THESIS

MICHIGAN STATE UNIVERSITY LIBRARIES
3 1293 00070 8572

LIBRARY
Michigan State
University

This is to certify that the

thesis entitled

SOCIAL SUPPORT, SOCIAL NETWORKS
AND THE TASKS OF DYING

presented by

Mary Clearing Sky

has been accepted towards fulfillment
of the requirements for

Masters degree in Clinical Psychology

Robert A. Caldwell
Major professor

Date Nov. 7, 1984

MSU is an Affirmative Action/Equal Opportunity Institution

MSU
LIBRARIES

RETURNING MATERIALS:
Place in book drop to remove this checkout from your record. FINES will be charged if book is returned after the date stamped below.

[illegible]
AY 1 003

SOCIAL SUPPORT, SOCIAL NETWORKS
AND THE TASKS OF DYING

By

Mary Clearing Sky

A THESIS

Submitted to
Michigan State University
in partial fulfillment of the requirements
for the degree of

MASTER OF ARTS

Department of Psychology

1984

ABSTRACT

SOCIAL SUPPORT, SOCIAL NETWORKS AND THE TASKS OF DYING

By

Mary Clearing Sky

This study examined the structure, quality, and stress-buffering effect of 20 dying persons' social networks. Subgroups of early and late Hospice admittees were expected to differ in structure and quality of their personal support networks and these variables were anticipated to correlate with distress, adjustment, and task completion. Expected relationships were not found. Network structure and support did not link significantly and neither related to the adjustment measures. Sample size, group composition, and personality variables were posited to account for the lack of significance. Future studies need to examine how time, treatment, and personality variables interact with social support. Recent quality of life research has found that such interactions contribute to buffering effects. The participants' enthusiastic responses to the present work and some mild trends in the data encourage further research.

DEDICATION

To those gracious souls who shared part
of their life and dying with me.

ACKNOWLEDGMENTS

I wish to acknowledge the kind support and widsom of Robert Caldwell, Ph.D., my committee chair and James Waun, M.D., my friend and colleague. They shared with me during many heartening and disheartening episodes related to this study. I appreciate the editorial discipline and insistence on clarity offered by committee member, John Hurley, Ph.D. and the encouragement and appreciation of my challenging project by committee member, Dozier Thornton, Ph.D.

Well, everyone can master a grief but
he that has it.

From: Much Ado About Nothing
By: William Shakespeare

The first person you will meet on your Gebeknong (journey to the spirit world in Ojibway) will be a beautiful Grandmother in white buckskins. She will give you a ripe juicy strawberry the size of a pumpkin which you may eat.

From: Verbal teachings
By: Albert Micko, An Odawa
Grandfather

Table of Contents

Page

List of Tables. vi

Introduction 1

Social Support and Social Networks 2
  Structure of Support. 2
  Quality of Support 3
  Support in Transition Periods. 4

The Transition of Dying. 5
  The Tasks of Dying 5
  Response to the Transition of Dying. 8
  Support Demands On A Stressed Network 8
  Support Buffers For the Dying. 9

Hospice: A Place to Die With Dignity and Support 10

Hypotheses 11

Methods 15

Results 24

Discussion 34

Appendix - Research Data Forms and Instructions. 44

References 63

List of Tables

Table Page

1 Intercorrelations. 23

2 Network Features Groups Based on Time in Hospice . 26

3 Further Analyses in Hospice Groups - Correlations . 28

4 Network Features of Groups Based on Time Since Diagnosis 30

5 Support and Task Correlations. 32

Introduction

Stress, its causes, and its effect on physical and psychological well being has been the concern of much research and popular press in recent decades (Pelletier, 1977; Simonton & Mathews-Simonton, 1975; Selye, 1950, 1956, 1974). Empirical support for the link between stressful life events and illness (Dohrenwend & Dohrenwend, 1975; Holmes & Masuda, 1974; Moos, 1974; Rabkin & Streuning, 1976; and Rahe, 1979) has grown and intervention and prevention theories have resulted (Bloom, 1979; Caplan, 1964). Personality variables that appear to ameliorate the impact of stress have been identified (Adler, 1982; Ekehammar, 1974; Garmezy, 1971; Kobasa, 1979; Sandler & Lakey, 1982). Environmental variables such as social support that may also buffer the disruption associated with stressful life events have been studied (Cassell, 1974; Cobb, 1976; Insel, 1980; Moos, 1974; Wilcox, 1981a, 1981b). Cobb (1976) presented a panorama of studies illustrating the moderating effect of support on events from birth through death.

As researchers asked where stress-buffering support comes from, who gives it, how it gets to the person, and what type of support is given, the concept of social networks was elaborated (Tolsdorf, 1976; Wellman, 1981). Network studies led to a focus on the networks of persons experiencing specific stressful life events ranging from new parenthood (McGuire & Gottlieb, 1979), divorce (Caldwell & Bloom, 1982; Hirsch, 1980; Wilcox, 1981a), and employment seeking (Granovetter, 1973, 1982) to entering graduate school (Goplerud, 1980),and bereavement (Hirsch, 1980; Walker, McBride, & Vachon, 1977). A few network studies have focused on aging (Conner, Powers, & Bultena, 1979; DiMatteo & Hayes, 1981; Lally, Black, Thornock, & Hawkins, 1979). Social networks have been shown to be facillitative in reducing the impact of bereavement (Hirsch, 1980; Vachon, Sheldon, Lancee, Lyall, Rogers, & Freeman, 1982; Walker, McBride, & Vachon, 1977). The crucial link in the final stages of life, dying itself, has received little attention in network research. In this study the structure, quality, and stress-buffering effect of dying people's networks were examined. These variables were anticipated to correlate with distress, adjustment, and task completion measures. The research topic was formulated by combining my interest in stress, social support, and Hospice. I assisted in the development of a Hospice program in Western Michigan. Relevant literature on social support, social networks, death and dying, and Hospice, the program which provided the care for the present subjects will be reviewed next.

Social Support and Social Networks

Structure of Support

Several models have been offered for the analysis of social networks (Barrera, 1981; Gottlieb, 1981; Hirsch, 1979, 1980, 1981; McCallister & Fischer, 1978). Network definitions have addressed both structure and quality (Mitchell & Trickett, 1980). Structural characteristics which have been measured include size, membership, and density. Size ranges from the corporate and political scale to mutual-help groups, to neighborhood helping arrangements (Davies, 1962; Gottlieb, 1981; Oberschall, 1978; Tilly, 1979). Membership varies from all social contacts (Gottlieb, 1981) to helpful relationships (Hirsch, 1980) to "contacts through which the individual maintains his social identity and receives emotional support, material and services, information and new social contacts" (Walker, McBride, & Vachon, 1979, p. 35). Hirsch (1981) more recently defined social network as a "personal community that imbeds and supports critical identities" (p. 160). People relate to the "satisfactory" parts of the network that support new identities resulting from adaptation to life change (Hirsch, 1981). Networks sometimes include persons who cannot support new roles, members who are not "satisfactory" but are members due to other ties (e.g., in-laws), others who are not liked, and some who detract from the adaptation tasks at hand (Kübler-Ross, 1969; Rosin, Wallach, & Assael, 1981). Density, whether members know each other and how they interrelate, helps determine the flow of support and is also an important structural measure (Hirsch, 1979).

Quality of Support

Subtypes of support have been identified and defined by several researchers (Barerra, 1981; Cobb & Erbe, 1978; Hirsch, 1979, 1980; Kahn & Antonucci, 1980). The present study measured three forms of support in interpersonal transactions: cognitive, emotional, and tangible (see Appendix for definitions). What combinations of support types are necessary for adaptation to stress has also become a research question. Hirsch (1979) developed the term "multiplexity" of support to indicate the mixture of support types flowing from network members to the individual.

Support in Transition Periods

Processing a major stressful life event and its associated changes has been denoted by the term, transition (Wiess, 1976). Several studies investigated the effect of social support in specific transitions. Conner et al. (1980) concluded that quality of support is more important to the adjustment of older people than network size or contact frequency. Walker et al. (1977) found the needs of bereaved women changed throughout transition. Support which met changing needs was most available when network characteristics such as density, size, and strength of ties, also changed. Hirsch's (1980) transition studies found support types correlated with adjustment measures. The crisis provoking the transition, time since the crisis, and internal and external factors were identified by Walker et al. (1977) as critical factors in the needs of people in transition. Caldwell and Bloom (1982) suggested the interaction of time, person, and situation moderates the mobilization of network supplies to meet transition needs. Transitions begin to emerge as dynamic processes "unfolding over time, in which life crisis events, their attendant stresses, and the social support resources available to individuals all combine to influence psychological adjustment" (p. 665).

The Transition of Dying

The present study viewed the transition of dying as the processing of the patient's reaction to the prognosis and several other tasks which many dying people wish to complete. The prognosis and the tasks represent loss and evoke stress or distress, the emotional or physical discomfort one experiences when the demands of the situation exceed one's resources (Lazarus, 1981). The renewing of stress with each task may be responsible for Schneider's (1984) transient phases in response to grief which he presented as reverberating like a "pebble in a pool of water". Schneider's phases moved away from the chronological order of early stage theories such as that of Kübler-Ross (1969).

The Tasks of Dying

The literature and Hospice personnel suggested many dying persons are concerned with and attend to a variety of issues or accomplishments. The present study named these issues tasks and developed a task list without chronological implications. The task list was utilized in the development of the Task Completion Scale administered to the subjects (see Appendix). Eleven tasks were identified:

1. Several studies suggest the chief task of dying as that of building a new identity. This role requires acceptance of

impending death, role restrictions, and new tasks. It also involves increased financial, emotional, and physical dependence (Cobb & Erbe, 1978; Corbett & Hai, 1979; DiMatteo & Hayes, 1981; Schneider, 1984.)

