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ABSTRACT

This volume contains papers presented at a symposium on death, dying, and bereavement. Papers were presented on: (1) "A Psychologist in Hospice Care" (Clifford Morgan and Barbara McCann); (2) "Assessment of the Kubler-Ross Stages in Counseling" (G. Michael Averett and Claire H. Averett); (3) "Making the Road Less Lonely: Role of Volunteers in Hospice" (Pamela S. Jones); (4) "Bereavement and the Older Woman: A Model for Caregivers" (Carol Payne); (5) "A Younger Alzheimer's Spouse Speaks Out" (Marjorie P. Westergard); (6) "An Evaluation of a Hospice Caregiver Service" (Mark de St. Aubin); (7) "So Long Sadie" (Michael L. Benedict); and (8) "Alzheimer's Special Care Units" (Ryan P. Thorn). (CB)

Hosted At: Brigham Young University
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PERSPECTIVES ON AGING

Death, Dying, Bereavement

Sponsored By: Resource Center
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PREFACE

It is with pride that we report on our stewardship for the preparation of the 1985 Symposium on Death, Dying and Bereavement. This Symposium on Aging Issues is the current focus in what has become a continuing program devoted to the development and enhancement of professional growth and awareness through presentation and publication of position papers from practitioners, educators, researchers and colleagues from allied professional areas and disciplines.

We would like to express appreciation to those who have participated in the Death, Dying and Bereavement Symposium: 1985 at BRIGHAM YOUNG UNIVERSITY. The quality of your professional efforts in research, innovative projects and programs have reached national recognition among our colleagues. We are especially appreciative of all those professionals (serving without remuneration) that enhanced the content of our symposium and conference proceedings. Our purpose in this Death, Dying and Bereavement Symposium is to enhance professional growth and awareness regarding age-related issues.

Howard R. Gray Ph. D. and Claire H. Averett M.A. Co-Editors/Directors

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SYMPOSIUM HOSTED BY THE BRIGHAM YOUNG UNIVERSITY RESOURCE CENTER ON ADULT DEVELOPMENT AND AGING, Phileon B. Robinson, Jr., Director.

A PSYCHOLOGIST IN HOSPICE CARE

A psychologist provides valuable contribution in consultation for patient care, staff training and providing staff support and counseling

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Abstract

Psychological support services can benefit Hospice programs in three ways: (1) consultation in the development of patient treatment plans, (2) assistance to team members as they cope with their own responses to working with dying patients and each other, and (3) the provision of staff training. We propose a model which has been successfully used in a Hospice Demonstration Project.

A PSYCHOLOGIST IN HOSPICE CARE

A psychologist provides valuable contributions in consultation for patient problems, staff training and providing staff support.

The use of the psychologist in home health care may be a new experience for many agencies. Recent Medicare/Medicaid Hospice Demonstration Projects have provided funding and guidelines for the use of psychologists in hospice care (VandenBos, Stapp, & Pallak, 1982). Recent Medicare hospice regulations also include provisions for psychological care to the terminally ill (Section 122 of the Tax Equity and Responsibility Act of 1982). The November, 1982 issue of American Psychologist contained a number of articles introducing psychologists to the philosophies and principles of Hospice Care. Thus, a need for a psychological consultant has been established to assist hospice staff in the development of care plans and to assist team members in coping with their own responses to working with dying patients and each other.

The HHHC-Hospice Care Program of Albuquerque has utilized psychological consultants since the program began in 1978. We have found that psychologists can benefit hospice patients, family and staff in important ways. We describe a model which we have developed through our experience.

Consultation

It has been useful for us to classify psychosocial problem in terms of emotions, behaviors and environmental problems. For example, some patients are so anxious and fearful that they impair their own physical and emotional well-being. Other patients have a problem being extremely depressed, which incapacitates them for a quality life. Some patients, occasionally, are dangerous to themselves or others, while occasionally a patient will display psychotic symptoms or become confused and disoriented and unable to maintain themselves in a home environment without intervention from the staff.

We have developed a psychosocial/emotional assessment process as an aide in evaluating patient problems and for the implementation of goals and psychosocial interventions. An assessment is done during the first or second visit after the patient is determined eligible. Table 1 gives the categories which have been developed by the hospice psychologist for the treatment staff to use as guidelines in making this initial assessment. Although the "rating scale" relies on observations by the staff member doing the assessment, and therefore not necessarily accurate, we have found the scale useful. It is simple and routinely done, and it is later reviewed by the psychologist.

The psychosocial issues of each patient and family are then identified at a weekly team conference and individualized psychosocial treatment programs are developed for each patient as necessary. The hospice psychologist may also be contacted directly to work with the staff on a particular case. Occasionally, the psychologist may go on a joint visit with the nurse or counselor to make a firsthand assessment. At other times, a staffing is scheduled with

Table 1

Psychological/Emotional Assessment Categories
for Initial Screening of Hospice Patients

Category	Example Assessment Notes
Cognitive, Communication	... Alert, Confused, Medication Side Effects, etc...
Emotional State	... Depressed, Agitated, Angry Flat Affect, etc...
Coping Style	... Resistant, Denial, Dependent, Exaggerated Helplessness, Other...
Behavioral Problems	... Isolated, Attention Needs, Bizzare, etc...
Family/Cultural Conflicts	... Communication, Disengagement, Neglect of Patient...
Quality of Psychological State	... No Interventions Needed, Minimal or Many Interventions Needed, etc...
Identified Problems	... Recommendations ...

the psychologist and a patient care plan is developed to help the patient and family with the problem. Occasionally, the family may be so disfunctional that the care of the patient is impaired. In this case, the psychologist may assist the nurse or counselor in having a family conference to work the situation out.

Staff Support

Staff support services which are facilitated by the psychologist take place on an individual and group basis. A support group is held for two hours, twice monthly, on Friday afternoons. The purpose of the support group is to provide a supportive atmosphere for staff to talk about work related issues on a personal basis. The support group is not considered group therapy or psychotherapy. Our philosophy of staff support is congruent with the hospice philosophy (Butterfield-Pickard, & Magno, 1982; Smyser, 1982; and Randolph, 1982). The purpose of the support group is:

-- Time out for staff away from patients, paper work and phones
-- Gives emotional support and care from staff to each other
-- Communication among staff about the meaning of hospice work
-- Enhanced cohesion as a team; a sense of belonging and common meaning
-- An opportunity for staff to model what is asked of our patients, responsibility for quality time.

We have also found that the support services offered by the hospice psychologist helps the staff cope with stress in the care of the terminally ill (Gunther, 1977; Vachon, 1979; & Barstow, 1980).

We consider that staff support is congruent with hospice care philosophy. Hospice care philosophy begins with each individual person

Table 2

Comparison of Hospice Philosophy with Purposes of Staff Support

Hospice	Staff Support
Enhanced quality of terminal patients' lives: goes beyond medical to psychosocial	Enhanced quality of staff lives goes beyond "business" of our work into satisfaction and joy of work
Can only be done as a team: no one profession can provide all the care necessary	Everyone at Hospice is equally important although they have different jobs and responsiblities
Care givers and family of patient are involved in the treatment program: patients treated in their own environment	Everyone is involved since we work as a team (Hospice)
Hospice philosophy begins with each individual person and extends to team and then involves patients and families	Care given to patients actually begins with ourselves and how we function together: support group is part of a philosophy of taking care of ourselves as a team

and extends to family, the case given to patients actually begins with staff members enhancing the quality of their own professional and private lives.

Table 2 compares the philosophy of hospice with the purposes of staff support. The psychologist is also available on an individual basis to see staff members. All support services provide for confidentiality of information for individuals.

Training

A psychologist may be effectively utilized in providing training for Hospice staff. Training needs change according to the specific needs of the staff and the direction of the treatment programs. Some examples of topics for training sessions which have been used are as follows:

Responding and setting limits to sexual overtures

Personal survival and prevention of "burn-out"

Dealing with alcohol abuse problems in the family

Understanding and dealing with the angry, abusive parent and/or primary care giver

The attention getting and manipulative patient

The helping relationship in hospice care

Facilitating family conferences

Actualizing the therapeutic relationship

In addition, staff members representing the various specialties on the hospice staff have presented cases which illustrate the unique contributions that each profession makes to the team.

Additional Roles

We suggest that there are also other roles and functions for psychologists in hospice care. Since 80% of the members of Eval Network as well as the Eval Research Project are psychologists, psychologists could function as a program evaluator for local or national programs. A psychologist might also function as a hospice administrator or director which was described by Liss-Levinson, (1982). Psychologists also could provide direct psychological services to patients and families (Kastenbaum, R. etal, 1981; Sobel, H., 1981). We have found that the psychologist may also provide an important training function by presenting case summaries from his or her own direct service sessions with patients and families ot other hospice staff members.

Conclusion

The psychologist can provide valuable services which indirectly benefit hospice patients and families. It is vital for the participating psychologist to understand hospice philosophy, patient populations, the responsibilities of various team members and issues related to death and dying. A basic knowledge of medical terminology, nursing services and factors related to the clinical care of terminal cancer patients (and other terminal patients) is also important. The psychologist must also communicate with the Hospice staff the training, skills, and knowledge of the consulting psychologist so that the services of the psychologist are utilized effectively. It would be helpful for psychologists to develop a statement similar to that developed by psychiatrists at the International Hospice Conference in London, 1980 (Feigenberg, 1980-81).

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Psychological/Emotional Assessment

I. Cognitive, Perceptual, Communication

☐ Alert, Oriented
☐ Confused
☐ Medication Side Effects
☐ Other ____________

Comments ____________ ____________________

____

II. Emotional

☐ Depressed, Hopeless
☐ Angry
☐ Suspicious
☐ Anxious
☐ Manic
☐ Alienation
☐ Guilt
☐ No Discomfort
☐ Loss of Control

Comments ________________________________

____

III. Coping Style

	Comments
☐ Passive Dependent	____________
☐ Resistant	____________
☐ Minimizing, Denying	____________
☐ Exaggerated Helplessness	____________

☐ Other ________________________________

____

IV. Behavioral

	Comments
☐ Isolated, Withdrawal	____________
☐ Attention Needs	____________
☐ Bizzare, Irresponsible	____________

☐ Other ________________________________

____

V. Family/Cultural

Comments

☐ Communication Problems ____________________

☐ Disengagement ____________________

☐ Neglect ____________________

☐ Problems with Individual Family Members ____________________

☐ Enmeshment ____________________

☐ Closed to Outsiders ____________________

VI. Quality of Psychological State

☐ Very good, no interventions needed

☐ Adequate, only minimal interventions needed

☐ Poor, interventions needed

☐ Potentially destructive to self and others

PROBLEMS	RECOMMENDATIONS
1.	
2.	
3.	

Comments ____________________

____

____________________ Evaluator

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ASSESSMENT OF THE KUBLER-ROSS STAGES IN THE COUNSELING PROCESS

G. Michael Averett, M.S.W. and Claire H. Averett, M.A.

In recent years the helping professions have been engaged in studying the subject of death and its many related issues. Even with this increased attention to the dying process, many professionals feel functionally illiterate and at a loss as to how to apply their helping skills to this aspect of the life cycle. Most helping professionals will, throughout their practice, be confronted with having to deal with a person who is dying. This professional role will also include helping the dying person's system deal with the patient's illness and death. Attempting to apply the usual helping skills often leaves the professional with feelings of frustration and inadaquacy. This is due to the inability of the counselor to apply skills developed to be used by clients as a "springboard to a long future of improved functioning" (McKitrick 1981 p. 165) where there is no longer a long future. As Kubler-Ross points out, the counselor's usual helping skills applied in the usual manner are not helpful to the dying patient or his network when the helping process is based on restoration of function for future behaviors. (Kubler-Ross 1969)

The objective of this paper is to examine the usual helping skills in relationship to the Kubler-Ross stages of death and dying and how they might be applied in providing a meaningful service to the dying patient.

