the extent of unfinished grief work is a critical social work task. The danger always exists however that social workers trying to offer comfort to dying patients and their families may be, in truth, agents of a conspiracy to contain grief." 98

This uncertainty of commitment from social work is reflected in the paucity of contributions to the literature made by social workers when compared to the input of other health disciplines, eg: Psychiatry, Psychology, Sociology and Nursing. I consider this situation anomalous. Certainly not every social worker needs to become a specialist in thanatology, but the majority should have a greater competence than has so far been attained, and this must be renewed in continuing education, if the profession is to gain the required credibility.
Working with the bereaved and responding to the survivors' needs is a well recognized role of the social worker but this has to be matched with the corresponding and also meaningful contribution which the worker can bring to the care of the dying themselves. These facets of care are congruent, often beginning simultaneously and can be amplified in the following scheme.

(A) EFFECTIVE INTERVENTION AROUND THE DYING

The expanding range of services for the dying which are being inaugurated through the hospice movement is leading to a definition of the role of social work in this context as Millett has indicated. However, the medical social worker in a general hospital has a traditional concern with the dying patient though often oriented towards the indigent. Moreover since death is universal it will reach into the caseload of any practicing social worker at some point. Effectiveness in this area then involves:

1. **Coming to terms with mortality as a central fact of life.** To know more than the content of the literature, but to have gained a recognition of one's own fears and anxieties successfully. As Miller puts it in her article *Teaching Death and Dying Content in the Social Work Curriculum*:

"Until the student can recognize his own fears and anxieties about death, receive encouragement to share his feelings in the classroom, and experience from peer discussions that others feel equally vulnerable, he is not prepared to reach out to the terminally ill or to the bereaved family. Regardless of his intellectual understanding of the grieving process or his knowledge of crisis intervention as a frequent means of intervening, the success with which he is able to reach out rests upon his 'use of self'." 100
2. Helping the dying person negotiate the fears typically encountered, as outlined in a previous chapter. Part of this involves accepting the patient's style of coming to terms with reality, of respecting the emotional defenses of the person and not enforcing their passage through some arbitrary series of stages in a procrustean fashion. This is not the peculiar task of social work but is usually the shared responsibility of the caregiving team.

3. Counselling the dying patient and family as they make arrangements and provisions for a change of status. This may involve facilitating the effective use of social services, helping the patient tidy up his personal affairs, assist the relatives in establishing funeral arrangements in accordance with the patient's wishes, and reviewing with them the nature of a Living Will. It would also involve helping the patient explore within the context of the family's circumstances the prospect of home versus hospital care during the closing period of the illness.

4. Dealing with stress in family interaction when a member is dying. This is likely to be a matter of degree, but when dislocation is severe the intervention of a social worker who has some skills in family therapy may indeed be of crucial benefit. Orcutt discusses an approach based on a psycho-familial social system conceptualization and makes a relevant contribution, though the time factor would mitigate against its general use.
5. **Support for staff.** This is to reiterate what has been mentioned in the previous chapter and discussed by Vachon, namely that staff in facilities where they are regularly exposed to dying patients are in need of an adequate support system themselves and a social worker may find a competent role in this connection. As Foster points out:

"Social work's ability to make explicit, teach, demonstrate, and deepen these helping skills is still needed. Furthermore, many of these skills offer a substantial basis for direct service to interdisciplinary staff groups concerned with the stress and sense of loss inherent in day-to-day work with dying patients and their families." 103

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(B) **EFFECTIVE INTERVENTION WITH THE BEREAVED**

Perhaps this is a prime contribution of the social worker and I would like to bring certain features and tasks under review.

1. **Participation in the detection of those at risk.** Not all of those at risk are within the range of the social worker operating in the usual established services and we must bear in mind that the social worker is seldom the only resource available. However, the following locations, I think, represent case finding sources in which a social worker might discover an appropriate and active role of interception.

(a) **Hospitals**

77% of deaths occur in hospitals and institutions, but it is the Intensive Care Units, the Children's Units and the Cancer Units which are especially relevant. The hospital also offers one of
1. (a) Hospitals continued

the best prospects of prevention, and I like to recommend:

I A follow-up visit to those survivors who come within the
categories of risk outlined earlier, but especially to
those with whom the hospital has had limited contact, such
as where a sudden death follows a first admission to hospital.

II Within the-hospital setting a social worker may be particularly
effective in working with high risk families, particularly
with potential widows and widowers and parents of children during
the course of terminal illness.

(b) The Coroner's Office

Social work does not normally work out of coroners' offices but
there is an outstanding example in Marin County, California, where
social workers were enlisted by an enlightened coroner to follow-up
on all cases of sudden death. It is a feature of the coroner's
office that all unnatural and unexpected deaths are reported to
him, which makes the possibility of access to suicide survivors a
realistic accomplishment. I am personally most impressed with
this program and am contemplating a proposal to the coroner's office
in Vancouver.
(c) Funeral Directors

Here again there is a most interesting precedent for a service to the bereaved organized by a social worker. The Life Service Centre in Phoenix, Arizona, grew out of a widow to widow program sponsored by a Funeral Home. This concept could be extended in many ways as funeral directors become more perceptive.