2. A related task is that of reinstating old relationships or choosing new ones if network members cannot accept the new identity (Schneider, 1984). This choice is sometimes necessitated by the fact that social network members often abandon the dying person. This abandonment is caused by the network member's fear of relating to the dying or by angry, rejecting behavior by the dying (Kübler-Ross, 1969).

3. Saying goodbye, also an important task, is often frustrated by the abandonment described above (Cobb & Erbe, 1978; Dunkel-Shetter & Wortman, 1981, 1982; Kahn & Antonucci, 1980).

4. Another corollary of the identity task is the support, reassurance, and bereavement help dying patients often choose to give those close to them (P. McQuistion, personal communication, January 25, 1984).

5. The task of pain control competes for first place. Pain and suffering from pain may be the cause of the depression and anxiety seen in many dying persons. It has probably confounded much of the research on the dying. Few physicians have begun to allow adequate and timely doses of narcotics to control pain and the fear of its return. Freedom from suffering allows the person to be concerned with the world (C. O'Shaughnessy, personal communication, March 18, 1983; Rosin et al, 1981; J. Schneider, personal communication April 7, 1983; Twycross, 1982). The task becomes that of learning

that pain control is both reasonable and available through assertion (Carey, 1974; Corbett & Hai, 1970; Corder & Anders, 1974; Hoffman, 1971).

6. Getting good care is a task that exhibiting autonomy and assertiveness can facilitate while it supports the patient's self-image as an effective person.

7. Kübler-Ross (1969, 1972) created wide awareness of the emotions she believed most dying persons experienced: shock, denial, anger, depression, bargaining, and acceptance. To experience these responses with acceptance, which often requires information that they are natural reactions that can be processed, is another task.

8. Finding some hope, a positive aspiration to some aspect of living and enjoying the present, is possible once a new identity is established (Cobb & Erbe, 1978; Rosin et al., 1981; Kübler-Ross, 1971; Schneider, 1984).

9. "Tying together loose ends" such as family finance details and funeral plans is often a task the dying wish to accomplish (Carey, 1974; Corbett & Hai, 1979; P. McQuistion, personal communication, January 25, 1983).

10. Mastery of the fear of the moment of actual death and the fear of abandonment during death has been identified by several studies as a task of dying (Cobb & Erbe, 1978; Corbett & Hai, 1979; Kübler-Ross, 1972; Rosin et al., 1981). Learning not to dwell on this unknown and learning to believe one will traverse it well and not die alone appear important.

11. A final self-evaluation has also been observed to be important (Corbett & Hai, 1979; Dudley, 1983; C. O'Shaughnessy, personal communication, March 18, 1983). Many dying persons want to share the productive past, enjoy past accomplishments, and be pleased with a job well-done.

Response To the Transition of Dying

People react to transitions and their associated tasks with varied levels of distress (Wilcox, 1981a, 1981b) and respond adaptively or maladaptively (Schneider, 1984). The adaptive response is a universal healing response to loss (Corbett & Hai, 1979; Dudley, 1982, 1983; & Schneider, 1984) marked by personal growth, life satisfaction, and progress in task completion (Schneider, 1984). A maladaptive response, caused by interference in the healing response, will increase stress, decrease life satisfaction, and impede progress with task completion. Interference includes denial by the person, network members, or health professionals, psychosis, over-reliance on old adaptation styles, lack of safety or support in relationships (Schneider, 1984), or pain.

Support Demands on a Stressed Network

It appears the dying person would fare better with a freely flowing supply of emotional, cognitive, and tangible support. Emotional support would assist with the wax and wane (Hinton, 1971) of intense feelings. Processing the thoughts about dying and the many tasks would be aided by cognitive support. Tangible support helps accomplish concrete tasks such as finding a lawyer or selling an unneeded car. Both flow and quality of support are disrupted however, by the death prognosis. Because members leave, many connecting links are missing or weak and network density is low. Members, too, must accept the prognosis, accept their loss and begin their bereavement. Until they learn how to give cognitive and tangible support appropriate to this transition, usually only emotional support is available--multiplexity is low. Thus networks, once rich in membership, density, and multiplexity, may become a small group of members not closely tied, who provide only emotional support. Regaining density and multiplexity is critical to the adaptation of the dying and their network members.

Support Buffers For the Dying

There is some evidence that social support can buffer the stress associated with and facilitate adaptation to the transition and tasks of dying (Cobb & Erbe, 1978; Schneider, 1984; Weisman & Worden, 1975). Carey (1974) found support significantly related to emotional adjustment in the dying. Corder and Anders (1974) suggested group discussions of patients provided emotional support and information (cognitive support). Cassell (1982), Corder and Anders (1974), and Twycross (1982) reported that patients who received support suffered less from pain. Usual support sources for the dying are family, friends, and health-professionals who let them know they will not be abandoned (Corbett & Hai, 1970; Kübler-Ross, 1972).

Hospice: A Place To Die With Dignity and Support

Belief in the effectiveness of social support and pain relief in facilitating "death with dignity" is the moving force in Hospice (Corbett & Hai, 1979; Saunders, 1978). The modern Hospice movement began in England in the 1950s. The first American Hospice was founded in 1974, and it is estimated that there are now 1,200 Hospices in the United States. Hospice has inspired many descriptive books and pamphlets but little empirical research (Buckingham & Lupa, 1982). Hospice admits only persons who have been told they are dying and have ceased curative medical efforts. They provide skilled nursing care and support for the dying person. Hospice's first goal is to control pain and other unpleasant symptoms so that the person <u>can</u> experience life beyond discomfort or suffering. "Dying persons have immense courage and dignity. If we can stop the pain, nausea, and shortness of breath, they can face death with courage, without pretense and with innate dignity" (C. O'Shaughnessy, personal communication, March 18, 1983).

Hospice views dying as a process patients and families need help coping with, accepting, and understanding. They do not believe that the phases of dying are chronologically locked nor that every patient experiences all phases (P. McQuistion, personal communication, January 25, 1983; C. O'Shaughnessy, personal communication, March 18, 1983; J. Waun, personal communication, February 17, 1983). Though the terminology differs, Hospice literature and personnel (Baldwin & Lorenz, 1981; Bresica & Lorenz, 1981; Buckingham & Lupa, 1982; Corbett & Hai, 1979; Jenkins & Cook, 1981; P. McQuistion, personal communication, January 25, 1983; J. Waun, personal communication, February 17, 1983) indicate that the role of Hospice personnel is to become new network members of the dying and their families by giving them and teaching them to give emotional, cognitive, and tangible support. Hospice sees its role as supporting the entire network, teaching about grief-work and assisting the dying to experience an adaptive response and to complete the tasks of dying. The tasks identified in this study are all recognized by Hospice as issues the dying deal with and for which they need support. Hospice's goal is to free the patient of pain and discomfort and support the network so that all members can cope with role transitions and enjoy whatever time they have left together.

It appears that Hospice support and teaching facilitate the restoration of greater network density and multiplexity. Newly admitted patients with disrupted networks show high distress, poor adjustment and lack of progress with task completion. Patients who have been with Hospice longer have more and multiplex support from restored networks, show less distress, greater life satisfaction, and more progress with the tasks.

Hypotheses

The concept of networks which provide social support throughout life, confirm identity, change to meet the needs of the developmental process at hand, support their dying persons in final transition, was reviewed. The study then examined the structure, quality, and stress-buffering effect of the social networks of dying persons and their progress in completing the tasks of dying. It was an effort to provide empirical evidence of the relationships among those concepts and to define the dynamics of those relationships. Such information could assist the design of interventions helpful to the dying patient (Bugen, 1977, 1979; Cohen & Sokolovsky, 1981). The present study was designed to examine such important questions as: What network changes must occur to assure completion of the tasks of dying? What kinds of support must a dying person receive to master those tasks? Is one structural form of network superior to another with these developmental tasks? Is quality of support an issue? Do different types of support seem associated with different levels of task completion? Who in the network gives which type of support?

Two groups of dying persons differing in time since admission to Hospice were studied. Measures of distress, adjustment, and task completion were performed. Correlations with measures of network structure and quality of support were then computed. Several hypotheses were tested:

Hypothesis 1. The composition of networks of the newly admitted patients (early) and those who had been there longer (late) would follow the general pattern: (a) The same number of family members would be named to the network by early and late patients. (b) More friends would be named to the network by the early patients than the later patients. (c) Fewer Hospice personnel would be named to the network by the early patients than the late.

Hypothesis 2. The total size of the network would be similar while accommodating the composition differences mentioned in Hypothesis 1.

Hypothesis 3. Network density would be lower for the early patients than the late.

Hypothesis 4. The support ratios (amount of each type of support divided by the total support) would follow this general pattern: (a) Early networks would provide more emotional support than later networks. (b) Later networks would provide more cognitive support than early networks. (c) Later networks would provide more tangible support than early networks.

Hypothesis 5. The multiplexity of early and late networks would follow this pattern: (a) Early networks would be much less multiplex than later networks. (b) Family relationships would be more multiplex in the late networks compared with the early networks. (c) Hospice relationships would be multiplex whenever the Hospice personnel were named to the network. (d) The multiplexity of friend relationships would be significantly different in the two groups.

Hypothesis 6. Greater multiplexity would be significantly related to favorable outcomes on stress and adjustment measures: (a) Patients in the early group whose networks were not expected to be multiplex would have low scores on the three adjustment measures: Task Completion Scale (TCS), the Life Satisfaction Index (LSI), and the Emotional Adjustment Scale (EAS). They would have high scores on the stress measures: Distress Scale (DS) and the Response to Loss Instrument (RLI). (b) Patients in later group whose networks were expected to be multiplex would have high scores on the three adjustment measures, TCS, LSI, and EAS. They would have low scores on the stress measures, DS and RLI.