The commencement of any counseling effort is the establishment of contact with the person and the development of a relationship. Volumes are published on this issue and the succeeding processes of counseling. (Egan 1982, Carkhuff 1979, Nicholson 1983) Compton and Galaway, in their discussion of beginning the therapeutic process point out that,

> "In preparation for the initial contact, workers will want to collect and review any pertinant data they have about the client system and the purpose of the coming encounter. In addition they may want to discuss with others in the setting the kind of help that the service system can offer.

> Because beginnings are important in establishing the pattern of ongoing relationships and because they wish to demonstrate respect and concern for the client system, the worker will want to do everything possible to reduce unnecessary obstacles to complete and free communication." (Compton and Galaway 1979 p. 279)

Many professionals take time immediately before entering a counseling experience to prepare themselves as Compton and Galaway suggest. Nicholson and Golsan in The Creative Counselor, suggest the need for possibly even more in depth preparation. They call their preparation period pre-attending. During this time the worker does the normal preparation for the session as well as considers the need to develop new skills for special situations. (Nicholson and Golsan 1983) Work with the dying person and his system is a "special situation". Kubler-Ross was frequently critical of professionals for being too technical and less human. She sees the emphasis on technology as a means of denying the dying process.

> "Is our concentration on equipment, on blood pressure, our desperate attempt to deny the impending death, which is so frightening and discomforting to us that we displace all our knowledge onto machines, since they are less close to us than the suffering face of another human being which would remind us once more of our lack of omnipotence, our own limits and failures, and last but not least, perhaps our own mortality." (Kubler-Ross 1969 p. 9)

Professionals working with the dying need to do a particular type of pre-attending. Studies which show the value of the counselor experientially examining his own views on death (Bugen 1980, Durlak 1978, Whelan and Warren 1980, Engel 1980) indicate that a useful part of the pre-attending process becomes an intense examination of the professional's attitudes and feelings of death. Kubler-Ross suggests that a personal look at ones own mortality is crucial in order to touch the understanding of the dying patient. (Kubler-Ross 1969)

The next facet of the counseling process is to make contact with the patient and begin the development of a relationship and what Egan calls exploration of the problem. (Egan 1982)

The usual skills of active listening, genuine warmth and empathy are all useful with the dying patient. Though Klass (1982) criticizes Kubler-Ross for a theory of practice based on feeling tools rather than scientific verification, the intimate period of the life cycle related to dying has little or no room for a scientific approach to counseling. This is a time when personal feelings and systems relationships intensify. If the professional attempts to apply the helping skills in a ridged step-by-step process of counseling, the patient will likely withdraw from the relationship.

Kubler-Ross indicates that a person who is dying will likely go through five stages or levels of experience. The five levels are denial, anger, bargaining, depression and acceptance. The counselor can use these stages as an assessment tool in evaluating the appropriateness of counseling intervention. The levels provide the professional with a guide to where the patient is emotionally at any point in the therapeutic process. Kubler-Ross herself cautions that these stages are not sequential. Dying people do not move through each stage in a specific way, on any specific time table and may fluctuate between stages returning again and again to any stage. No one stage is the optimum experience for the dying person. The task of the counselor is to help the client process the problems inherent in each stage according to the client's needs. There is no "right" way to die. Because of this, the professional must be creatively involved in the therapeutic process.

> "Such is the case with creative counseling. It represents counseling at its very best - firmly founded in the basic principles of helping, but never tied to any ridged system of techniques. It flows with the clients' needs and draws upon whatever resources are needed to meet them."
> (Nicholson and Golsan 1983 p. xi)

Denial is the first of the stages. This is a period of shock or disbelief. The patient is saying, "This can't really be happening to me. The doctor must be wrong." The denial process acts as a buffer for the overwhelming knowledge that one is dying. Therefore, denial is not a negative process in the usual sense. It is simply a part of the process a person goes through in coming to grips with the termination of life. Beilin states that denial seems to act as a stabilizing influence upon relationships. People naturally withdraw from the dying person. Denial allows the patient to keep his social system intact for a while longer even though it is fragile. Denial also allows the patient time to process this life event. Denial can also work against the counseling relationship in that it may add to the clients' resistance to being involved in a counseling process. A patient may choose to stay in the denial stage. The role of the professional is to help the patient to attempt to solve the problem using the usual problem solving methods. This allows the patient to choose the way he/she will die or as Beilin puts it, to die an "appropriate death" for his/her system. (Beilin 1981 p. 32)

The second stage outlined by Kubler-Ross is anger. In this stage the patient is saying, "Why is this happening to me?" The person, especially an adolescent, feels anger about all the things in life that he/she will miss. He is also angry about not being in control of the outcome. Frequently, anger will be directed towards others, friends, family and especially the medical and helping professionals. The counselor may need to strategically retreat from but not abandon the patient. The counseling focus may turn to support of the patient's network. Contact should be maintained with the patient in order to allow him the opportunity to intensify the helping relationship when he is once again able to do so. In some few instances the professional will be asked not to continue with the patient.

The third stage is labeled, bargaining. A patient will frequently bargain with God as he understands him and/or the medical practitioner to take the problem away or at least prolong life. At times the patient may desperately seek any means of treatment to take away the threat of death. As denial is a buffer from the initial threat, so is bargaining a tool to maintain hope. Bargaining is a partial acceptance of the reality of the patient's condition. "I will accept this condition if..." The bargaining phase is a natural time to explore options open to the patient.

Once the patient realizes he actually has no control over his life, a sense of helplessness takes over. Martin Seligman (1975) empirically demonstrates that depression is in large part a frightening perception of not having control. The terminally ill patient cannot control this last aspect of life, death. Thus, the difficult phase of depression begins. In the traditional counseling process, problem solving skills are taught the client. "If therapy is to end properly, it must begin properly - by negotiating a solvable problem." (Haley 1976) For the terminally ill patient, death is not a solvable problem. Here is where the counselor can feel most inadequate which may be a reflection of the counselor's own inadequacy to control his own death. This inadequacy may cause the professional to withdraw from the helping process. By changing the focus from the future to the here-and-now, the client can be assisted to gain an accurate picture of things that can be controled. Some issues which can be controlled by the patient are his medical treatment; who will treat him, what treatments will be accepted and where he will be treated. The counselor can aid the patient in "negotiating the labyrinth-like maze of the world of health care reimbursement",(Liss-Levinson 1982) taxes, wills, social security etc. Though the "meat" of the dying process may be the confrontation of death to the counselor, the patient and family may have more need for help with practical details. Gaining control over some elements of the dying process may help move the patient out of depression and toward what Kubler-Ross calls acceptance.

Acceptance is where the patient gains an understanding of the terminal condition and deals to some degree with the reality of death. As one patient put it "It is not the dying the concerns me, its the leaving." Acceptance is not a state where the patient is happy with death, but rather at peace with death. The role of the counselor specific to the acceptance stage is frequently one of maintenance. It may involve periods of being accessible or with the patient and his system as they desire.

The professional role is to assist the patient with what they are trying to deal with at any time during the dying process. As helping professionals, it is important to be open to following the agenda of needs of the dying person rather than focusing on our own covert agenda. An elderly man with a long history of health problems who had nearly died several times but was revived each time, recently committed suicide. He had frequently said he was ready to let nature take its course but others would not allow him to die. The man finally succeeded in completing the process of dying by choosing a less acceptable form of death because it was the only choice not controlled by others. By using the Kubler-Ross stages and the counseling process, the creative professional can help others to explore feelings, identify solvable problems and to make appropriate choices. This process will help the dying person in his struggle to come to terms with the final stage of life.

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"MAKING THE ROAD LESS LONELY"

The Role of the Volunteer in Hospice

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The hospice volunteer, assigned to care for a terminally ill person and that person's family, wears many hats: that of companion, confidant, advisor, listener, comforter, nurse, teacher...and sometimes student, for we can learn much about life from those who are dying.

The hospice volunteer is a quiet, caring presence in the life of the patient and family. Hospice views the volunteer's most important role to be that of a loving, supportive friend[1]...going as far down the road as possible with the dying person...to make it less lonely...to turn the pain around...to understand their loss[2]...to care.

Hospice believes that a dying patient, after all treatment is exhausted, has the right to live his final stage of life in peace and comfort. Hospice care is identified by a number of elements: 24-hour-a-day availability of care, informed consent and participation of the patient's private physician, emphasis on symptom and pain control, and always, the inclusion of volunteers as an integral part of the hospice team.[3]

In practice, most hospices have integrated these components into their programs--but none more so than the importance of the volunteer.[4]

Even most large hospice organizations with inpatient facilities use their buildings as back-ups for home care, relying largely on home visits by staff nurses and dedicated volunteers.[5]

Although the hospice movement has done pioneer work in pain control, psychology of death and dying, and other areas[6], the overall emphasis of hospice care is not so much on new technology as on personal care: detailed medical and nursing care in a warm, open, supportive environment.[7] And at the heart of this care is the volunteer.

The key to successful volunteer performance is thorough training and preparation. Volunteers are recruited, selected, and trained under careful supervision, and their performance is monitored frequently during assignments.

With the almost unlimited human resources available to hospice volunteers--the medical director, volunteer director, primary physicians, staff nurses, clergy, advisory council, and other health professionals associated with hospices--he/she need never feel alone or overwhelmed with a problem concerning a patient or family. An integrated team approach is the basis for hospice care.

Selection is made of potential volunteers who are well-adjusted, have patience, energy, and warmth--and can give their time as required when with a patient (usually two to ten hours a week).[8] Most hospice programs will have some sort of restriction about accepting a recently bereaved person as a volunteer. Although volunteers who have suffered the loss of a loved one often bring a special sensitivity to their duties, their bereavement process must be completed or problems can develop. To avoid this, the hospice program may mandate a "waiting period" (usually six to twelve months) after any major loss of family member. This sometimes includes divorce.[9]

The volunteer training is intense, usually covering twelve to thirty hours in various subjects and exercises designed to give the participants a strong foundation and understanding of hospice care and philosophy. Content areas are likely to include: history of hospice movement, pain control, palliative care, role of the volunteer, spiritual care, cancer and related therapy, family centered care, communication skills, grief and bereavement, fear of death, physiology of death, psychological aspects of death and dying, community resources, legal issues, and funeral planning (which may include a mortuary tour).[10]

Following the training, volunteers are ready for the beginning of practical experience. Often a new volunteer will be paired with an experienced one. The first visit is always hard--but by relying on their training, maintaining an attitude of openness and receptivity to the needs of the patient and family, and by respecting the family's desires and beliefs, the volunteer's relationship with the patient and family unfolds naturally.[11]

Most programs stress the importance of hospice being called in soon after a diagnosis of terminal disease is made, rather than waiting until the patient's condition deteriorates. If the volunteer is to be effective in aiding the family in time of crises, he/she needs time to establish a relationship with the patient and family, and the family and patient need to build trust and confidence in the volunteer.

Some of the tasks volunteers perform for the patient/ family unit may be routine, especially early in the assignment: meal preparation, writing letters, family shopping, homemaking chores, babysitting for the family's children, relief for family caregivers. But providing help of this nature can mean much to a spouse or other family member physically and emotionally overwhelmed by coming to terms with and caring for a loved one with terminal illness.

Performing other supportive tasks--transporting a patient to and from treatments or doctor visits, dressing, feeding, bathing the patient and other nursing measures--can mean substantial financial relief to the family, and at the same time show the patient loving care and attention. By allowing the family to feel confident and competent about the care given the patient by themselves and the volunteers, the patient can often be kept out of a hospital or other care facility, lifting the financial burden and keeping the patient in familiar surroundings among loved ones.

The volunteer's role as liaison between medical persons and the patient and family can mean detailed attention and care. The volunteer will often notice subtle changes in a patient's condition when he/she sees the patient regularly. The family can be alerted to potential problems before they get out of hand. The volunteer's training in observation and reporting can be helpful to the attending nurse or physician in determining if the prescribed course of care is appropriate or needs to be altered.