2. Mode of Intervention

It is widely held that the most effective model to conceptualize a mode of giving help to the bereaved is that of Crisis Intervention. It was formulated by Lindemann and Caplan and though covering many situations of personal instability, had its origins in Lindemann's original work on grief already mentioned. It is contended that certain hazardous events (amongst which bereavement is prominent) induce a state of crisis - "An upset in a steady state", the habitual problem-solving activities are not adequate and do not lead to a restoration of balance. The scope of this paper does not permit further elaboration except to say that crisis intervention aims to promote in the individual a solution of his problem because he has learned additional and healthier ways of coping with these circumstances. Consequently, it focuses on the immediate problem situation and not on extensive pathology or patterns of character. Parad has noted that "crisis intervention is now a generally accepted mode of intervention in social work practice" and hence there is some possibility of it becoming a universal tool of the profession.
3. Social workers regularly involved with the bereaved must become aware of their range of Socio-Economic Needs and must have a familiarity with the resources locally available. This includes a recognition of a variety of ethnic customs around mourning, an understanding of funeral procedures and burial/cremation requirements as well as detailed knowledge of appropriate legislation regarding entitlement to benefits, eg: homemakers, pension, etc.

It is especially important for the social worker to know of existing groups and services in the community which are sustaining these in bereavement. A local example is the Widow to Widow Program organized by Mrs. E. Palmer and inspired by a similar and well known program in Boston, created by Phyllis Silverman herself a widowed social worker.

(C) PARTICIPATION IN VOLUNTEER PROGRAMS WORKING WITH THE BEREAVED

The range of volunteer work with the dying and the bereaved is growing and two different roles appear to be emerging. One is task-oriented and may involve accommodating to the patient or survivors' problems at home and their personal needs; while the other is in a direct supportive and counselling capacity with dying persons and the bereaved. These though not usually exclusive, do tend to be designated quite specifically by the parent organization and correlate with the comprehensiveness of care which that organization offers. Thus, in the most fully established hospices, eg: St. Christopher's, London, the Palliative Care Unit in Montreal and Hill Haven Hospice in Arizona, the commitment of the volunteers does not include any elaborate therapeutic goals with the patient or survivors.
On the other hand, such a centre as the Shanty Project in San Francisco facilitates its services entirely through volunteers, but has professional staff, including social workers as consultants. Locally, Pilgrimage, a program of Volunteer Visitors for the Dying, is operating under the auspices of the Catholic Community Services.

The potential role of the social worker in volunteer programs is considerable and involvement may be as an instigator or director, or in the selection and training of volunteers, or as a principle resource to support their optimum functioning.

(D) MACRO PLANNING.

It is important not to overlook macro level considerations in the area of dying and bereavement as it is generally conceded that not enough programs have been implemented to cover the needs of the terminally ill and of vulnerable survivors and many unresolved issues still predominate. Social work should be involved in the following considerations:

1. Ethical debate as it relates to such contentious issues as euthanasia with its impact on the patient and society.

2. Social policy decisions regarding benefits afforded to survivors such as widows and orphaned children.
3. Effecting policies regarding the co-ordination of services to the dying and the bereaved which are at present scattered through medical services, social services and charitable auspices.

4. Innovation of new and pilot services, eg: for the Hidden Mourners whose grief is socially prohibited as mentioned above.

5. Public education to lift the cultural ambiguity about death and facilitate awareness of coping methods and appropriate resources.

(E) RESEARCH AND EVALUATION

Several areas present themselves as appropriate for social work research and should be considered. One level of enquiry should be to ascertain whether the socio-economic support systems and mental health programs currently available are meeting the needs of the dying and the bereaved. Another aspect of research would be the evaluation of specific programs convened for the patient and survivors, especially those deploying volunteers and those of a self-help nature. Not to be overlooked is the prospect of gaining insight from a systematic survey of personal case studies. Another area of investigation, vitally important, which has received little attention so far, is the degree of stress experienced by staff working with the terminally ill. How do these caregivers deal with the almost continuous experience of loss and what kind of support might they require whilst working in such settings?
In this paper we have discussed some of the cultural changes around death which have occurred in recent generations as well as the endeavour which is currently proceeding to understand the process of dying with an objective point of reference. A new approach to palliative care has been reviewed whose implications for social work are becoming increasingly apparent. The nature of bereavement has been explored and there has been an attempt to delineate those groups of survivors who may be deemed to be at risk and for whom planned programs of support might be inaugurated. The potential challenge for social work implicit in all of this has been shown to be far ranging but as yet little comprehended by the profession as a whole. Perhaps the urgent conclusion I would reach is that the present level of preparation of social work graduates is insufficient for the tasks they should be undertaking which, however, does not necessarily distinguish them from their fellow students in other disciplines.

Learning is important indeed, but perhaps it needs to be guided by a realization of the intensely personal impact of it all for, to resume that introductory quotation of Donne:

"...send not to ask for whom the bell tolls, it tolls for thee."
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