Hypothesis 7. Greater network density would be significantly related to favorable outcomes on stress and adjustment measures: (a) Patients in the early group whose networks were not expected to be dense would have low scores on the three adjustment measures: Task Completion Scale (TCS), the Life Satisfaction Index (LSI), and the Emotional Adjustment Scale (EAS). They would have high scores on the stress measures: Distress Scale (DS), and the Response to Loss Instrument (RLI). (b) Patients in later groups whose networks were expected to be dense would have high scores on the three adjustment measures, TCS, LSI, and EAS. They would have low scores on the stress measures, DS and RLI.

Methods

Subjects

Ten persons who were dying and had been admitted to the Hospice program within the previous four weeks and ten dying persons who had been Hospice patients longer than four weeks were interviewed. The initial plan was to interview twelve persons who had been admitted within the previous six weeks and twelve who had been at Hospice three to four months. This plan was abandoned after months of standstill with the research project. Subjects ranged in age from thirty-nine to eighty-eight with a mean age of 68. Eleven were females and nine were males. Two patients were black, eighteen were white. Most were retired and occupations represented included housewife, teacher, janitor, bus driver, factory worker, nurse, and waitress. Wealth ranged from minimum social security through very wealthy with the mean in the middle class. Ten persons were heads of households, three were not contributing to the income, and seven were joint contributors. All were parents but only four had dependent children. Fifteen were married and five had been widowed. They had known their diagnosis for 4 months to 6 years with a mean of 19.5 months. Their knowledge of their terminal prognosis ranged from 1 to 12 months, with a mean of 5.4 months. They had abandoned efforts to restore life 1 to 9 months prior with a mean of 3.7 months. All Hospice patients have decided to halt curative medical measures and generally have less than six months to live. Subjects were those who could physically tolerate an interview and wished to do so.

Procedure

Hospice of Southeastern Michigan administrators and Board of Directors read and approved the proposed research. The study was next explained in meetings with nurses. No one was compelled by administration to assist (see Appendix). The general notion of the research was described but specific hypotheses were not discussed with these groups who served as "blinded interviewers". Staff members were asked to discuss the study with patients (see Appendix). Assurance was given that Hospice care was not contingent upon participation. Confidentiality of shared information was assured. Patients were told they could withdraw from the study at any time. From October to late December, 1983, no progress was made by the nurses in instituting the research. Hospice staff was busy preparing for a federal on-site review in conjunction with their application for Medicare funds. In January I was given a new group to work with, the Volunteers staff. Of 121 patients enrolled during January, February, and March, 1984, Hospice volunteers interviewed three. Of 40 volunteers asked to interview patients for this study in January, thirty-four agreed. The three interviews were completed by this group. Others were unable or unwilling to complete their assignment. Forty more volunteers were asked for assistance in February, but proved unwilling or unable to assist. Administrative staff enthusaism in each department was followed by lack of progress. Excuses ranged from fear of harming the patient to fear of being sued to fear of upsetting the patient and not being able to "handle their emotions". Resistance to performing the interview was apparent to me then. Therefore, in March, I finished interviewing seventeen patients who wished to participate regardless of their time since admission. Thirty patients were present while I was interviewing and only one person declined to be interviewed. Several patients whom I was told would not allow the interview welcomed the interview when I was allowed to make the request. One patient whom I was told was unable to communicate asked me to interview him when he over heard me interviewing his roommates (see Discussion). I completed the network analysis, the Life Satisfaction Scale, and the Response to Loss Instrument (see Appendix). This interview lasted 20-30 minutes. The staff and I completed the remainder (see Appendix). Whenever possible, staff completed the final part alone.

Avoidance of interfering with the patient's needs was a primary concern. Giving time to the patient who wished it was regarded as important as gaining the information they wished to give. Patients, however, are often more ready to talk than researchers or staff believe. They are often less afraid then we project (Cobb & Erbe, 1978). This was borne out in this study. Care was taken to remain aware of the patient's comfort. Patients were encouraged to signal when respite was needed. When necessary, I returned hours or even days later. Each instrument was confined in length to minimize intrusion. Time was planned for discussion and management of the needs which arose in answering the questions. Needs for care or caring were often seen by other researchers (Strain & Chappell, 1982). During this data collection such needs were relayed to the primary-care-giver as appropriate. Time was planned to allow patients to discuss their questions or feelings about the study or those brought up by the study. Most patients were not reluctant. Most were pleased to be a part of the project. Many were thankful for the "meaningful" and "helpful" questions of this interview. I was invited and returned several times to visit with many of the patients. To allow the patient time to visit without measurements, a minimum of one follow-up visit to each person was made.

Primary care givers and patients were told the exact nature of the research after data collection was completed (see Appendix).

Measures

Network Analysis. The network analysis in this study used Kahn and Antonucci's (1980) circle diagram to display network membership. Other interview questions then obtained information regarding structure and quality of support of the network. Size and density of the network, support types, and support multiplexity were measured (see Appendix).

Grief Measure (RLI). A distillation of Deutsch's (1982) Response to Loss Instrument was used (see Appendix F). This instrument is based on Schneider's loss model and assesses six dimensions of grief: cognitive, physical, emotional, spiritual, behavioral, and an imaginative dimension. Only two statistically weak measures of grief existed at the time of her writing. These measures lacked theoretical back-up, as well. This study used only the cognitive and emotional dimensions of Deutsch's Instrument. Deutsch reported reliabilities with Cronbach's Alpha of .84 for the Cognitive scale and .88 for the Emotional scale (Deutsch, 1982). The instrument appeared a valid measure of grief in Deutsch's research, N = 152. It was able to distinguish between severely depressed and normally grieving persons and track the impact of loss over time. Patterns of scale combinations typical of normal, severe, and less severe grief, and severe depression emerged. Since scores range from 0-21 on the cognitive scale and from 0-30 on the emotional scale, the scores were converted to percentages before being compared. If the two scores are approximately equal it indicates normal grief processing. If the cognitive scale is higher processing is mainly intellectual. If the emotional scale is higher the person may be experiencing strong feelings and not connecting them to a cognitive understanding of the reason for those feelings (Deutsch, 1982).

Life Satisfaction Index (LSI). This is a 13-item short form of Neugartin, Havighurst, and Tobin's 1961 Life Satisfaction Scale. Wood, Wylie, and Sheafor (1969) reported that the original scale yielded 95% interrater reliability and that the short-form yielded .79 reliability coefficients (Kuder-Richardson Coefficient Alpha). Wood et al. (1969) stated it is not as precise as the original 90-minute instrument but approximated the latter's information without demanding extended time from the patient. Wood et al. (1969) validated the instrument by comparing it with a more detailed Life Satisfaction Rating scale which was based on rating by trained judges (psychologists) (Neugarten, Navighurst, & Tobin, 1961). The correlation was .57, significant at the .01 level and beyond. Wood et al. (1969) reported the index had been used in several studies of urban and rural populations. Conner et al. (1979) reported the measure "correlated significantly with other measures of morale" (p. 118). This scale was used in a 1979 study of late-life social interaction and life satisfaction (Conner, Powers, & Bultema, 1979). They reported the measure yielded an internal consistency value of .93 (Cronbach's Alpha) (see Appendix). Scores range from 0 to 26 and higher scores indicate better adjustment.

<u>Carey's Emotional Adjustment Scale Abridged (EAS)</u>. This six-item scale was designed by Carey (1974) to measure "the extent to which a terminal patient was able to cope interiorly and exteriorly with his limited life expectancy." Inner peace and self-possession, not resignation or acceptance were included in Carey's concept of emotional adjustment. Eleven interviewers in Carey's study consistently obtained a strong negative relationship

between scores on the Discomfort Scale and Emotional Adjustment Scale among the 86 patients interviewed. In the present study the EAS was positively correlated with the LSI, an adjustment measure which had been widely used and had wider validity indications. Carey (1974) reported interrater reliability for the total scale score was .95 (Pearson correlation coefficient). Questions 5 and 6 were added to adapt the scale to this study (see Appendix). Scores range from 0 to 7 and higher scores mean better adjustment.

Carey's Discomfort Scale Abridged (DS). This five-item scale was suggested by Carey to evaluate the patient's degree of pain disfigurement, dependence and difficulty with eating and sleeping. The DS appeared a valid measure of distress. It consistently had a strong negative relationship with the EAS in Carey's study (1974). It was positively correlated with the RLI (another distress measure) and negatively correlated with the adjustment measures (EAS and LSI) in the present study. Reliability ratings and actual scale are not in the literature. Items 8, 9, 10, 11, and 13 make up this scale (see Appendix). Scores range from 0-25 and higher scores indicate greater discomfort.

Task Completion Scale TCS. The tasks of dying are itemized and defined. The degree of completion of each task is measured on a scale of 0-5 (see Appendix). Scores range from 0-55 and higher scores indicate progress in completing the tasks. TCS content was derived from a comprehensive review of the tasks other studies of the dying have suggested. Some tasks are repeated in several studies (see Tasks of Dying section). Interrater reliability ratings were not performed.

Demographics. Age, length of illness, and recency of terminal illness were added to Part IV but not scored with Carey's Discomfort Scale.

Intercorrelations of Scales. Because reports on the validity of several of the instruments were brief or unavailable intercorrelations of these scales were computed and are reported in the Results section (see Table 1). Distress scales (RLI and DS) correlated positively with each other and negatively with the adjustment scales. Adjustment scales (LSI and EAS) correlated positively with each other. Scale intercorrelations supported the validity of the scales. The Task Completion Scale had weak positive correlations with all other scales. The TCS was not clearly an adjustment measure then. It appeared to reflect an achievement dimension, independent of both the stress-evoking nature of the tasks and adjustment.