Personal attention to the emotional needs of the patient is equally important. Talking to them...listening to their fears and concerns...holding their hand...helping them to learn a craft or skill...or better yet, letting them teach a skill or talent can make that patient feel useful and important, and let them know that they matter right up until the minute they die. Helping them to tape record or write their life history or songs and stories for their children or grandchildren can help them to let go more peacefully, knowing that they will be thought of and remembered after their death.

Family members need moral support, too...not necessarily someone to "do" anything, but someone to listen...to react and absorb their outpourings. It is a difficult role, but it can be immensely rewarding.[12]

All hospices provide some sort of bereavement services for the surviving family members after death has occurred. Some programs also offer socialization opportunities to the bereaved. Again, it is the volunteer who provides the continuity of care for the family with frequent visits and phone calls at first, gentle encouragement to return to activities as they feel ready, extra attention around holidays and anniversaries--times that can be painful because of past memories. A volunteer often remains a lasting friend to the family for years after the active hospice involvement is over.

The variety of the work is one of the reasons hospice volunteerism is so rewarding; but the stress level is high. The volunteers will experience grief of their own whenever a patient dies, and sooner or later the volunteers themselves need support and comfort.[13] Since the volunteers are so crucial to the hospice programs, it is crucial that the programs provide outlets to these stresses: group discussions, inservice educational sessions, and the opportunity for leaves of absence or switching to nonpatient-care work, if desired.[14] The incidence of volunteers leaving hospice work permanently is low.

Hospice volunteers are special people. They are strangers, initially, who end up providing unconditional love and support at a time when former friends and acquaintances may turn away. They view their hospice duties as a privilege. They revel in being a part of something uniquely useful and desperately needed.[15] To put it simply: they care.

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BEREAVEMENT AND THE OLDER WOMEN

A Model for Caregivers

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INTRODUCTION:

Death of a spouse is one of the most traumatic of all human experiences. Dealing with profound loss is a very personal, individualized process and we each react differently to loss at various levels asnd within certain circumstances. This training deals with older women in stage of grief and, subsequently widowhood. The concepts and ideas presented herein are suggestions for you as caseworkers to provide support and help direct older women through the difficult first steps of the transition between marriage and widowhood. The model is intended for women in "normal bereavement". Should specific content areas trigger profound responses in your client, further exploration and assessment should be rendered (i.e., unresolved guilt, chronic self-defeating behavior, prolonged grief).

The major emphasis of therapy for many widows is on (1) recognition of the loss, (2) open expression of grief, (3) reassurance that they will survive, and (4) how to do it. As a caseworker, sensitivity to the degree of loss, based primarily on the quality of the relationship, is of utmost importance. Appreciation and recognition of the client's pain of separation will enhance the therapeutic process. Reassurance and support cannot be overemphasized. Although some people choose to remain in an unresolved grief stage indefinitely, research has found that many older women, with direction and support, appropriately work through grief and bereavement to lead fulfilling, worthwhile, self-satisfying lives as widows. With this special awareness to the needs of older women, let's begin our training session.

TRAINING:

The program will be divided into three content areas that "blend" in terms of overlap and sequence. Due to limited time availability, a cursory view of these concepts will be provided: (1) Grief - Mourning - Bereavement, (2) Environmental Boundaries, and (3) Re-Directing and Energizing. As indicated on the program format, time for evaluation, comments and feedback will be provided at the conclusion of the training.

I. GRIEF - MOURNING - BEREAVEMENT

What is grief? How does it differ from mourning and bereavement? Clarification of these facets of feeling loss is helpful to the caseworker in identifying the particular stage of a client's feelings and progression. According to psychologist, John Bowlby, grief is the acute expression of emotion immediately following death (3-5 days). Mourning is the

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period that follows (from 1 week to 10 days) including rituals of funerals, memorializing the dead. Bereavement is the extended prolonged reaction (up to one year) after the death. Recognize that these are only suggested timeframes. The length/intensity of each stage is highly correlated to the length and quality of the relationship that has ended. Many older women are in a bereaved state for several years. This is not necessarily indicative of severe neurotic or psychotic coping mechanisms. Professional judgment must be used in each individual case.

After the numbing shock of the first several days following the death wears off (grief), your client may experience feelings of disbelief, loneliness and despair. Physical as well as psychological symptoms may accompany this stage. This is a part of mourning. The next stage is bereavement - an extended period, generally lasting up to a year or more. Again, specific symptomatic behaviors can occur during this time (refer to attachment, Lamers, 1979). Rather than elaborate on the details, please refer to the attached cycle of healing. As practitioners, be aware of symptoms accompanying bereavement so as to assure your clients that their feelings, actions, and behaviors are normal. There is no right or wrong way to grieve. When a client asks, "How am I supposed to feel?" the best repsonse is, "The way you are feeling." Comments such as, "Time heals", "I know just how you're feeling", "Chin up", "Don't feel so sad", "You'll get by just fine", are totally inappropriate. Again, recognition of feelings (owning your feelings) is the only way expression and resolution can occur. Facilitate this process with your client. Explore, recognize, verbalize, affirm - these are key elements.

Many older women feel they are "going crazy" during bereavement. They hear their husbands' voices, catch a glimpse of him turning the corner in a grocery store aisle, hear his footsteps on the front porch, feel him lying in bed next to them, smell his pipe tobacco. All of these reactions are normal when one is bereaved. Assurance of sanity is critical. All behavior has meaning regardless of how irrelevant or inappropriate it may seem.

Lindemann's model of grief work is helpful in successful treatment. Grief work is not easy. It is painful, demanding work - physically, emotionally, psychologically, spiritually. There is nothing easy about it. Tears will come easily. Depression, loneliness, insomnia, loss of appetite, physical pain are all common within grief work for many. Subtle reminders of "him" may evoke overwhelming emotional responses - a song on the radio, seeing an old business colleague of his, a phrase or pet saying. Tears, memories, talking are all ways to cleanse and "work" through the grief. Widow support groups are often helpful for many women. Understand the need to talk about the deceased person. Allow that; don't avoid it. Just because he has died does not mean he never existed. Help the client to integrate the past with the present and the future on a continuum. Encourage clients to recognize their own support groups - family, friends, church, community organizations, clubs. Often widows need to be coerced into letting others care about them - allowing those who love them, to love them. This is especially relevant in those situations where a wife has taken care of a sick husband for a long period of time. She perceives herself as the "caregiver", not the one receiving care and support. Identifying feelings, venting, viewing actions/thoughts as "normal" responses to loss, utilizing support systems, allowing others to love and care for them and most of all knowing that grief work is <u>work</u> are the most important psychological issues for the client to deal with in the initial stages of widowhood.

There are many "helps" in doing grief work, but in the final analysis, it's the client herself that must do it. As caseworkers, your role is to provide understanding, patience, support, empathy, caring, encouragement and positivism to your client.

II. ENVIRONMENTAL BOUNDARIES

After several months have passed, most widows begin to slowly re-enter life. A conspicuous absence is felt. It is generally therapeutic to help the client acknowledge that her life is changed, it will never be the same as it was. So, what does she do now? Honesty and realism in assessing options is your responsibility. When considering a client's opportunities, motivations and ability must be addressed. During this stage of therapy, focus is generally in the areas of building self-esteem and confidence, and identifying life opportunities.

Often older women suffer from poor self-image. In recently widowed women, this can be compounded by guilt, anger, depresion from the recent death. A treatment approach should include focusing on positive attributes, strengths of the client. This process is often very slow to enact. Perserverance and optimism in therapy is a must.

Recognition of shrinking environmental boundaries and the impact of that process on older women clients is useful to you as a therapist in understanding feelings of inability, lack of motivation, "aloneness", anxiety, frustration and apprehension about the future. Identifying elements within the client's environment is necessary as most areas have been altered somehow by the death of the spouse. Those areas to be addressed include finances, social participation, health, transportation, family relations, religion, and leisure time. This list is not all inclusive but looks at major life areas.

Changes in finances occur through income reduction, hospital/funeral expenses, altered lifestyle patterns. Social interactions for many older women are contingent, for the most part, on their husbands' contacts through former employment, social clubs, business acquaintances, etc. Often the widow loses her "connection" to many social functions. She will notice being treated differently by friends and/or in groups - an aspect of being a "single" in a "double's" world. Fear of prolonged illness or chronic, debilitating disease is an area of concern. Mobility and access to many necessary places and services (doctor appointments, grocery store, shopping, visiting friends) is greatly restricted if the older woman does not drive. Dependency on others for transportation can be limiting and troublesome. Support from family members is sometimes changed after the death. Clients often feel imposing and burdensome on their children. Religious involvement tends to fluctuate in intensity during early widowhood until a more stable life pattern evolves. The question of filling time is often overwhelming. Clients focus on empty hours, quietness in the house, lonely rooms, sad nights. As a counselor, awareness of these feelings in clients is necessary.

Although optimism is part of the nurturing therapy, realistic review of the client's abilities and resources needs to take place. There will likely be limitations, either

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self-imposed, circumstantial, or societal, but an important factor is to focus on the positive. Again, reiterate value of the "now".

III. RE-DIRECTING AND ENERGIZING

Two key components have been specifically identified as focusing on the positive and drawing from individual strengths. With this outlined, the redirecting and energizing process can generally fall into place gradually. Several important premises can be made:

(1) the first step is the hardest
(2) you have to start somewhere
(3) you can choose to have control over your life

These are easily listed but obviously difficult to initiate. As a counselor, encourage your client (when she is capable - not necessarily ready) to take that first step of re-entry. Suggest she do something - anything. Have her daughter over for lunch; go shopping for a new blouse; walk to the library; meet a friend for coffee; visit a senior citizen center; write a letter; read a book. Have her identify a very small, immediate, easily accessible goal - then go for it. Don't suggest a major undertaking. The widow needs to succeed, not fail at the task. If she can begin to complete one small, positive act each day, her self-image, interest in life, energy level, feelings of worth are bound to be affected. During the first

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several months to a year following the death, the client should be discouraged from any major actions, be it investments, selling her home, moving out of town, etc. There will be time for all of that, but allow time for bereavement. It is often useful to counsel with your client about the value of continuity. Death is very disruptive with every aspect of life being somehow touched by the loss. To maintain some sort of stability and continuity (as much as possible) often eases the transition that naturally occurs following major loss. Now is not the time for your client to impose added confusion, upheaval and trauma upon herself.

As the days, weeks and months pass, her outlook will probably begin to brighten. She can expect some minor setbacks, but the good days will begin to outnumber the bad. If your client expresses an interest in added involvements, have a healthy list of options to present her. These can include: volunteer work, gardening, part-time jobs, classes in school, community projects, leisure tours, social club membership, support groups (Widow-to-Widow), handicraft classes, short vacations, exercise programs, church involvement, etc. Your abilities as a resource person through information and referral and liaison may be called upon. Familiarize yourself with community services and programs that are available (i.e., Homemaker Program, Chore Service, Legal Aid, Employ-

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ment Services, Retired Senior Volunteer Program). Another helpful hint for many older women that live alone is to get a pet. As there are sometimes restrictions on cats and dogs in housing complexes, fish, turtles or birds can be purchased. Most of us have a need to be needed. If pets are not an option, houseplants are suitable. For your client to be surrounded with living things - signs of growth, life - is conducive to her own growth and healing process.

SUMMARY:

As we look over the content of this training, it is evident that many issues have not been addressed or developed at length. However, as a general guide and aid to awareness of special needs of widowed older women, I feel we have touched on some relevant issue areas. Hopefully, this training has sharpened your skills as a clinician and has opened your thoughts and imaginations toward creative counseling with a very special segment of our population - the widowed older woman.

EVALUATION:

Time has been allowed for feedback, questions and answers and general comments regarding the training. Please share your feelings with regard to the information presented.

Carol Payne

TABLE 1.

Stages of Ordinary Grief

Timetable	*Manifestations*	*Recommended management*
STAGE 1: Begins immediately after death, lasts one to three days	Shock Disbelief, denial Numbness Weeping Wailing Agitation	Home visit Arrange office visit Nighttime sedation Avoid daytime use of sedatives or tranquilizers
STAGE 2: Peaks between two to four weeks after death; begins to subside after three months, lasts up to one year	Painful longing Preoccupation Memories Mental images of the deceased Sense of the deceased being present Sadness Tearfulness Insomnia Anorexia Loss of interest Irritability Restlessness	Periodic office visits Encourage expression of feelings Explanation of grief process Reassurance that what bereaved feels is part of the normal grief process Nighttime sedation Avoid daytime use of sedatives or tranquilizers
(In rare cases of severe depression, consider [1] antidepressants, [2] hospitalization, [3] psychiatric consultation and [4] electroshock therapy.)		
STAGE 3: Should occur within a year after death	Resolution Decreasing episodes of sadness Ability to recall the past with pleasure Resumption of ordinary activities	When indicated, discussion of anniversary reaction

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William [illegible], MD
1979

A "YOUNGER" ALZHEIMER'S SPOUSE SPEAKS OUT

By

Marjorie P. Westergard

President, Ogden Alzheimer's Support Group

In February 1980 I was informed that my husband, who had just completed four days of testing at the University of Utah Medical Center, was suffering from Alzheimer's Disease. At that time "Alzheimer" was not a word familiar to the general public. As Dr. Christensen explained what this diagnosis meant, I realized my life, as I had known it, had just ended. I was 49. Harold was 56. Three of our four children, ages 17 to 25, were still at home. We were about to begin a new chapter in our lives.

In telling my story, I speak for Alzheimer spouses everywhere who are suffering from this tragic disease along with their mates. Many feel that the true tragedy of Alzheimer's Disease is never shown in the television specials that have frequently appeared in recent months. A victim's loss of memory is only a small part of the devastation that takes place in the family.

Harold was a loving, caring father and hsuband who, for 25 years, provided well for his family. He very successfully operated a small business, was active in civic affairs, and had served as bishop of his ward. He had dedicated his life to serving others, and had found his greatest source of happiness through this service.

Then Harold began to change. When he first began to forget appointments, etc., the family would jokingly blame his absent-mindedness on the pressures he had had when he was bishop. But then other changes began to occur. His behavior became very inapporpriate at social functions, causing extreme embarrassment to the family; he became paranoid, accusing certain people, especially me, of being against him; he became easily angered; he was rude to many of his business customers and soon lost, not only customers, but employees; his feelings of concern for his family were gone. When our youngest son faced a serious problem in his life, Harold did not want to hear about it. He just didn't care. He was arrested for shop-lifting, and on the evening he was to receive an award from a local service club for his outstanding service to the community, Harold was facing a judge in another area of the county on charges of evading a police officer. I accepted the award on his behalf.

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These events, and others, spanning a period of two years, finally led to the visit to the Medical Center and the resulting diagnosis: Alzheimer's Disease.

During the ensuing months I discovered the nightmare was just beginning. We had lost all of our health and life insurances because premiums had not been paid. (Some of the life insurances were reinstated, but not all.) Taxes had not been paid, resulting in heavy penalties. My dear husband, who had never believed in going into debt for anything, had left me a business buried in debts. In the course of two years he had spent or lost all of our money and had ruined a profitable business. Our banker, on looking back, still doesn't see how it could have happened, but it did happen.

Harold had become obsessed with buying things. He had subscribed to every magazine, book, stamp, coin, record, tape, or hobby club that sent him applications and promises of free gifts. He was on everyone's mailing list, and he made everyone happy. I discovered that he was a frequent and popular participant at all the local auctions. It took almost a year to get his name off of these mailing lists, and some of the magazine subscriptions must have been life-time, because I am still receiving them.

As I look back on the effect these events had on my emotional state, I sometimes wonder how I survived, but I did survive, and I will survive. Emotionally, I went through three stages:

1. Complete Frustration

   During the year preceding diagnosis of the disease, I frequently asked the question, "How could this man, who had always been so thoughtful and considerate, turn his back on his wife and family?" For the first time in 25 years I began to quarrel with him. I scolded him. I even made him attend a marriage counseling class. But to no avail. (My son recently found a letter I wrote to him, accusing him of forsaking the vows he had made at our wedding.) I was at my wit's end. I just did not know what to do or where to turn. During this period I had confided in no one. I felt guilty for having these feeling for my spouse and kept them within myself.

2. Shock - Grief

   When the doctor pronounced my "life sentence", numbness overtook my body. I did not then fully comprehend what was in store for us, which was a blessing. I feel, now, that I must have experienced the same grief one feels when a loved one dies, only flowers and expressions of sympathy didn't come pouring in, because my loved one was still physically present. Because Alzheimer's Disease is such a slow death, this period of grief probably extends over a longer period of time than after normal deaths. I have found, in working with the support group, that many spouses can't seem to leave this stage. They don't want their life-patterns altered, and so refuse to accept the fact that their spouses, as they knew them, no longer exist.

3. Acceptance

After the initial shock subsided, I began to understand the reasons for his drastic behavior and personality changes. My little family, though young in years, were very mature in facing this crisis; in fact, it was actually a relief to all of us to know that "Daddy" wasn't responsible for the actions that had caused us so much grief and concern. We determined to do our best to give him the love and care he deserved. Unfortunately, not all families of Alzheimer spouses offer this kind of support, and spouses are often left to face the task of caring for their loved ones alone.

Some decisions had to be made immediately. I had inherited a business that had been mismanaged for two years, I had just acquired a new "son", seven years my senior (my role had changed from "wife" to "mother"), and I had suddenly become sole provider for my family. Although I had helped my husband in the business, I knew nothing about finances or business management.

Advice came from many directions. I listened to it all. Bankruptcy and divorce were frequently mentioned. It was suggested that if I divorced Harold, he would no longer have any assets, and Medicaid would then pay for his medical expenses after we could no longer care for him at home. Although I don't criticize those who choose this path, I could not do it. I had vowed to love my husband in sickness and in health, and, to me, one divorces a spouse when the two no longer love each other. I also decided to try to save the business. Since we owned a music store, I adopted the motto from a song in the musical "Unsinkable Molly Brown" called "I Ain't Down Yet."

At this time I gained a respect for the LDS Church Welfare System. When picking beans on our welfare farm, I used to feel good, knowing that we would be entitled to food if a disaster struck our family. Disaster did strike our family, but food we didn't need. I discovered the welfare program encompasses much more than food. An advisor was called to assist me in settling the financial problems of the business and in teaching me management techniques. A bishop, whom I had never even met, took over my books, which were in terrible shape, and kept my records for two years at no charge.

Aware that many problems still lay ahead, but with a constant prayer in my heart, I began my new life. Since our home is just three doors away from our store, I was able to care for Harold and manage the store for four and a half years, but it was almost an impossible task. Convincing him that he had "retired", that he no longer needed to drive were just a few of the challenges we faced each day.

He came to the store every day, as usual. At first, I let him keep his desk in his office, and provided him with simple tasks, such as stamping envelopes, etc. We tried to treat him with the dignity and respect that he deserved. Later a special chair was placed in the store just for him. Often I would have to follow a customer to his car, apologizing for my husband's inappropriate remarks, explaining his condition; Occasionally Harold overheard my apologies and became furious, sometimes violent.

Excessive wandering is a characteristic of Alzheimer's victims, and I believe my husband could have won the "gold medal" in the distance wandering event. So while waiting on customers, we also had to observe the direction in which he was heading. Then when we had a free moment, one of us would go in search. As the disease progressed, the wandering became more hazardous because he would not watch for traffic. As his body began to tire, he found that hitch-hiking got him places much faster. Only he never knew his destination. On one occasion my son flagged down a car on the inter-state, carrying Harold as a passenger. The older couple were on their way to St. George, and Harold had said that was where he was going, also. He still looked respectable and dignified, and respectable people picked him up, but I shudder to think what would have happened if the wrong type of person had stopped for him.

As the disease progressed, I learned to adjust my life to the stage he was in at the time. Our social life virtually stopped. Fewer and fewer friends invited us to social functions, and I could understand why. Although he could no longer attend the opera, symphony, or theater (a few humiliating experiences taught me that lesson), there were still some things we could do to break the routine of the work day. I just had to learn to be creative in planning these events, and changes were made constantly as Harold changed. Of course, I could never completely relax, but it was better than nothing, and I looked forward to these little planned activities and outings, sometimes just the two of us, but more often with other family members.

In 1982 I assisted Jean Kobler, a nurse, and Jo Fox, whose mother-in-law suffered from the disease, in forming the first Alzheimer's Support group in Ogden. This group then branched out into support groups in Logan, Salt Lake City, and Provo. If ever a group of people needed an outlet for discussing problems and needs, it is the family members of Alzheimer's victims.

Through all the heartaches and frustration of the last five years, I have been able to maintain a sense of humor, most of the time. Although some of the people who attend our meetings state they can see nothing funny about Alzheimer's Disease, Shakespeare once said that there was a thin line between tragedy and comedy, and I strongly believe it is my sense of humor that has kept my sanity during these trying times. When we discovered all the cardboard centers of our two years' supply of toilet tissue missing, and later found them all spray-painted gold, it was frustrating, but funny. We laughed. Laughing released many of the tensions during very stressful times. We never laughed at Harold, but we laughed at many things he did, not always at the time they occurred, but later. Recently our county commissioner visited our support meeting and told how he had asked Harold to put up small signs for him around the county the first time he ran for office in 1980. Harold agreed, and the next morning Commissioner Hunter's signs and pictures were nailed to all the traffic signs in the north part of Weber County. That was his first experience with Alzheimer's Disease. Laughter has been a form of medicine to me. I have learned to subsitute it for tears whenever possible.

Families of Alzheimer's victimes are in dire need of assistance, both financially and from supportive programs that will offer relief to the caregivers. Since the Alzheimer victim can no longer work to support his family, this burden falls on the spouse, and sometimes it is impossible to support the family and take care of the victim, too. Families with Alzheimer victims usually lose most of their financial security. Government programs will assist when there is nothing left, but some type of financial assistance should be made available to spouses so they can still maintain some degree of dignity and have a few comforts of life. The National Alzheimer's Disease & Related Disease Association is doing much to publicize the disease and to make the public more aware of some of the problems associated with it, but local public officials still need more education on the subject.

Recently, the former chief of detectives of Ogden, an Alzheimer's victim,was arrested for shop-lifting. His wife was too embarrassed to tell the store manager of her husband's condition. Instead, she suffered humiliation as the police were called in, and she later went to court and paid the fine. This need not have happened, especially in Ogden, because our chief of police is well aware of Alzheimer's Disease now. After Harold was diagnosed, I called him and explained our situation. He helped me through many difficult times, and his officers will help in locating "lost" wanderers. Law enforcers and public officials need to be educated to the characteristics of the disease so that they can offer assistance when called. Then families need to know that they are willing to assist them.

One wife saw her husband step onto a UTA bus, but she did not know its destination. She called UTA, and a courteous gentleman assured her he would "track" her husband down. He finally located him in Farmington on his way to Salt Lake. He stepped on the bus, introduced himself to the victim, and said, "On behalf of UTA, we want to thank you for the fine job you did. I have a company car ready to take you back to Ogden." He treated the victim with respect, offered him his hand, and the victim left the bus without any trouble, and was returned home safe and sound.

I feel [illegible]t civic groups could offer some type of volunteer programs where caregivers could leave their "patients" for a few hours once in awhile. Churches, especially, need training programs to help their members assist suffering families in their congregations with respite care. I often hear complaints that "my Minister", "my Bishop", or "my Relief Society President" just don't care. I don't agree with this. I think they care, but don't always know what to do.