Table 1. Intercorrelations All N's = 20.

	RLI	TCS	LSI	EAS	DS
Response to Loss Instrument (RLI)	-	.19	- .50**	- .29	.17
Task Completion Scale (TCS)	.19	-	.02	.13	.09
Life Satisfaction Instrument (LSI)	.50**	.02	-	.48*	- .34
Emotional Adjustment Scale (EAS)	- .29	.13	.48*	-	- .14
Discomfort Scale (DS)	.17	.09	- .34	- .14	-

* $p \leq .01$ two tailed test.
** $p \leq .05$ two tailed test.

Results

Data analysis quickly revealed that the groups chosen by time since admission to Hospice were not characteristic of the Hospice groups originally intended. The early group included several persons close to death who had only recently learned of and joined Hospice, while the late group contained many newly diagnosed people. The early group's mean time since admission to Hospice was 2.8 weeks and their mean time since diagnosis was 17.30 months. The late groups mean time since admission to Hospice was 11.1 weeks and their mean time since diagnosis was 21.80 months, not significantly different from the early group. When the planned analyses yielded nonsignificant results, further analyses were performed to examine these apparent differences and to search all data for other meaningful relationships. These further analyses confirmed the group composition problems.

All the analyses were then repeated on data rearranged into groups based on time since diagnosis. Five cases in each group switched groups. The data are reported as Hospice Groups and Diagnosis Groups, designating the groups based on time in Hospice or time since diagnosis.

Network Composition, Size, Density, Types, and Multiplexity of Support in Hospice Groups

The first five hypotheses were tested utilizing *t*-tests (see Table 2). None of Hypotheses 1-5 regarding network composition, size, density or multiplexity were supported with the exception that family memberships and Hospice multiplexity were the same for both groups. Three significant differences appeared. All were reverse of the prediction (friend membership, network size, and tangible support ratio were larger in the late networks).

Multiplexity and the Stress and Adjustment Scores

Pearson correlation coefficients were utilized to test the relationships of multiplexity with the stress and adjustment scores. No significant relationships were found between general multiplexity and any of the measures. Correlations range from .06 to .42. Hypothesis 6 regarding the relationship of multiplexity to the measures of stress and adjustment was rejected.

Density and the Stress and Adjustment Scores

Pearson correlation coefficients tested the relationship of density to the stress and adjustment scores. The results showed no significant relationships of density to any of the measures. Hypothesis 7 regarding the relationships of density to stress and adjustment outcomes was not supported.

Non-Significant Differences in Hospice Groups

Given the small sample size and the apparent group composition problem, the lack of statistical significance was not surprising.

Table 2. Network features of Groups Based on Time In Hospice.

Feature	Group	Mean	t
Network Composition, Size, and Density			
Family membership	Early	3.90	1.42
	Late	5.60	
Friend membership	Early	.60	2.26*
	Late	4.00	
Hospice membership	Early	.60	1.18
	Late	1.00	
Network size	Early	5.00	2.63*
	Late	9.70	
Network density	Early	.96	-2.16
	Late	.75	
Types of Multiplexity of Support			
Emotional Support Ratio	Early	.32	1.47
	Late	.43	
Cognitive Support Ratio	Early	.22	1.30
	Late	.30	
Tangible Support Ratio	Early	.47	-2.58*
	Late	.27	
General Support Multiplexity	Early	2.27	-1.16
	Late	1.97	
Family Support Multiplexity	Early	2.12	- .25
	Late	2.03	
Hospice Support Multiplexity	Early	2.88	-1.35
	Late	2.25	
Friend Support Multiplexity	Early	2.11	-1.05
	Late	1.58	

*$p \leq .05$.

Further examination of the planned analyses were performed. Mean differences appear meaningful in several instances although most often in the unpredicted direction (see Table 2). Mean differences in the expected direction included: greater Hospice membership and cognitive support ratio in the late groups. Mean differences opposite the direction expected were: greater family and friend membership and greater network size, greater emotional support ratio, smaller tangible support ratio, and smaller general and family multiplexity in the late group.

Further Analyses in Hospice Groups

Further analyses were performed to examine these apparent contradictions of the Hypotheses and to search for other meaningful relationships in the data. Pearson correlation coefficients yielded no significant relationships of the new variables, time since diagnosis, time since stopping medical heroics, patient's measure of pain, and network size, to the stress and adjustment measures. These interesting though not significant correlations appear: the relationship of time since diagnosis and Response to Loss Instrument, $\underline{r} = .41$ ($p = .08$), and the relationship of time since quitting medical heroics and the Discomfort Scale, $\underline{r} = -.42$ ($p = .07$). Further $\underline{t}$-tests on additional features were calculated. These results are reported in Table 3. Early patients had higher mean pain scores than later patients as expected. No significant group difference in the gap between patients' emotional and cognitive responses to the RLI scale was seen in the means. Both groups were processing their cognitive responses more than their emotional responses. The

Table 3. Further Analyses in Hospice Groups - *t*-tests

Feature	Group	Mean	Decimal Scores	*t*	*p*
Months Since Diagnosis	Early Late	17.30 21.80		.68	.50
Months Since Quit Medical Heroics	Early Late	3.90 3.60		- .27	.79
Patients Pain Scale	Early Late	4.70 3.30		- .86	.40
RLI Emotional Scale	Early Late	13.70 9.50	.46 .32	-1.50	.15
RLI Cognitive Scale	Early Late	16.60 14.40	.79 .69	-1.08	.30
TCS	Early Late	42.80 42.50		- .07	.95
EAS	Early Late	.55 .76		2.10	.74

later group had higher mean scores on the EAS. Time since diagnosis and time since medical heroics were not significantly different, contradicting the intended group composition. Since a problem with group selection was apparent, all of the *t*-tests were then performed on two new subgroups to look for a time since diagnosis effect rather than time in Hospice effect.

Analyses of Diagnosis Groups

Data were median split on time since the terminal diagnosis was made. These reformulated data were then submitted to the same *t*-tests. None of the *t*-tests reached significance in either direction. Family membership and network size, which were expected to remain stable, were the only variables to gain the predicted results. The mean differences for these new groups appeared meaningful but only half were in the predicted direction.

Means: Network Composition, Size, Density Types, and Multiplexity of Support

The means that were in the predicted direction indicate slight differences between the groups in greater Hospice membership in the late network, and greater general, family, and Hospice multiplexity in the late network (see Table 4).

Means: Further Analyses in Diagnosis Groups

Early patients (see Table 5) had greater mean pain scores as expected. The gap between the emotional and cognitive scales of the RLI differs very little in character. Both groups used

Table 4. Network Features of Groups Based on Time Since Diagnosis

Feature	Group	Mean	Decimal Score	*t*	*p*
Network Composition, Size, and Density					
Family Membership	Early	5.90		2.01	.07
	Late	3.60			
Friend Membership	Early	2.30		0	1.0
	Late	2.30			
Hospice Membership	Early	.50		-1.86	.08
	Late	1.10			
Network Size	Early	7.90		.53	.61
	Late	6.80			
Network Density	Early	.87		.30	.77
	Late	.84			
Types of Multiplexity of Support					
Emotional Support Ratio	Early	.35		- .51	.62
	Late	.40			
Cognitive Support Ratio	Early	.26		.16	.87
	Late	.25			
Tangible Support Ratio	Early	.38		.35	.73
	Late	.35			
General Support Multiplexity	Early	1.99		- .95	.36
	Late	2.24			
Family Support Multiplexity	Early	1.85		-1.34	.20
	Late	2.30			
Hospice Support Multiplexity	Early	2.20		- .96	.36
	Late	2.64			
Friend Support Multiplexity	Early	1.84		.33	.76
	Late	1.67			

Table 4 (Continued)

Feature	Group	Mean	Decimal Score	*t*	*p*
Further Analyses					
Months Since Diagnosis	Early	10.9		-3.27	.01
	Late	28.2			
Months Since Quit Medical Heroics	Early	4.10		.65	.53
	Late	3.40			
Patient's Pain Scale	Early	4.70		.86	.40
	Late	3.30			
RLI - Emotional Scale	Early	9.40	.31	-1.58	.13
	Late	13.80	.46		
RLI - Cognitive Scale	Early	14.90	.72	- .58	.57
	Late	16.10	.77		
TCS	Early	40.60		- .94	.36
	Late	44.70			
EAS	Early	.67		.34	.74
	Late	.63			

Table 5. Coefficients of Support Types and Task Types. All N's = 20.

	Behavioral Tasks	Cognitive Tasks	Emotional Tasks
Behavioral Tasks	-	.76***	.52**
Cognitive Tasks	.76***	-	.26
Emotional Tasks	.52**	.26	-
Tangible Support	-.21	-.36	-.02
Cognitive Support	-.06	-.31	.09
Emotional Support	.15	-.10	-.15

***p < .001 by the 2-tailed test.
**p < .01 by the 2-tailed test.

cognitive responses to grief more than emotional responses. Slightly greater means on the EAS were seen for the early group. Time since quitting medical heroics was slightly less for the late group.

Support and Task Correlations

To investigate whether specific support types could be shown to facilitate the completion of the tasks, the TCS was divided into behavioral, cognitive, and emotional tasks. Their Pearson correlation coefficients are presented in Table 5. Correlations of the subdivided tasks with tangible, cognitive, and emotional support, as suggested by recent literature (Revenson, Wollman, & Felton, 1983; Barrera & Ainlay, 1983), were also performed and are presented in Table 5. All task intercorrelations are significantly positive except the cognitive-emotional correlation which is positively but not significantly correlated. All support and task correlations are negative though not significant except that emotional support is positively though not significantly correlated with behavioral tasks.