When my two daughters decided to get married a year after Harold was diagnosed, friends and members of my ward insisted that they give themlovely wedding receptions. The priesthood members of my ward helped remodel my store. I shall always be grateful to these wonderful people, but friends and members were afraid to do things for Harold. When they asked me what they could do to help, I'd say, "Just take him for a ride for an hour, get him an ice cream cone or little treat." Just to have an hour to be able to read the newspaper, just to have an hour to relax without worrying about Harold would have been the greatest luxury. In four and a half years, before it was necessary to place him in a care center, other than family members, two people took him for a ride. Many of our friends would pick him up when they saw him wandering out on the freeway, but they didn't offer to take him. Why? It wasn't because they didn't care. The "old" Harold they knew was gone, and they didn't know what to expect from the "new" Harold living in his body. They were afraid.

Since Alzheimer's Disease is the fourth leading cause of death in older people, I believe it is imperative that organizations within the churches learn how to handle these victims, that they offer spouses respite care. Too many spouses are dying before their mates because of the exhausting daily routines that never offer relief.

The medical profession needs to show more concern for the caregivers. I was fortunate to have a doctor who did spend part of our appointment each time addressing my problems, and I always felt he was genuinely concerned about me as well as my husband, but many spouses do not receive this support from their doctors. A frequent complaint I hear is that the doctor makes his diagnosis and then states that nothing more can be done, leaving the spouse bewildered and confused. The Alzheimer spouse needs to know that there are those concerned about the care-giver's well-being also. Some of the aides in the care centers are especially kind and considerate to families; others need training in this area.

I am not a member of the medical profession; I don't profess to understand the field of medicine; but I do understand Alzheimer's Disease. I tell my story in behalf of all Alzheimer spouses who are struggling valiently to make new lives for themselves and their loved ones in the midst of tremendous challenges and pressures. The course our lives have taken was not of our choice, but with support from family, friends, and community we will move on.

AN EVALUATION OF A HOSPICE CAREGIVER SERVICE

MARK de ST AUBIN

The hospice concept of care is fast becoming a part of the health care system in the United States. Since the founding of the first hospice in 1974, the number of health care facilities providing hospice care has grown rapidly. By 1982, the National Hospice Organization Directory had identified 464 hospice programs as well as 33 state level hospice organizations and an additional 353 programs in various stages of development (12).

There are three basic settings in which the hospice mode of care is generally given: 1) the free standing inpatient hospice, an example of which is the St. Christopher's Hospice in London (1); 2) the hospice unit within a general hospital which serves as a palliative care facility for those hospital patients who are terminally ill; and 3) the home based hospice program with its own staff and medical team which care for the terminal patients primarily at the home of the patient or caregiver, but who will also work with the hospital staff if the patient needs such facilities and care.

One such home-based program, Hospice of Utah County located in Provo, Utah, has been in existence since April, 1982 and was the subject of this study. Of the 19 program objectives of Hospice of Utah County, three of them deal with the agency's care and service delivery to the terminal patient's caregiver and/or family. This study had a dual purpose, the first being to evaluate the effectiveness of this agency's achievement of three program objectives; secondly to the extent that this agency was representative of home-based hospices in general, to evaluate the effectiveness of home-based hospice care in serving the caregivers of the terminal patients as compared to traditional care of the terminally ill.

Several studies on the effectiveness of hospice care have been done in the last decade (1-7), and two major studies are currently being conducted (8,9). Of these, at least six have examined the impact of hospice care on the primary caregiver/family of terminally ill patient. The reader is referred to these sources for a review of the research in this area.

PROGRAM DESCRIPTION

Hospice of Utah County (referred to hereafter as "Hospice") is a home-based facility which has served, in its first year and a half, 120 patients and their families. This agency is staffed with a program director, seven non-salaried staff members, ten nurse volunteers and approximately 30 community volunteers. Hospice implements a program in which emphasis is placed upon palliative and supportive care to meet the special needs of its patients and their families during the final stages of illness. Full scope health services are provided by an organized interdisciplinary team, available on a 24-hour-a-day, seven-days-a-week basis.

The program objectives of Hospice relating to caregiver service are the following:

1. To provide emotional support for both the patient and the familiy/caregiver.
2. To involve the patient and family/caregiver in patient care planning and decision making.
3. To assist the family members or caregivers in healthy resolution of grief after the death of the patient.

The above objectives as they relate specifically to the caregiver were the ones tested in the study.

During the period of time between December,1983 and December,1984 Hospice served a total 73 patients and their caregivers, of which, 46 were included in this study. For the group of 28 Hospice caregiver respondents the mean number of weeks of Hospice care per patient/family was 7.5; the. Regarding the number of Hospice visits (by staff, nurses, and community volunteers) per patient/family for this group the mean was 21.6. Post-death bereavement support was offered to each of the caregivers at the time of the patient's death, though not accepted by all of the 28 respondents. Of the 23 that had received some bereavement support, the mean number of Hospice/caregiver contacts were 2.1. In addition to the bereavement contacts made by staff, the Hospice also ran a 6-session bereavement support group three times during 1984. This group consisted of bereaving Hospice caregivers and those interested from the community. Attendance at each session by one of the Hospice group respondents was counted as a single bereavement contact for the purpose of this study.

HYPOTHESES

The three hypotheses for this study were developed from the three program objectives relating to caregiver service. They are as follows:

Hypothesis 1: Hospice care significantly increases caregivers' perception of emotional support received from medical staff.

Hypothesis 2: Hospice care significantly increases caregivers' feelings of involvement in patient care during the terminal illness.

Hypothesis 3: Hospice care (including the period from beginning of hospice intervention through post-death bereavement follow-up) significantly increases the caregivers' resolution of grief.

METHODOLOGY

Samples:

Two sample groups of ex-caregivers (subjects selected after the death of the terminal patient) participated in this study. The first group of 73 caregivers were selected from the 46 families served by Hospice whose terminal family member had died in the past 14 months. The second group of 66 caregivers were selected from obituaries published in a local newspaper and then contacted by phone to determine willingness to participate in the study. Pertinent demographic data of these two groups of caregivers are given in the Demographics Table.

Procedure:

After the caregivers from both sample groups had been selected, they were each mailed the questionnaire accompanied by an introductory letter briefly describing the study and inviting them to participate in it. To preserve confidentiality, each questionnaire was coded with an identification number which corresponded to the respondent's name on a master list. This list was kept in the researcher's possession.

Of these two groups to whom were mailed the questionnaires, 20 from the Hospice and 43 from the non-Hospice group returned them within the first ten days. After a follow-up call to those who had not returned them, another eight were received from the Hospice group and eleven from the non-Hospice group making a total of 28 (63%) from the Hospice group and 53 (80%) from the non-Hospice group who responded. One possible reason for a higher return rate from the non-Hospice group was that the caregivers from this group were contacted by phone prior to the sending of the questionnaire whereas the Hospice caregivers were not. Upon reviewing the questionnaire responses, it was found that four of the non-Hospice respondents had, at some time during the terminal illness, received hospice care (from a hospice other than Hospice of Utah County). These questionnaires were excluded from this study as the data from them might make obscure any relationship between Hospice care and the independant variables being measured. The remaining 49 respondents constitute the non-Hospice group for the study.

Instruments:

The questionnaire included instruments to measure the following dependant variables related to the program objectives:

1. Perception of emotional support received from the medical staff during the terminal illness ofthe deceased.
2. Feelings of involvement in patient care.
3. Caregiver resolution of grief (based on indices of present unresolved grief in the areas of: social participation, involvement with friends and relatives, levels of morbidity, and feelings of adjustment to loss of the deceased).

To measure the above variables, specific instruments were chosen or developed for inclusion in the questionnaire. The following scales were used in the study: "Perception of Emotional Support Received from Medical Staff Scale" (developed specifically for this study); "Feelings of Involvement in Patient Care Scale" (originally taken from the NCI Hospice Study an later adapted and used in the UCLA Hospice Evaluation); "Morbidity Scale", "Participation in Social Activities Scale", "Contact with Friends and Relatives Scale", (all adapted from the UCLA Hospice Evaluation); "Texas Inventory of Grief" (also adapted for use in the questionnaire).

The above measures formed a questionnaire of 44 items concerning repondents' attitudes, feelings, social activities and health. The questionnaire also included items regarding demographic information which were used to determine comparability of sample groups and possible outside factors influencing the above dependant variables.

RESULTS

A statistical analysis of the data indicated the following results in a comparison between the Hospice and non-Hospice groups: perception of emotional support received from the medical staff during terminal illness was significantly higher with Hospice caregivers than with non-Hospice caregivers. Analysis showed a Hospice group mean of 7.78 (on a five-question scale from one to nine with one being "Not at all" and nine being "Extremely so") as compared to a mean of 6.53 for the non-Hospice.

It was also found that the death of the terminally ill family member was perceived as significantly less stressful in the lives of the Hospice caregivers than in that of the non-Hospice. Though this is not an explicitly stated objective of Hospice, it is implicit as an overall purpose of service. Again, using a scale from one to nine with one being "Not at all" and nine being "Extremely so," the Hospice group had a mean score of 6.01 while the non-Hospice had a mean score of 7.1.

In comparing the data for "feelings of involvement in patient care", a t-test of the group means again revealed no significant difference between the Hospice and non-Hospice groups. There did exist a slight difference between these two groups again in the direction hypothesized, but this was not a significant level.

In the area of grief resolution, a t-test of the group means showed only a slight difference between the two groups in each of the four scales used to measure resolution of grief. Though the difference between the two groups pointed in the direction hypothesized, the difference was not significant.

DISCUSSION

The study's results indicate a significant level in the achievement of the Hospice program objective of providing emotional support for the caregiver of the Hospice patient. These results were hypothesized prior to the start of this study based on the assumptions that the Hospice method of patient/family care with its frequent home visits (by nurse staff and volunteers) would create more emotional support for the caregiver than would the traditional hospital care treatment. It was also thought that the Hospice team interaction with the other non-Hospice health professionals providing patient care would increase non-Hospice care providers sensitivity to the patient's emotional needs, and that this higher level of patient need awareness would increase the emotional support given to the patient by the patient care medical team.

A second possible reason for these results is that the increased number of visits by a professional patient care provider (from Hospice) increased caregiver feelings of medical staff support. In other words, it wasn't "Hospice care" that exclusively facilitated caregivers' perception of emotional support, but rather just the increased number of medical staff contacts with the caregiver.

Though reduction of stress experienced by the caregiver from the death of the family member was not a specific Hospice goal, it could be assumed that a decrease in such stress would occur as a result of Hospice care as compared to more traditional care. This would be expected based on previous research findings (4) which indicated that during the time period of hospice care, spouses of the terminal patients perceived less stressed emotionally, compared to prior care.

Another possible reason for the Hospice sample perceiving themselves as experiencing less stress than the non-Hospice group could be the fact that the mean number of "months of patient illness" and the "months confined to home" were considerably higher in the non-Hospice than in the Hospice sample. As the time of terminal illness is generally a time of considerable stress on the caregiver and family, it would be expected, then, that those who had been responsible for patient care would experience a higher level of stress.

It was also hypothesized that Hospice care would facilitate significantly more effective resolution of caregiver grief than traditional care because of Hospice efforts to assist the caregivers in dealing with the anticipatory grief during the terminal illness prior to death, and the post-death bereavement visits. Other evaluative research (7), supportive of this hypothesis, has shown that hospice interventions resulted in the promotion of normal recovery from grief; and bereavement counseling, both professional and professionally supported voluntary services (both of which Hospice of Utah County provide), are seen as being beneficial in reducing negative effects of bereavement and in facilitating a healthy resolution of grief (10). The study's results, however, indicated that this was not the case. There are two possible reasons for these results. 1) this Hospice agency did not implement its program effectively enough to significantly impact the level of grief experienced by Hospice caregivers. This could have occurred as a result of Hospice staff failure to help the caregivers deal with the issue of anticipatory loss during the illness and/or ineffective bereavement follow-up after the death of the family member; 2) perhaps Hospice care may give emotional support to its caregivers, but this support alone does not necessarily facilitate resolution of caregiver grief. "Working through" grief is a result of accomplishing certain tasks of mourning, the handling of which is dependant upon more than just the receiving of emotional support (11).

Regarding the Hospice objective of involving the caregiver in patient care planning and decision making, the Hospice group of caregivers reported feeling no higher level of involvement than did those from the non-Hospice control group. There was, however, a very high level of feelings of involvement expressed by respondents from both groups. Perhaps this high rating seen in both samples could be a result of the caregivers' active daily involvement in the care of their terminal family member. They reported feeling very involved because in all cases, they were the ones primarily responsible for the daily medical and emotional care of the terminally ill patient while the patient was at home.

IMPLICATIONS OF EVALUATION FOR HOSPICE AGENCY

After having evaluated the Hospice of Utah County caregiver service program, the researcher presents the following suggestions for improvement of this area of Hospice care:

1. It is suggested that Hospice establish more clear and measurable agency objectives relating to caregiver service. In preparing for the

evaluation of the three caregiver service objectives, the researcher found the stated objectives, in their present form, to be too broad and unmeasurable. For these reasons, the objectives, as stated in the Hospice program description, were difficult to be evaluated. In addition, the specific criteria to be measured (as well as the satisfactory level for Hospice achievement of each objective), did not come from the agency itself, but from a source outside of the agency (the program evaluator). It is then, the researcher's suggestion that Hospice consider revising its stated caregiver service objectives in the above-mentioned ways to provide clear program outcomes which are measurable and therefore able to be more effectively evaluated.

2. Because the Hospice program is delivered to the client patients/families primarily by agency volunteer workers, it is the evaluator's suggestion that Hospice provide more effective volunteer training and supervision, particularly in the area of bereavement counseling. Even though new Hospice volunteers are given a 2-day workshop of training and orientation to the Hospice program, a continuous (perhaps monthly) educational program is needed. Such training should consist of material which deals with the volunteer skills which are needed in working with caregivers of the terminally ill before and after patient's death.

3. It is suggested that Hospice provide a more effective bereavement service by working more closely with the caregivers before the patient's death with their anticipatory grief, and by ensuring adequate post-death bereavement follow-up with each caregiver. It became obvious to the researcher as the questionnaire data from the Hospice group was being compiled that the bereavement needs of many of the caregivers were not being met by the two or three visits made by the Hospice workers. As the

bereavement process can last anywhere from a few months to several years, it is the researcher's suggestion that contact with the bereaving caregiver continue throughout the entire period of bereavement.

Demographic Data	**Hospice Sample**	**Non-Hospice Sample**
Number of Respondents	28	49
Mean Age of Caregiver (in years)	62.1	60.15
Relationship of Caregiver to Deceased		
Spouse	19	32
Parent	3	7
Son/Daughter	6	7
Brother/Sister	-	1
Type of Terminal Illness		
Cancer	19	32
Heart Disease	1	4
Lung Disease	-	6
Non-cancer tumor	2	-
Blood Disease	1	2
Other	3	11
Average Months of Terminal Illness	28.4	44.8
Average Months Confined to Home	6.1	16
Average Weeks Confined to Bed	13.3	14.7
Average Months Caregiver was Responsible for Patient Care	24.4	28.4
Average Months Since Death of Family Member	8.8	7.8
Health Care Received from:		
Hospital	26	48
Private Nursing Care	2	4
Community Nursing Care	8	6
Nursing Home	-	13
Other	9	8

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SO LONG, SADIE

by

MICHAEL L. BENEDICT, M.A.

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SO LONG, SADIE

by

MICHAEL L. BENEDICT, M.A.

Michael L. Benedict is a recent graduate of the Full Funded Fellowship Master of Arts Program at Brigham Young University. During the course of his graduate studies, he completed Certification in Gerontology from the Resource Center on Aging, received an M.A. in Recreation Administration. His undergraduate degree in Youth Leadership was awarded from BYU in 1980. He is married to the former Judith Ann Harris, and as of the 9th of May will be the parents of one child (assuming they don't have twins).

"So Long Sadie" is drawn from a composite perspective, relating to the patterns of experience and feeling which have taken place in the lives of those who have been close to the bereavement process. Through such a composite, we may come to understand how the cycle of feelings and recollections give substance to the mourning process during the post-mortem period.

SO LONG, SADIE
by
MICHAEL L. BENEDICT, M.A.

Making due with what they had,
For better or for worse.
Sacrificing with heart so glad,
They saw that I came first.

God was kind and He was wise,
To send ones as him and her,
For they blessed my oft-torn life
And gave comfort to my world.

The winter of life, it has come now
Their lives, they have gone by.
Yet, they aged with grace so proud,
They were a source of pride.

For everything that I would hope to do,
Or whatever I might be,
I owe to ones as such were few,
Who were as kind as these.

May my life then be their sure reward
For all that they have done.
In their steps, may I go forward
To dwell with God's own Son.
— Michael L. Benedict (1985)

Soft rays from the April sun dart through the windows as memories of years past cadence through my mind. The memories, flowing freely and in no particular order seem to run a course between near oblivion and stark reality. Cherished days seem faded with time and yet, the numbness of their death subsides as I taste the sweetness of memory's teardrops upon my lips.

Tears and memories are all that I have left of them. All that is, but photographs and momentos. All that is, but those words which I write in this- a last letter to one who gave me life and taught me of life. To preserve my fondest images of her, I reach out my hand once again.

In days past my hand reached out for hers. As our hands entwined, the warmth of her grasp comforted my soul. Now, as my hand becomes entwined with pen and paper, the warmth of her memory gives solace to my spirit. As memories flow freely within my mind, words flow freely upon these pages. The memories seem to come ever clear once again as they symbolize themselves in these lines.

Somehow, I see more than words. I see images. I see faces smiling at me. Her face and Dad's face glance lovingly back from the tablet as I recollect and reminisce. I realize that their spirits, like these fond recollections, are still very much alive. And so, perhaps Mother can in fact hear me as I write that which speaks from the depths of my soul. Through this last letter, I might best preserve my memories of her and Dad. Memories are best preserved in the archives of the soul. Recording them as a means of expression augments their radiance. And so, memories and feelings trace themselves for present expression and future recollection as I write one last letter to Sadie, my mother.

Dear Mother:

Your death was no surprise. The staff at the nursing home told us that you would not last too long. Last week, at your funeral, I realized that your death was a blessing. Certainly none of us, yourself included, wanted you to suffer more than you already had. We realized how you wanted to be with Dad once again. So why should I feel sad in knowing that you have been granted the desire of your heart?

Still, your death came as hard as did Dad's. Even though death is inevitable, and in your case, expected, the reality of loosing you is still hard to accept. Perhaps that is why we expressed a collective sigh as they closed the lid to your coffin. We each exhaled quietly and once again the tears began to flow. We shed tears of gladness for your reunion with Dad, yet we also shed them of sadness. Saying "So Long" is never easy, especially when the name "Sadie" is attached at the end of the same sentence.

Yet, I realize that the tears of loss are selfish tears. Certainly, we who have been left behind may chronicle our emotions as feelings of loneliness for those departed whom we have loved. Yet, in so many instances, when we become overwhelmed by the obstacles of daily living, we may also feel a longing for our time to come. Though the circle of loss has expanded itself to our missing the two of you now, I am comforted in knowing that the two of you will never again be seperated. Such comfort will sustain me in the months ahead.

As I write, I reflect upon the times that we spent alone, just the two of us. It seems that during those times, we both felt an ever growing bond. The sweetness of those moments made the hours following your funeral bittersweet. Though your remains laid in the coffin as being still, soft and and silent, the softness of your spirit remained then and remains now, ever so close.

I ponder the hereafter. I ponder the reunion after this life, when I will see you and Dad once again. Some ask if there is a life hereafter. The doubt of remorse says perhaps not. Theologians argue with philosophers. Skeptics ridicule the reverant. Still, hope overpowers pain. For the love which you and Dad shared was real. The love that you gave to us was real. And though you are gone now, the love that I still feel for you is real.

What God would allow emotion and love that run so deep to last for only a lifetime? Did not the Savior proclaim Himself as being the source of all love? Did He not proclaim Himself as being Eternal? So I also take strength in knowing that the reality of a hereafter is more than a longing. Such a knowledge allows me to experience this closeness to you, even as I write.

I drove home alone from the nursing home the night of your death. As I drove, I heard a song on the radio. It was the spiritual, "Sometimes I Feel Like A Motherless Child." I pulled the car off to the side of the road. I was so overcome with grief. Right then I did feel like a motherless child. I asked myself who would give me advice when my bread wouldn't rise. I asked myself who would babysit when we wanted to go to the football game. At that moment, I felt as you must have when you stepped out onto the back porch one afternoon last summer. As you did so, you looked upon the peach tree, split in two by the weight of the ripe fruit. I recall how you cried when you saw what had happened. I remember your having made the statement, "Oh, if only your father were here. Had he been here this wouldn't have happened. If your father were here, things would be easier to face."

It was at that moment that I realized the extent of your grief. Feeling your frustration at that moment, I came to understand how grief can come to make the comparatively insignificant situations seem insurmountable. Was your grief transcending a desire for him to be with us again? Or was it an expression of your desire to be where he had gone and where you now are?

Regardless, I understand how you must have felt. For the tree has been split again. This time, it is the Family Tree. Your spirit, like Dad's became ripe and full. Your spirit, weakened by age and perfumed with wisdom, had filled the measure of its creation. One branch of the Family Tree, then, has retired to the hereafter. Now it is up to us, the young and tender branches, to bear good fruit.

The weight of responsibility overpowers me. For in so many ways loosing both of you has weakened the entire Tree. I am assured, however, in knowing that we are of your stock- the same stock which bore such pleasing fruit and which perfumed the air with the sweet scent of kindness.

The Bishop stopped by the night before your funeral. I am amazed by his timing. For at that moment I was feeling quite bitter. I kept asking myself why God had to do this to me. I demanded to know why you couldn't have been left to stay with us just a little bit longer. I even began to feel the same longing for Dad which until that moment, had diminished by the passing of time.

As the Bishop and I began visiting together, I asked him what words of comfort could he possibly speak that would take away the sting of loosing you. Afterall, it wasn't his mother who had died. I asked him how many times he had been forced to face the death of a loved one. I accused him of trying to subdue pain with vain phrases of pompous innuendo that leave one cold.

Then we prayed together. As we did so, my troubled heart was stilled. Afterwards, he challenged me to remember that Death is the ultimate expression of God's love, for both our own deaths and the death of Christ allow us to progress ever Heavenward. He reminded me that through the the Death of Christ, we are allowed the opportunity to become united with Him and with each other.

As he left, I thanked the Bishop for subduing my pain with phrases of reassurance that left me hurting less than before.

After the Bishop left, I couldn't help but reflect upon how the lives of you and Dad paralleled. Your lifestyle was a bee-hive, full of energy and industry. Like the bee-hive your labors were always sweet.

To feel the warmth of your kind deeds! To taste your sweetness on my lips once again! Teardrops continue to moisten my lips. The taste is bitter-sweet. I taste the bitterness of loosing you. Yet I also taste the sweetness of your deeds.

I remember what you always used to tell us, that if we are to continue to taste the sweetness of what others have done for us, we must continue to labor for the comfort of others. I recall your telling us that each deed we perform in this life reflects upon our character. May we follow in your footsteps.

Even your death was a labor. Through the way in which you died, you taught me something that I might not have learned otherwise. One afternoon, as I sat by your side, feeding you with a spoon, your eyes seem to have whispered what your voice could no longer express. Yours was an expression which captioned the command given by the Savior, "Feed My Lambs." As you sat there eating, independent of spirit yet restricted in movement from a stroke, I realized that you too were a Lamb- a Lamb of God. And though your body and mind were weak, your spirit and faith remained strong. You had lost your ability to speak through your tongue. Yet, somehow, you maintained your dignity. You spoke through your example as you had always done.

How hard it must have been for you to accept help in such a menial task. Yet, I know that as a child, you felt it was your privilage to feed me. Then it was my turn to feed you as a child- a Child of God.