Discussion

The findings of this study failed to statistically support its hypotheses. The effort, however, serves as an important pilot in research of its kind with dying patients. The Discussion will briefly review the lack of statistical support, the methodological problems and insights, the success in accomplishing such research with dying people, the resistance of Hospice staff, the utility of the interviews themselves to the dying patient, and the findings of a few recent studies.

The findings of the planned analyses present significant statistical support for only one of the hypotheses. Small sample size and faulty group composition may have contributed to this problem. Where significant findings occurred, they were not in the predicted direction.

When the groups were divided by time since the diagnosis of terminal illness, mild trends in the data appeared. Some predicted though non-significant differences in size, composition, and multiplexity of support appeared. Network size was similar and Hospice membership was greater. All sources of support multiplexity were greater in the late group except that emotional support of friends was greater while cognitive and tangible were smaller.

The late group experienced less pain. Both groups used cognitive responses to process grief more than emotional responses. These characteristics were more like that expected but still far from the hypothesized results.

Because nothing in the data suggested that support helps patients complete the tasks of dying (by buffering the associated stress), I next looked for conceptual problems. The global concept of support was divided into support types and correlations of specific support types and specific task types were performed. This test was suggested by Revenson et al. (1983) and Barrera and Ainlay (1983) who had concluded that studies of social support ought to investigate specific types of support and their effect on specific types of stress. They offered that interrelationships which provide a good match between support given and needed will act as effective buffers. Positive intercorrelations of the behavioral, cognitive, and emotional tasks of dying indicate the Task Scale does represent a unified concept. Negative correlations of subdivided support and subdivided tasks mean that the more highly distressed patients who lag in task completion receive the most support. However, emotional support was the preponderant type of support reported by the patients and has the only positive correlation. A small but negative gain in the relationship of support and tasks was made by this analysis. Another area for further studies to examine is the definition of support and support types given to the patient and interviewers. Improvement of the wording, presentation, and scoring of these concepts may contribute to increased precision of measurement. The apparent paradox of the patients' acclaim for the care they receive at Hospice and the unexpected findings of this study is, in my opinion, reason to improve and pursue research in this area. Further work also may help clarify the interesting issue raised by Revenson et al. (1983) and Barrera and Ainlay (1983). If types of support and types of tasks and responses correlate significantly in larger samples, is timing of the type of support also important in the accomplishment of these tasks and responses? Repeated measures may also be a helpful design element in such studies.

Thus, none of these analyses yielded the predicted picture of the structure, quality of support, or stress-buffering effect of the dying person's network. However, further research is encouraged by the success of this study in accomplishing such interviews with dying people. The patients' very low refusal rate (5% of those I interviewed), the many comments by dying persons that the interview contained important questions that they wished to discuss, and the many enthusiastic "thank-yous" and expressions of encouragement by these dying persons contrast the strong resistance of the staff. Use of the measurements themselves as tools for discussion is encouraged by the responses of the patients. Patients said the questions helped them to think, talk, and sometimes to cry about, issues whose discussion is difficult to initiate. Some of the instruments could be used as a matter of protocol to help staff increase their comfort with the issues and to help patients know that their issues are common, acceptable, and can be talked about. Such direct questions can serve as a catalyst for dialogue, thinking, support and catharsis, as an assessment tool, and as an added guide in treatment planning.

The most poignant example of both the utility of the interview and the marked contrast in patient and staff attitude toward it involves a man whom staff said could not communicate with me and could not complete such an interview. He begged me to talk to him and ask him the questions after he overheard part of his roommate's interview. The man expressed great emotion over childhood pain, current family problems, and fears. I returned to visit him several times and gradually we could laugh and smile together and we gained staff assistance with his family problems. At one departure he said to be sure to see if he was still there when I came back and "You tell your family there's an old man lying in a hospital in Detroit who loves you." Tears that fall on the research paper will probably be deleted. The experience confirmed for me that dying people do wish to communicate and that direct questions can be helpful access tools. Initiation of these discussions appears more manageable by interviewers and desired by patients than staff indicated. Staff resistance to the study in contrast to the enthusiasm of the patients became one of the most important findings and may help guide future researchers. The inaccurate screening of subjects, the continued postponement of research goals, and the many excuses for not interviewing (see Methods), slowed the project by several months. It also contributed to the sampling problem, and to the loss of control over researcher bias because I decided to interview the total willing population myself rather than wait for interviews of my originally planned groups to be completed by staff.

Staff resistance indicates a need for their involvement in early planning and education about the research. It also points out the discrepancy between the Hospice ideal of dealing with emotional issues and the avoidance of those topics seen here.

Are Hospice staff protecting the patient's emotions? Are they protecting their own emotions? Are they so overworked and/or overstressed that they avoid discussions which may create more work and/or more stress? Are they resistant because they are not invested or informed early in the research? Are they tired of researchers getting in their way as some indicated? Are they resistant because they see no immediate benefit? These are important questions for future researchers to examine early in their project.

Researchers must have knowledge of the high stress load (Chiriboga, Jenkins, & Bailey, 1983) and heavy work load of Hospice staff. Researchers should be prepared to do most of their own interviewing and to seek and gain staff understanding and trust early in the research; probably even before approval by administrators. Acceptance that the interview will not harm the patients or create management problems for staff is important. The long weeks of standstill in this research included many staff reports of discomfort with and inability or unwillingness or fear of, administering it. Their discomfort was suggested by responses ranging from "We'll get sued." to "He would get upset and cry." to "This is a cruel thing to ask people." These responses were surprising, for Hospice (ideally) is staffed by people more at ease with their own death issues and able to discuss others'. The imbalance of cognitive and emotional responses with all patients may reflect an unwillingness of many Hospice staff to deal with emotion. The need for careful screening, training, retraining, and social support of Hospice personnel seems evident. The need to carefully train and retrain staff regarding research projects is also illustrated. Allowing the patient, rather than the staff, to screen who will be an appropriate candidate for study then is more possible. It is certain that staff screening of patients in this work precluded the interview of a wider range of patients, therefore skewing the group's composition. Additionally, group composition was affected by the refusals and elimination of those physically unable to respond. The data from these patients might have changed the direction of the results. Had this research retained the original intent to choose newly admitted patients (within 7-10 days) for the early groups and "veteran" patients (3-4 months since admission), rather than interview as many as possible and split them at the four week median, clearer group differences might have occurred.

Much larger sample sizes and stringent group selection methods are needed for further studies. Comparison groups should be used to examine whether a "Hospice" effect or a "time since diagnosis" or a "time since quitting medical heroics" is taking place.

Scale intercorrelations reported in the Results section support the validity of the scales. Data indicate the RLI and DS are measuring different factors than the LSI and EAS, as expected. The positive correlations of the TCS with all scales may indicate that task completion is both an indication of adjustment to the death prognosis, and a source of additional stress. While the dying person does complete a task, indicating they may be accepting or adjusting to their death, performing that task may be distressing. Some task completions consist of unwilling or passive participation in family-led activity (e.g., wills, financial arrangements). Often these tasks are painful reminders of impending death. Because task completion may be both stressful and relieving of stress, the TCS alone cannot be used as a measure of adjustment.

Measures designed specifically for dying persons and data analysis sensitive to the wax and wane character of the transition are also needed. When does a large amount of reported distress mean a patient is currently in distress? When is it a departure from previous denial and, thus, an improvement in condition? These issues and method problems need to be addressed in future studies.

The design of future studies of social support in the transition process of dying will also be aided by more recent studies and conceptualizations of social support structure and how it interacts with person, time, and event variables. One study questions the stress-buffering effect of social support for cancer patients and provides several related questions to answer in continuing research on support and dying (Revenson et al., 1983). Others lend support to the present study, and to its conceptualization of the phenomenon being studied as a transition process characterized by several tasks (Felner, Farber, & Primavera, 1983; Godkin, Krant, & Doster, 1984-84). The literature also recommends the extraction and study of personality and coping variables which may be interacting with social support (Zautra & Reich, 1983; Zautra, 1983). Finally a physician-philosopher (Dagi, 1983) and a psychologist (Wiess, 1976) ask the researcher and the professional to assess the individual human needs of the dying before prescribing support or other research findings or beseeching them to have courage in the face of death. Dagi (1983) says elegantly:

> People may choose to live in ignorance of their fate and condition . . .and perhaps it is best that we not be compelled to live up to an ideal of personal autonomy. The freedom of choosing one's own style of living and dying should be, *prima facie*, respected (p. 434).

Each of us brings to our transitions a substantial history, particular strengths and weaknesses, ways of utilizing support to solve the tasks and cope with the distress of that transition, and idiosyncratic meanings or perceptions of that transition and the events which mark its path. Learning those elements of a dying person's style and allowing them to die in their way continues to be the challenge to the researcher and clinician interested in the process of dying.

Appendix

Pre-Research Briefing for Staff

Good morning,

As you know, there has been very little research done with Hospice patients. Although quite a bit with Hospice families. What I want to do is provide a first step for that kind of research. My project is to learn from dying patients about their support networks and their concerns and feelings. The research instrument has two parts. I will interview the patient and fill out one part. You will fill out the second part. I will now go through all the questions with you and you may ask questions of me.

When we finish all the interviews I will explain more precisely what I was trying to find out.

Only patients who wish to answer should be involved. If they say Yes I will get an informed consent. I trust you to "back off" if some one is too tired and to take time to counsel or hold a hand when you see that the questions provoke thoughts or emotions. I will do the same with my part.

Pre-Research Explanation For Patients

Good morning, Joe. We have a woman here who wants to write a research paper about what its like to be a Hospice patient. She wants to share this information with other psychologists, nurses, and doctors who are interested in Hospice. Would you like to answer some questions about yourself, your feelings and concerns and tell us a little about your support group?