Even at that moment, that very moment, you shoved your humiliation and embrassment aside. You maintained dignity as you expressed a humbling nod of thanks. Oh Mother! You are so very welcome. I am the one who should have been thanking you for the memories, the discipline, the the devotion and the gifts of support. What is staying by the side of a wonderful mother during her final hours when compared to your having stayed by my side from the very beginning of my life? It seems a small comparison at best. For throughout your life, and even through death, you showed me how to meet adversity with dignity. You taught all of us of the power of love- how it may sweeten the sad times and make memorable the glad. Your silent dignity taught me again.

Our was always a home where sweet memories were being made. One that comes to mind is the smile that you always offered Dad as he went to work. As he opened the door to leave each morning, you always gave him a hug. Then he kissed you. As he strode toward the car, he would always say, "So Long, Sadie. We will see you soon." Then you would blow kisses and wave until he drove out of sight.

After he was gone, you would repeat the same ritual as we left for school. As we walked toward the school bus, you would always say, "So Long, Kids. We will see you soon." As the bus drove out of sight, we would look back toward the house to see you blowing kisses and waving.

The holidays and special times with relatives also stand out in my mind. But Mother, you made every day seem like it was a holiday. Every day of your life was a celebration of love. Each of us left the house to begin our life's adventures, thankful that we had lived in such a home. And we were always grateful in knowing that some of the ritual was still being carried through. It was genuine indeed.

I can almost imagine what it must have been like on the day that Dad left to go on his trip. No doubt, he gave you a hug. Then, as he strode to the car, he said, "So Long, Sadie. We will see you soon." Then the phone call came. It was a call that preceeded your call to us, informing us of the heart-attack that took Dad before he returned home from his trip.

There were no preliminary symptoms. He got up on the morning he left, as usual, got packed, ate breakfast, and away he went. He apparently had a massive heart-attack and fell to the floor of the conference room in which his meeting was taking place.

You told me that one of the conference participants had tried CPR on him, but to no avail. The man with the magic smile had died. He said "So Long" for the last time. Yet, as those who witnessed his death told us at his funeral, his final words were, "So Long, Sadie. We will see you soon."

As we flew home, we were still hoping that things would be alright when we got there. Afterall, even for his 52 years, Dad was in excellent health. He still walked at a brisk pace, had no major health problems such as heart or lung disease. Why, he had just climbed the Tetons all the way by himself last summer. But when we met Uncle Adam at the airport, he quickly ushered us to a secluded spot and told us that it really was over.

When we got to the house, there you were- not crying, but in a state of numbness. We began trying to talk about the unforseen event in hopes of comforting you. Instead, you began trying to comfort us. It seemed as if you were trying to transform your trauma into a source of strength for each of us. "After all", you said, "None of us knows how much time we have left."

I recall his funeral. I recall how we felt bewilderment as we gazed upon Dad one last time. There he was, still, soft and silent. We reached for his hand which had become cold and hard. We tried not to cry, but for us the loss was very deep. We kept saying among ourselves, "We didn't even get to tell him 'Goodbye'. We didn't even get to say, 'So Long Daddy. We will see you soon.'"

Then there was a long period of silence. The words ran out. The expression of feelings took over. Those seem to have been the same feelings I felt later as I spoonfed you at the nursing home. You never let us feel bitter toward Dad's death. Instead, you strengthened us. I do not know how you did it, but you transformed the tragedy into a period of peace for each of us. I can only hope that you gained some of that peace for yourself.

As time wears on, two scenes come to mind whenever I think upon the events which gave form to that week. I shall never forget how you stood at the graveside, blowing kisses and hugging the flag which had drapped his coffin. I can remember the tingle I felt, the incredible respect I felt for you as I heard you say, quietly, "So Long, Sam. We will see you soon." I have played that scene over and over in my mind, time and time again. It has given special meaning to the other scene which I recall frequently.

We were at the airport, getting ready to board. There you were, standing at the gate, waving goodbye and blowing kisses as the plane taxied down the runway. You gave us a hug before we boarded, saying, "So Long, Kids. We will see you soon."

A common feeling teased our subconcious as our plane took off. We seem to have been denying the reality of what each of us knew had taken place. The numbness of the moment had become sparked with the sibling comments which

Still, soft and silent.
Reflecting tender deeds unceasing.
A source of meekness pure and kind
Has now taken the grasp of time.

Life be but a rendezvous,
As we plot our course and chart it.
Yet grace and strength to us are given
Through thoughts of those who have parted.

Where is it now, that breath of life?
Where, after the curtain has been passed?
Gone on, now, to other things,
A finer work and task.

One reached down as one reached out
And the hands have become entwined.
Through deeds of them and deeds of Him,
Their lives have become enshrined.

Yet so to Christ, may we reach out-
The hand of the Great "I Am."
For He showed us how to live and die
As meekly as a lamb.

Through deeds of them and deeds of Him
We may become united.
Tears we shed upon seeds of Faith
In the Garden which has been planted.

Still, soft and silent.
Reflecting tender deeds unceasing.
A source of meekness pure and kind,
Reality's pain is releasing.

For they run a parallel,
The lives of Christ and them.
So too, may we our paths take
The road that has been walked upon.

For through the same hand
We may find the Promised Land
And Feast in the Upper Room
With Christ, the Noble Groom.
Michael L. Benedict

seemed to make an attempt at balancing the loss. Yet, when we looked back to see you repeating the ritual at the gate, the reality had begun to settle in. We realized that you were the one who had been thrust into the vanguard.

We realized that you were the one who had become the Head of the Family. That reality brought about a pledge to myself that I would come back in the area to look after you. Although no child can take the place of a lost spouse, I know you needed the moral support. Although yours was an unspoken need for that support, it was there nonetheless.

Having seen you linger as you did until you died, I have no regrets about having made this decision. My only regret now is that I didn't take greater advantages of opportunities to express my love directly to you. I always prayed for you. And we always shared in our mutual affection for you. But did I tell you often enough? Couldn't I have found it in myself to say "I love you", just once more?

It is too late for accusations. Yet, it is not too late to say, "I love you Mother." I will always think of you. Tears and memories will continue to fall freely. The subconcious will continue to ellude me. I shall hear your voice and see your face within the chambers of my mind.

But reality will prod me on and somehow, life will continue. Be still, oh my heart. Let not the sadness of the moment crush the fragility of one whose loss I mourn. Let me celebrate the treasure of having had one so dear share her life with me. May I rejoice that the Savior shared His life with us. Through such celebrating and through such rejoicing, I too may become victorious over death- my death, as well as the death of one whom I love. By so doing, my Mother and my Savior shall not have lived or died in vain.

"So Long, Sadie. We will see you soon."

ALZHEIMER'S SPECIAL CARE UNITS

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Dementia represents one of our nations major health problems afflicting millions of Americans and disrupting the lives of many more family members. It is estimated that 4-6% of persons over the age of 65 suffer from severe dementia and that another 12% are affected to a mild or moderate degree. Alzheimer's disease which is a progressive, debilitating and inevitably fatal neurological disease accounts for over 50% of all dementia type individuals. Alzheimer's is the nations fourth leading cause of death in adults after heart disease, cancer and strokes. Since there is no cure at this time one needs to prepare and find new ways to cope with this ever demanding responsibility of caring for someone with Alzheimer's disease.

The ability to give continuous undivided attention can be cumbersome to the care giver and the time may come when an alternative method of care is needed. Several factors must be viewed when considering this approach.

First and foremost, are the cares and needs of the afflicted person being met? Are there any types of mind stimulation methods being used or is the person just living day to day with very little mental activity. Does the person attempt to do things that may result in provoking some type of danger to himself or his surroundings? How is the care giver coping with the constant

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STRESS BEING PLACED UPON THEM? WE FIND THAT CARING IS TRULY A 24-HOUR JOB. IT IS ANALAGOUS TO THE CARE A SMALL CHILD REQUIRES WHILE ROAMING WITHIN THE HOME. A METHOD USED TO RELIEVE THE PRESSURE OF THE CARE GIVER, WHO IS USUALLY THE SPOUSE OR FAMILY MEMBER, IS TO LOOK TO AN OUTSIDE SOURCE.

HISTORY OF NURSING HOMES

THE ALZHEIMER PATIENT HAS EXHIBITED UNMET NEEDS HISTORICALLY WHICH HAVE BEEN INEFFECTIVELY ADDRESSED BY LONG TERM CARE FACILITIES. THESE TYPES OF CARE CENTERS ARE DESIGNED TO DEAL PRIMARILY WITH THE STANDARD INFIRMITIES OF THE ELDERLY WHICH ARE PHYSICALLY BASED. THE NURSING HOME PROFESSION HAS NOT GENERALLY GIVEN QUALITY CARE FOR THOSE WHO REQUIRE SPECIAL SERVICES TO MEET DIFFERENT NEEDS. CONSEQUENTLY THE FOLLOWING CONDITIONS OCCUR:

1. ALZHEIMER'S PATIENTS HAVE BEEN ADMITTED TO NURSING HOMES AND PHYSICALLY RESTRAINED TO PREVENT WANDERING. THE MAJORITY OF THE NURSING HOME PATIENTS DO NOT WANDER AND THUS NO EFFORT HAS BEEN TAKEN TO OFFER CREATIVE SOLUTIONS TO THIS BEHAVIOR. PHYSICAL RESTRAINTS CAN ALSO CONTRIBUTE TO AGITATION AND AGGRESSIVE BEHAVIOR.

2. ALZHEIMER'S PATIENTS HAVE BEEN ADMITTED TO NURSING HOMES AND CHEMICALLY RESTRAINED TO CONTROL BEHAVIORS. AGAIN, BECAUSE THE MAJORITY OF NURSING HOME PATIENTS DO NOT EXHIBIT MALADAPTIVE BAHAVIORS, NO EFFORT HAS BEEN TAKEN TO OFFER CREATIVE SOLUTIONS TO THIS PROBLEM. OFT TIMES THESE FORMS OF RESTRAINTS ARE MERELY FOR THE CONVENIENCE OF THE STAFF INSTEAD OF THE WELL-BEING OF THE PATIENT.

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3. THE NURSING HOME STAFF OFTEN HAS LITTLE COMPREHENSION OF THE NEEDS AND POTENTIAL OF THE ALZHEIMER PATIENT . THE MAJORITY OF THE PROGRAMS HAVE BEEN DESIGNED TO MEET THE NEEDS OF THE MAINSTREAM POPULATION AND THEREFORE ACTIVITY, MEDICAL, NURSING AND SOCIAL SERVICE APPROACHES HAVE BEEN "OUT OF SYNCH" WITH THE NEEDS OF THIS POPULATION.
4. FAMILY INVOLVEMENT AND INTERACTION HAVE BEEN CONSISTENTLY DENIED, AND THUS THE PEOPLE THAT MEAN MOST TO THE ALZHEIMER PERSON ARE CUT OFF FROM ANY LEARNING PROCESS THAT MAY OCCUR.
5. THE FAMILIES OF THE ALZHEIMER PATIENT HAS BEEN THE TRUE VICTIM OF THE DISEASE. HOWEVER THEY HAVE RECEIVED NO SUPPORT FOR THEIR OWN LIFE ADJUSTMENTS AND DIFFICULTIES.

WHAT CAN BE DONE TO ALTER THE INCONSISTENT APPROACH IN CARING FOR THE ALZHEIMER PERSON? IN WHAT WAYS CAN WE CHANGE THE METHOD AND QUALITY OF CARE SO THAT THE NEEDS OF THESE PATIENTS CAN BE MET? WHAT KIND OF ENVIORNMENT WILL BE MOST APPROPRIATE AND WHAT ACTIVITIES WILL BE MOST MEANINGFUL?

THE HILLHAVEN CORPORATION HAS SEEN THE NEED TO SPECIALIZE IN THE CARE FOR THIS POPULATION GROUP. FOR THE PAST 3 YEARS THEY HAVE BEEN DEVELOPING SPECIAL CARE UNITS THROUGHOUT THE WESTERN STATES INCLUDING ONE UNIT IN SALT LAKE CITY. WITH 30 YEARS OF NURSING HOME CARE BEHIND THEM, HILLHAVEN IS ENDEVORING TO PROVIDE A SPECIALIZED SERVICE TO THOSE FAMILIES WHO HAVE BEEN STRICKEN BY THE "DISEASE OF THE 80'S".

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A SPECIAL AND UNIQUE SERVICE

IN THE FEW YEARS THAT HILLHAVEN HAS BEEN INVOLVED WITH THE CARING OF THESE PEOPLE THEY HAVE DEVELOPED AN UNDERSTANDING OF THE EFFECTS THAT ALZHEIMERS HAS ON THE PATIENT AS WELL AS THE FAMILY. IT IS FOR THIS CAUSE THAT THEY HAVE STRUCTURED A SPECIFIC SET OF GOALS AND OBJECTIVES TO HELP DEAL WITH THEIR PATIENTS AND FAMILIES WHO SUFFER FROM THIS DISEASE.

1. OUR FIRST STEP WAS TO PROVIDE AN ENVIORNMENT DESIGNED SPECIFICALLY FOR THEIR NEEDS. AN EMPHASIS HAS BEEN MADE ON PROVIDING A SEPARATE UNIT WHICH IS COMFORTABLE, SAFE, AND SECURE. THE UNIT IS STRUCTURED TO ALLOW COMPLETE FREEDOM OF MOVEMENT AND TO CONTINUE WITH THEIR PREVIOUS DAY TO DAY STYLE OF LIVING.

2. A CONSULTING GERIATRICIAN WHO TRAIN PROFESSIONAL AND FACULTY STAFF TO THE NEEDS OF THOSE WITH THIS DISEASE. OUR CONSULTANT HAS EXTENSIVE INVOLVEMENT WITH PATIENTS AND AN IN-DEPTH UNDERSTANDING OF THE EFFECTS ALZHEIMERS HAS ON BOTH THE PATIENT AND THE FAMILY.

3. HILLHAVEN HAS A CORPORATE CONSULTING REPRESENTATIVE WHO HAS EXTENSIVE BACKGROUND IN WORKING WITH THE PATIENT AND THE FAMILY THROUGH SUPPORT GROUP SYSTEMS.

4. WE OPPOSE THE USE OF PHYSICAL AND CHEMICAL RESTRAINTS BY:
   - A. OFFERING SECURITY DOORS TO PREVENT THE DANGERS OF WANDERING.
   - B. OFFERING MONTHLY DRUG REGIMEN REVIEW TO ENSURE THAT ALL MEDICATIONS ARE MEDICALLY NECESSARY. MEDICATIONS ARE NOT FOR THE CONVENIENCE OF OUR STAFF BUT RATHER FOR THE THERAPUTIC BENEFIT OF OUR PATIENTS.

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5. INDIVIDULAIZED PROGRAMS ARE DESIGNED BY A SPECIAL RECREATIONAL THERAPIST TO PROVIDE ACTIVITIES THAT ENCOURAGE AND ACTIVATE THE THINKING PROCESS. THROUGH PROPER ACTIVITIES SOCIAL INTERACTION WILL DEVELOPE AND THEREFORE ENHANCE THE LIVING CONDITIONS AND SENSE OF BELONGING.

6. AN IMPORTANT ELEMENT IN OUR SPECIAL CARE UNIT IS THE INVOLVEMENT OF THE FAMILY. THIS IS DONE THROUGH THE ADMISSION PROCESS, PATIENT CARE PLANNING, PROGRAM DEVELOPMENT PROCESS, FAMILY COUNCILS AND OUR MONTHLY SUPPORT GROUP. THE PATIENT CAN IDENTIFY BEST WITH A FAMILIAR FACE AND THEREFORE FAMILIES ARE ENCOURAGED TO PARTICIPATE IN AS MANY OF THESE AREAS AS POSSIBLE.

7. THE PROGRESSION OF ALZHEIMER'S DISEASE GENERALLY OCCURS IN STAGES AND AS A RESULT HILLHAVEN CAN OFFER 3 PROGRAMS INCLUDING DAY CARE, RESPITE CARE, AND STANDARD RESIDENTIAL 24-HOUR CARE.

UNTIL A CURE IS FOUND, HILLHAVEN WILL CONTINUE OT PROVIDE THE HELP AND SUPPORT THAT IS REQUIRED TO CARE FOR THESE INDIVIDUALS. THEIR SPECIAL CARE UNIT IS OPEN TO THE PUBLIC AND IS LOCATED AT 41 SOUTH 900 EAST IN SALT LAKE CITY OR FOR MORE INFORMATION YOU MAY CALL 532-3539.

Alzheimer's Disease
and Related Disorders Association, Inc.
360 North Michigan Avenue • Chicago, Illinois 60601

National Headquarters
Phone: (312) 853-3060

FACT SHEET ON ALZHEIMER'S DISEASE

DEFINITION: Alzheimer's disease is a progressive, debilitating and inevitably fatal neurological disease that affects an estimated 2.5 million American adults. It can strike in early and mid-life, however, most victims are over 65. It is the most common form of dementing illness. It ranks as the fourth leading cause of death in adults, after heart disease, cancer and stroke.

SYMPTOMS: Symptoms of Alzheimer's disease include progressive memory loss, decline in ability to perform routine tasks, impairment of judgement, confusion and disorientation, personality change, difficulty in learning, difficulty in movement and speech, inappropriate and/or diminished response to outside stimulation. There is great variation in the process and rate of change from person to person. In most severe cases, the disease will eventually render its victims totally incapable of caring for themselves.

CAUSE: The cause of Alzheimer's disease is not known and is currently receiving intensive scientific investigation particularly focused on a number of new and promising clues that set directions for increased research activity. Alzheimer's disease is not caused by hardening of the arteries, and there is no evidence that it is contagious. Emotional upsets and stress may temporarily affect the person's mood and behavior, but they do not cause the disease.

Major hypotheses currently under study have investigators working to determine if Alzheimer's disease is caused by: (1) a deficit in the brain's cholinergic system of neurotransmitters; (2) selective cell death provoked by slow virus or infectious agents; (3) a genetic predisposition; (4) a biochemical defect that leads to diminished production of new protein in the brain.

In research supported by the National Institute of Health and ADRDA, scientists are applying the newest knowledge

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and research techniques in histology, virology, immunology, toxicology and biochemistry to find the cause, treatment, and cure for Alzheimer's disease.

DIAGNOSIS: Before diagnosis of Alzheimer's disease is made, other illness which may cause memory loss must be excluded. Reversible conditions including depression, adverse drug reactions, poor nutrition and minor head injuries which can mimic Alzheimer's disease can either be ruled out or specifically treated.

Each person suspected of having Alzheimer's disease should have thorough physical, neurological and psychiatric evaluations. Computerized tomography (CT scan), electroencephalography (EEG), and occasionally special studies of the spinal fluid system are required. Comprehensive blood studies including tests for detecting several metabolic disorders must also be carried out.

TREATMENT: Proper medical care and sound guidance can help the victim and family. Tranquilizers can lessen agitation, anxiety and unpredictable behavior. Appropriate medication can also improve sleeping patterns and can be used to treat depressions. Proper nourishment and fluid intake are important as are physical exercise and social activity according to the individual's capabilities. It is important to create a calm and pleasant environment, and help the afflicted person maintain as much comfort and dignity as possible.

ADRDA: Alzheimer's Disease and Related Disorders Association (ADRDA) was founded in 1980. It is a privately-funded volunteer national health organization comprised of more than 100 chapters in 39 states with headquarters in Chicago at 360 N. Michigan Avenue. Funds are used for support of research, chapter development and family support services, and education of lay and professional publics.

HOTLINE: An information hotline has been established on a nationwide, 24-hour basis to link families who need assistance with nearby chapters. Those interested in help may call 1-800-621-0379. (Illinois residents call 1-800-572-6037.) The direct Chicago line is 1-312-853-3060.

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Hillhaven Opens Alzheimer's Unit

Alzheimer's Disease — an untreatable, irreversible, rapidly progressive loss of memory.

Dr. Lewis Thomas, science writer and chancellor of the Memorial Sloan-Kehering Cancer Center, was quoted in the New York Times calling Alzheimer's "the disease of the century," because, "of all the health problems in the 20th century, this one is the worst."

Utah nursing homes are daily learning more about dealing with Alzheimer's patients and their families.

Hillhaven Convalescent Center in Salt Lake City has made a major step toward helping families to cope with the problems. Hillhaven has recently opened a unit designed especially for Alzheimer's patients, and has begun a chapter of the Alzheimer's Disease and Related Disorders Association.

Dr. Victor Kassel, gerontologist, is the medical consultant for the Alzheimer's Special Care Unit, according to Bob Eskew, Hillhaven Administrator.

According to a recent *Deseret News* article, "there are 2.5 million Alzheimer's sufferers currently in the U.S. Sixty percent of the nursing home population is afflicted with the disease, and 95 percent of those who develop it will eventually be placed in a nursing home. Approximately two percent of those who reach the age of 65 will get Alzheimer's, and as the population ages, the prevalence is expected to more than triple in the next 50 years.

Problems of memory, particularly recent or short-term memory, are common in the early stage of the disease. Mild personality changes, such as less spontaneity or a sense of apathy and a tendency to withdraw from social interactions, occur early in the illness, according to Gene D. Cohen, M.D., Chief, Center for Studies of the Mental Health of the Aging.

As the disease progresses, problems in abstract thinking or intellectual functioning take place. Later in the course of the disease, the afflicted may be confused or disoriented about what month or year it is. Eventually, they may wander, not engage in conversation, become erratic in mood, uncooperative, incontinent, and, in many cases, totally incapable of caring for themselves.

Marilyn Little, R.N., shares information on Alzheimer's Unit with Hillhaven Director of Public Relations Ryan Thorn.

The Alzheimer's Unit at Hillhaven is specifically designed to care for these individuals. It is a secure wing of the nursing home, designed to allow as much freedom for the resident as possible, while still protecting them from wandering or harming themselves or others.

According to Marilyn Little, R.N., charge nurse for the special care unit, a major goal is to help residents to keep functioning at their optimum level for as long as possible. Outside stimuli is kept to a minimum, and staff members are trained to give maximum attention to the residents on an individual basis. "They're in an environment where they're accepted, and that makes all the difference in the world," she said, noting that as residents adjust to the environment many times medications can be reduced or eliminated.

Individuals are encouraged to participate in group reality orientation, reminiscing, van rides and other activities, eat in a common dining area, and are free to enjoy the outdoors in the secure patio and garden area.

Mary Ann Laubacher, geriatric nurse practitioner, is at Hillhaven to assist with the Alzheimer's Unit, thanks to the Robert Wood Johnson Foundation teaching nursing home project. She has worked with Alzheimer's patients intensively for the past two years. Because Hillhaven is designated as a "teaching nursing home," consultants and experts from the University of Utah and throughout the country are available to assist the staff in developming the Alzheimer's unit and in dealing with specific problems. "We'd like to make Hillhaven a real community resource for the management of Alzheimer's," she said.

Hillhaven has 26 beds in the Alzheimer's Special Care Unit. Respite care and daycare are available in addition to 24-hour care.

Join AARP

American Health Care Association has developed a very positive working relationship with the American Association of Retired Persons to coordinate senior programs. This program will, over a period of time, help to provide a clear and accurate background on the role of the long term health care provider to a large segment of the senior population.

AHCA is inviting long term care professionals to become involved within local areas with AARP. Dues for individuals are $5.00 for one year; $12.50 for three years; and $35.00 for ten years. To join, individuals should send their name, complete mailing address and date of birth, along with a check made out to AARP in the proper amount to:

American Association of Retired
Persons
Membership Processing Center
215 Long Beach Boulevard
Long Beach, California 90801