MICHIGAN STATE UNIVERSITY

Department of Psychology

DEPARTMENTAL RESEARCH CONSENT FORM

1. I have freely consented to take part in a scientific study being conducted by: Mary Clearing-Sky

   under the supervision of: Robert Caldwell, Ph.D.

   Academic Title: Associate Professor of Psychology

2. As you know this study will collect the thoughts and feelings of dying people about life in general about people who are important to them and about their present situation. The purpose of the study is to learn ways for friends and health care providers to be most helpful to dying persons and their families and to help them with the things they want to accomplish.

3. The study has been explained to me and I understand the explanation that has been given and what my participation will involve.

4. I am aware that responding to the instruments in this study might lead to unpleasant emotions.

5. I understand that I am free to discontinue my participation in the study at any time without penalty.

6. I understand that the results of the study will be treated in strict confidence and that I will remain anonymous. Within these restrictions, results of the study will be made available to me at my request.

7. I understand that my participation in the study does not guarantee any beneficial results to me.

8. I understand that, at my request, I can receive additional explanation of the study after my participation is completed.

Signed:____________________

Title of Exper. Social Support, Social Networks and the Tasks of Dying

Date: ____________________

Network Analysis
Circle of Support Script

I. Bill, Sarah ____, one of the things I'd like to have you help me with is what your circle of family and friends and important people is like at this time whether or not you like them. For example, how big the group is, who's in the group, and what sort of things they do for you or with you. I'd like to start by having you (or having you help me) fill in this circle). We're going to write down all the people who are important to you or to whom you are important. I want to talk about how it is right now, this week. Later, if you want, we can talk about how it was earlier, OK? You're in the middle circle. The people we'd put in the next circle are those closest to you--the most important people in your life. Any questions? This is sometimes pretty hard work, so if you want to take a break anywhere just let me know. Then out here are important people, but not the closest. Maximum = 20 (Most will be many fewer).

II. Now I want to write on here friend, family members, or Hospice worker. Is ____ Jane, etc. ____ a friend, family member, or Hospice worker, or other? Place Code to left of name. Code: 1 = family, 2 = friend, 3 = Hospice, 4 = Other.

III. Next I'd like to have you tell me which people know each other in this group. Let's start with Jane. Does she know Darin?

Draw lines between people who know each other.

IV. How are you doing? Do You want to rest a while? This next part will tell me what sort of things this circle of people does for or with you (and you do for them too).

There are three kinds of things people in our circles usually do for us. Let me describe them to you. (If it's easier for you you can read this description . . .) Let's read all three and think about them first. READ FROM LIST OR LET PATIENT READ. Do you have any questions? Okay, I'll do one at a time. The first is emotional support. By that I mean people who

READ FROM LIST OR LET PATIENT READ (Code = E)

Can you tell me which people do that for you? Place code to right.

The second set of things our circle of friends and family does for or with us in cognitive or thinking it through kinds of things. Here are the examples again:

READ FROM LIST OR LET PATIENT READ (Code = C)

Can you tell me which people do that for you?

The third group is tangible help or direct help, things you can put a finger on easily (Code = T). Here are the examples:

READ FROM LIST OF LET PATIENT READ

One more question. Now that we have this all filled in and have an idea of what kinds of support people give and who gives it can you tell me what you think about your circle as a whole?

For example: Is it big enough? _____ Are you getting what you need from your circle? _____ Is there some kind of support you'd like? _____(etc.). On a scale of 1-10 on how satisfied you are with what your circle of support how would you rate your circle?

OK, that completes the information about your circle of support. Do you want to talk about any of the information you shared with me? Do you have any questions about any of that? Are you ready for more questions on a different subject? Would you like to rest and have me come back later? Do you need anything before we begin?

Circle of Support Descriptions

Emotional Support = E

People who let you know they like you, love you, or admire you.

People who let you know you are an important part of their group.

People who let you know they appreciate your love, admiration or respect.

People who let you know its okay if you vent your feelings, to cry, be sad, angry, upset, or confused.

Cognitive Support = C

People let you know they think you're doing things well.

People let you know they think what you say is correct.

People who help you make sense out of what is going on with you daily or as a whole.

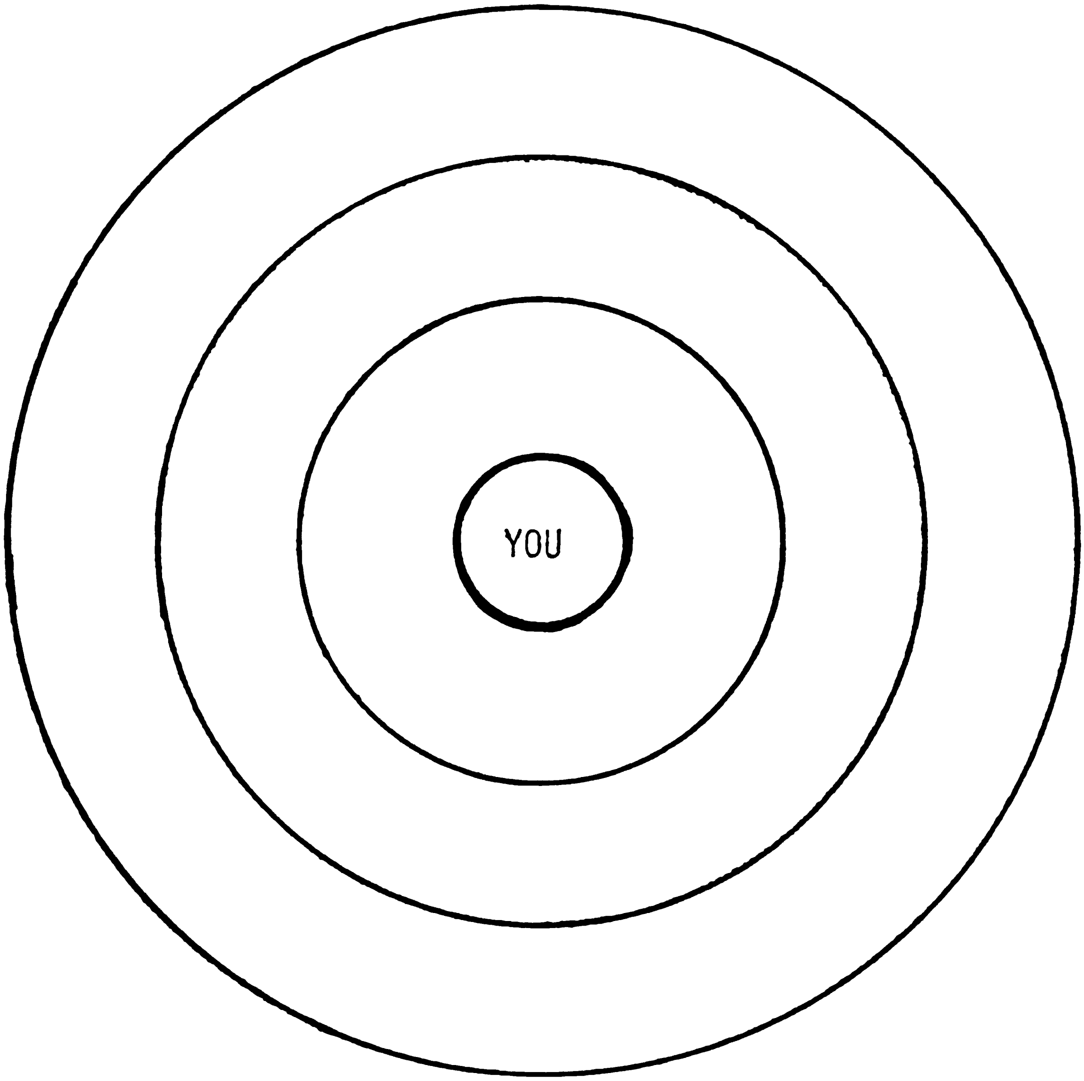
People let you know you are an important, worthwhile, valued person.

Tangible Support = T

People who help you with business matters, like wills, estate business, insurance.

People who will get information on things you may need like getting a nurse or a social worker to visit, finding a hospital bed, or a walker.

People who would come in and clean the house or help with your bath, shovel, cut the grass, get groceries or medicine.


YOU

#______________________

Life Satisfaction Index

Section I

Here are some statements about life in general that people feel differently about. Would you read each statement on the list (or AS I READ EACH STATEMENT ON THE LIST) and if you agree with it put a check mark in the space under "Agree". If you do not agree with a statement, put a check mark in the space under "Disagree". If you are not sure one way or the other, put a check mark in the space under "?". Please be sure to answer every question on the list.

	Agree	Disagree	?
1. As days go by, things seem better than I thought they would be.	_____	________	_____
2. I have gotten more of the breaks in life than most of the people I know.	_____	________	_____
3. This is the dreariest time of my life.	_____	________	_____
4. I am just as happy as when I was younger.	_____	________	_____
5. These are the best years of my life.	_____	________	_____
6. Most of the things I do are boring or monotonous.	_____	________	_____
7. The things I do are as interesting to me as they ever were.	_____	________	_____
8. As I look back on my life, I am fairly well satisfied.	_____	________	_____
9. I have made plans for things I'll be doing in the next few weeks.	_____	________	_____

#____________________

	Agree	Disagree	?
10. When I think back over my life, I didn't get most of the important things I wanted.			
11. Compared to other people, I get down in the dumps too often.			
12. I've gotten pretty much what I expected out of life.			
13. In spite of what people say, the lot of the average man is getting worse, not better.			

#_______________________

Deutsch's Response To Loss Instrument

Section II

The items below consist of possible responses to your illness. Answer the items below in terms of your response to your illness during the last 2 weeks including today. You can indicate the degree to which you are having these responses according to the following scheme:

0 = does not describe me
1 = sometimes describes me
2 = most of the time describes me
3 = accurately describes me

_____ 1. My illness began _____ months ago.

_____ 2. My decision to stop medical treatment occurred ______ weeks/months ago.

_____ 3. When I focus on my illness, I feel that I have nothing to look forward to.

_____ 4. I have many feelings about my illness.

_____ 5. I think about my illness, and I think about how my life is being affected.

_____ 6. I often weep or sob about my illness.

_____ 7. I am aware of what will never again be a part of my life because of my illness.

_____ 8. I feel angry about some of the consequences of my illness.

_____ 9. I think about my illness a lot.

_____10. I feel sadness whenever I am reminded about my illness.

_____11. I am angry with some people associated with my illness.

_____12. I know that my former good health will never return.

_____13. When I admit it to myself, I feel sad most of the time about my illness.

_____14. I spent time sifting through past experiences related to my illness.

#_______________________

0 = does not describe me
1 = sometimes describes me
2 = most of the time describes me
3 - accurately describes me

_____15. The tears have been hard to stop this week.

_____16. I feel guilty about my illness.

_____17. I know I am helpless to change the situation and bring back my health.

_____18. I find myself longing for the return of the days when I was not ill.

_____19. Many more people irritate me now than did before my illness.

_____20. On a scale of 0-10 I am experiencing this intensity of pain. (Write in a number from 0 to 10.)

#____________________

Carey's Emotional Adjustment Scale Abridged

Section III

Instructions: Please fill this section based on your knowledge of the patient's feelings, thoughts, behaviors in the last 7-10 days. It is important that you think of now, not several weeks or months ago.

NOTE: Statements 6 and 7 could possibly both be answered Yes. Try to decide which one best characterizes how the patient has seemed most of the time in the last 7-10 days.

_____ 1. Has seemed willing to discuss feelings about death and dying openly and frankly with loved ones.

_____ 2. Has seemed willing to discuss feelings about death and dying openly and frankly with close friends.

_____ 3. Has seemed willing to discuss feelings about death and dying openly and frankly with Hospice personnel.

_____ 4. Seems to be able to divert mind to things that used to be of interest and not dwell continuously on the thought of dying.

_____ 5. Now (within the last 7-10 days) thinks of self as a victim of cruel fate, or that God is punishing them.

_____ 6. Seems to have inner peace.

_____ 7. Is still fearful, anxious or guilty.

8. Write any comments related to these items that you wish to share:

#________________________

Carey's Discomfort Scale Abridged

Section IV

Instructions: Please think of how the patient has been in the past 7-10 days when filling out this part of the questionnaire.

Thank you.

1. This patient's age is _________.
2. Does this patient have a spouse? _________
3. This patient's position in the home before the illness was

   ____
4. Does this patient have children? _________
5. This patient's children are:

   independent of patient financially _________
   dependent on patient financially_________
6. This patient's terminal illness has been under treatment for _____ years _____ months.
7. Remedial efforts with this patient's illness were abandoned __________________ date (as close as possible).
8. This patient's pain is

   _____ non-existent (never occurred)
   _____ well controlled
   _____ occasionally a problem
   _____ not yet controlled
   _____ complicated because patient is not yet ready to take large doses of medication
9. This patient's amount of disfigurement is

   _____ none
   _____ little
   _____ moderate
   _____ moderate but not visible
   _____ great

#________________

10. This patient's difficulty in eating is

_____ well controlled
_____ none
_____ little
_____ moderate
_____ great

11. This patient's difficulty in sleeping is

_____ well controlled
_____ none
_____ little
_____ moderate
_____ great

12. When was this patient told their illness is terminal?

____

13. This patient's degree of dependence on other is

_	_	_	_	_____
1	2	3	4	Total
little		moderate		

#________________________

Task Completion Scale

Section V

This is a list of things which Hospice patients may or may not experience during their time with Hospice. As you know, dying persons have individual experiences and no one is expected to fit any particular pattern. There is no good or bad pattern. We are just looking for information about what does happen. This will help give information to all of us working with dying people and their families.

Instructions When you complete this Section please think about how this patient has felt and acted and what he/she has reported to you in the very recent past, the last 7-10 days. It is important to think about the present time, now how they were at another time. Each item is scaled from 0-5 to allow you to tell whether this patient has completed this task fully (5) has not begun to accomplish it (0), has just begun (1) and so on. If you have any questions after our meeting explaining the form, please call me at 845-5733. Thank you.

0 = has not begun this task
1 = has just begun this task
2 = has made some progress with this task
3 = has made about average progress for Hospice patients with this task
4 = has almost mastered this task
5 = has accomplished this task fully

_____ 1. This patient sometimes thinks there is hope for something nice however small it may seem to others.

#_________________________

0 = has not begun this task
1 = has just begun this task
2 = has made some progress with this task
3 = has made about average progress for Hospice patients with this task
4 = has almost mastered this task
5 = has accomplished this task fully

_____ 2. This patient knows its OK to take pain pills and will tell people if medication for pain is needed.

_____ 3. This patient has taken care of business matters such as wills, estate, insurance.

_____ 4. This patient will tell someone if they do or do not want to be alone.

_____ 5. This patient reassures family members that things are going OK and can be handled.

_____ 6. This patient reassures family members that they are appreciated and helpful.

_____ 7. This patient participated in treatment plans.

_____ 8. This patient has been able to evaluate life--to look at the past and see accomplishments.

The last three questions should be answered taking into account the patient's entire time with Hospice.

_____ 9. This patient knows abouttheir terminal state (they have stated this to you or another care giver.)

_____ 10. This patient has shown emotional aspects of grieving such as sadness/ anger, tears, crying, sobbing.

_____ 11. This patient has expressed grieving thoughts such as: helplessness, meaninglessness, overwhelmed, anger, fear, disbelief.

_____ 12. If you want to explain more about this patient as related to any of the items, please write below and place the item number next to your comment.

Post-Research Briefing for Staff and Patients

Thank you again for helping. More precisely what I was looking at is how social support networks help Hospice patients process their thoughts and feelings and help them finish several tasks before they die. I wanted to learn if different size networks, different degrees of closeness in the network, different kinds of support--thinking, feeling, and concrete supports, affected those processes. My idea is that they do have an effect. I will be coming back to Hospice with a copy of the results to share with everyone who is here when I finish. Any questions? Can I explain a little deeper?

References

References

Adler, P. (1982). An analysis of the concept of competence in individuals and social systems. Community Mental Health Journal. 18, 34-45.

Baldwin, M. & Lorenz, L. (1981). Bereavement: A guide for training. Bronx: Rutgers Medical School. (Available from National Hospice Organization, McClean, West Virginia).

Barrera, M., Jr. (1981). Social support in the adjustment of pregnant adolescents: assessment issues. In B. H. Gottlieb (Ed.), Social Networks and Social Support (pp. 69-96). Beverly Hills: Sage.

Barrera, M., Jr. & Ainlay, S. J. (1983). The structure of social support: A conceptual and empirical analysis. Journal of Community Psychology, 11, 133-143.

Bloom, B. L. (1979). Prevention of mental disorders; recent advances in theory and practice. Community Mental Health Journal, 15, 179-191.

Bresica, F. & Lorenz, L. (1981). Pain control in advanced cancer. Bronx: Rutgers Medical School. (Available from National Hospice Organization, McClean, West Virginia).

Buckingham, R. W. & Lupa, D. (1982). A comparative study of Hospice services in the United States. American Journal of Public Health, 72, 455-563.

Bugen, L. A. (1977). Human grief: a model for prediction and intervention. American Journal of Orthopsychiatry, 47, 196-206.

Bugen, L. A. (1979). Fundamentals of bereavement intervention. In L. A. Bugen (Ed.) Death and Dying: Theory, Research, Practice, (pp. 99-112). Dubuque: William C. Brown.

Caldwell, R. A. & Bloom, B. L. (1982). Social support: Its structure and impact on marital disruption. American Journal of Community Psychology, 10, 647-667.

Caplan, G. (1964). A conceptual model for primary prevention. In G. Caplan, Principles of Preventive Psychiatry (pp. 26-55). New York: Basic Books.

Cassel, E. J. (1982). The nature of suffering and the goals of medicine. New England Journal of Medicine, 306, 639-645.

Cassel, J. (1974). Psychosocial processes and "stress": theoretical formulation. International Journal of Health Services, 4, 471-482.

Carey, R. C. (1972). Emotional adjustment in terminal patients: a quantitative approach. Journal of Counseling Psychology, 21, 433-439.

Chiriboga, D. A., Jenkins, G., & Bailey, J. (1983). Stress and coping among hospice nurses: Test of an analytic model. Nursing Research, 32, 293-298.

Cobb, S. (1976). Social support as a moderator of life stress. Psychosomatic Medicine, 38, 300-314.

Cobb, S. & Erbe, C. (1978). Social support for the cancer patient. FORUM on Medicine, (11), 24-30.

Cohen, I. & Sokolovsky, J. (1981). Social networks and the elderly: Clinical techniques. International Journal of Family Therapy, 3, 281-294.

Conner, K. A., Powers, E. A., & Bultena, G. (1979). Social interaction and life satisfaction: An empirical assessment of late-life patterns. Journal of Gerontology, 34(1), 116-121.

Corbett, R. L. & Hai, D. M. (1979). Searching for enthanatos: The hospice alternative. Hospital Progress, (3), 38-43.

Corder, M. P., & Anders, R. L. (1974). Death and dying: Oncology discussion group. Journal of Psychiatric Nursing and Mental Health Services, 12, 10-14.

Dagi, T. F. (1983). An how can one die better? Courage, faith, and fatalism. The Journal of Medicine and Philosophy, 8, 431-435.

Davies, J. C. (1962). Toward a theory of revolution. American Sociological Review. 27, 5-19.

Deutsch, D. (1982). Development, reliability, and validity of an instrument designed to measure grief. Unpublished doctoral dissertation, Michigan State University, 1982.

DiMatteo, M. R. & Hays, R. (1981). Social support and serious illness. In B. H. Gottlieb, (Ed.) Social Networks and Social Support (pp. 117-148). Beverly Hills: Sage.

Dudley, C. (Producer). (1982). A Time to Die. Film. Hospice of Southeastern Michigan, 22401 Foster Winter Drive, Southfield, Michigan 48075.

Dudley, C. (1982). Going gently into that good night: A resident's guide to the psychological care of the terminal patient. Unpublished residency chair's paper. Wayne State University.

Dunkel-Schetter, C. & Wortman, C. (1981). Dilemmas of social support: Parallels between victimization and aging. In S. B. Kiesler, J. N. Morgan, & V. K. Oppenheimer (Eds.), Aging: Social Change (pp. 349-374). New York: Academic Press.

Dunkel-Schetter, C. & Wortman, C. B. (1982). The interpersonal dynamics of cancer: Problems in social relationships and their impact on the patient. In H. S. Friedman & M. R. DiMatteo (Eds.), Interpersonal Issues in Health Care (pp. 69-100) New York: Academic Press.

Ekehammar, B. (1974). Interactionism in personality from a historical perspective. Psychological Bulletin, 11, 1026-1048.

Felner, R. D., Farber, S. S. & Primavera, J. (1982). Transitions and stressful life events: A model for primary prevention. In R. D. Felner, L. A. Jason, J. N. Maritsuga & S. S. Farber (Eds.) Preventive Psychology: Theory, Research and Practice, N.Y.: Pergamon (pp. 199-215).

Garmezy, N. (1971). Vulnerability research and the issue of primary prevention. American Journal of Orthopsychiatry, 41, 101-116.

Godkin, M. A., Krant, M. J., & Doster, N. J. (1983-84). The Impact of Hospice care on families. International Journal of Psychiatry in Medicine, 13, 153-164.

Goplerud, E. (1980). Social support and stress during the first year of graduate school. Professional Psychology. 4, 283-290.

Gottlieb, G. H. (1981). Preventive interventions involving social networks and social support. In B. H. Gottlieb (Ed.), Social Networks and Social Support (pp. 201-232). Beverly Hills: Sage.

Granovetter, M. (1973). The strength of weak ties. American Journal of Sociology, 78, 1360-1380.

Granovetter, M. (1982). The strength of weak ties, a network theory revisited. In R. G. Marsden & N. Lin (Eds.), Social Structure and Network Analysis (pp. 105-130). Beverly Hills: Sage.

Hinton, J. (1971). Assessing the views of the dying. Social Science and Medicine, 5, 37-43.

Hirsch, B. (1979). Psychological dimensions of social networks: a multimethod analysis. American Journal of Community Psychology, 7, 263-277.

Hirsch, B. (1980). Natural support systems and coping with major life changes. American Journal of Community Psychology, 8, 159-172.

Hirsch, B. (1981). Social networks and the coping process: creating personal communities. In B. H. Gottlieb (Ed.), Social Networks and Social Support (pp. 149-170). Beverly Hills: Sage.

Hoffman, E. (1971). Don't give up on me. American Journal of Nursing, 71, 60-62.

Holmes, T. H. & Masuda, M. (1974). Life change and illness susceptibility. In B. S. Dohrenwend & B. P. Dohrenwend (Eds.), Stressful Life Events: Their Nature and Effects (pp. 45-72). New York: John Wiley.

Insel, P. (1980). Social climate and mental health. In P. M. Insel (Ed.) Environmental Variables and the Prevention of Mental Illness (pp. 9-26). Lexington, MA: Lexington Books.

Jenkins, L. & Cook, A. S. (1981). The rural hospice: Integrating formal and informal helping systems. Social Work, (9), 414-416.

Kahn, R. L. & Antonucci, T. (1980). Convoys of social support: a life-course approach. In P. B. Baltes & O. Brim (Eds.) Life-Span Development and Behavior (Volume 3, pp. 383-405). New York: Academic Press.

Kobasa, S. C. (1979). Stressful life events, personality, and health: an inquiry into hardiness. Journal of Personality and Social Psychology, 37, 1-11.

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

Kübler-Ross, E. (1971). What is it like to be dying? American Journal of Nursing, 71, 54-59.

Kübler-Ross, E., Wessler, S., Avioli, L. V. (1972). Therapeutic grand rounds: On death and dying. Journal of American Medicine, 221, 174-179.

Lally, M., Black, E., Thornock, M., & Hawkins, D. (1979). Older women in single room occupant (SRO) hotels: A seattle profile. The Gerontologist, 19(1), 67-73.

Lazarus, R. S. (1981). The costs and benefits of denial. In B. S. Dohrenwend & B. P. Dohrenwend, (Eds.), Stressful Life Events and Their Contexts (pp. 131-156). New York: Neale Watson Academic Publishers.

McCallister, L., Fischer, C. (1978). A procedure for surveying personal networks. Sociological Methods and Research, 7, 131-148.

McGivney, W. T. & Crooks, G. M. (1984). The care of patients with severe chronic pain in terminal illness. Journal of American Medical Association, 251, 1182-1188.

McGuire, J. & Gottlieb, B. (1979). Social support groups among new parents: An experimental study in primary prevention. Journal of Clinical Child Psychology, 8(2), 111-116.

Mitchell, R. E., & Trickett, E. J. (1980). Task force report: Social networks as mediators of social support: An analysis of the effects and determinants of social networks. Community Mental Health Journal, 16, 27-44.

Moos, R. H. (1974). Evaluating treatment environments. New York: John Wiley.

Oberschall, A. (1978). Theories of social conflict. Annual Review of Sociology, 4, 291-315.

Pelletier, K. R. (1977). Mind as healer, mind as slayer: A holistic approach to preventing stress disorders. New York: Delacorte.

Rabkin, J. G. & Struening, E. C. (1976). Life events, stress, and illness. Science, 194, 1013-1020.

Rahe, R. H. (1979). Life change events and mental illness: An overview. Journal of Human Stress, 9, 2-10.

Revenson, T. A., Wollman, C. A., & Felton, B. J. (1983). Social supports as stress buffers for adult cancer patients. Psychosomatic Medicine, 45, 321-331.

Rosin, A. J., Wallach, L., & Assael, M. (1981). Understanding the dying patient. The Practitioner, 225, 196-201.

Sandler, I. N. & Lakey, B. (1982). Locus of control as a stress moderator: The role of control perceptions and social support. American Journal of Community Psychology, 10, 65-80.

Saunders, C. M. (1978). The management of terminal diseases. London: Hogarth Press.

Schneider, J. (1984). The nature of loss, the nature of grief: A comprehensive approach to understanding and facilitation. Baltimore: University Park Press.

Selye, H. (1950). Stress. Montreal: Acta Medical Publishers.

Selye, H. (1956). The stress of life. New York: McGraw Hill.

Selye, H. (1974). Stress without distress. New York: Lippincott.

Simonton, O. C. & Mathews-Simonton, S. (1975). Belief systems and management of the emotional aspects of malignancy. Journal of Transpersonal Psychology, 7(1), 29-47.

Strain, L. A. & Chappell, N. L. (1982). Problems and strategies: Ethical concerns in survey research with the elderly. The Gerontologist, 22, 526-530.

Tilly, C. (1979). Collective violence in European perspective. In H. D. Graham & T. R. Gurr (Eds.) Violence in America: Historical and Comparative Perspectives. Beverly Hills: Sage.

Tolsdorf, C. C. (1976). Social networks, support, and coping. An exploratory study. Family Process, 15, 407-417.

Twycross, R. G. (1982). Ethical and clinical aspects of pain treatment in cancer patients. Acta anesthesia, 74, 83-90.

Vachon, M. L. S., Lancee, A. R., Lyall, W. J., Rogers, W. A., & Freeman, S. J. J. (1982). Correlates of enduring distress patterns following bereavement: Social network, life situation and personality. Psychological Medicine, 12, 783-788.

Walker, K. N., MacBride, A. & Vachon, M. L. S. (1977). Social support networks and the crisis of bereavement. Social Science and Medicine, 11, 35-41.

Weisman, A. D. & Worden, J. W. (1975). Psychosocial analysis of cancer deaths. Omega, 6, 61-75.

Wellman, B. (1981). Applying network analysis to the study of support. In B. H. Gottlieb (Ed.) Social Networks and Social Support (pp. 171-200). Beverly Hills: Sage.

Wiess, R. S., (1976). Transition states and other stressful situations: Their nature and programs for their management. In G. Kaplan & M. Killilea (Eds.), Support Systems and Mental Help: Multidisciplinary Explorations (pp. 213-232). New York: Grune & Stratton.

Wilcox, B. (1981a). Social support in adjusting to marital disruption: A network analysis. In B. H. Gottlieb (Ed.), Social Networks and Social Support (pp. 97-115). Beverly Hills: Sage.

Wilcox, B. (1981b). Social support, life stress, and psychological adjustment: A test of the buffering hypothesis. American Journal of Community Psychology, 9, 370-386.

Wood, V., Wylie, M. L. & Sheafor, B. (1969). An analysis of a short self-report measure of life satisfaction: Correlation with rater judgments. Journal of Gerontology, 28, 465-469.

Zautra, A. J. & Reich, J. W. (1983). Life events and perceptions of life quality: Developments in a two-factor approach. Journal of Community Psychology, 11, 121-132.

Zautra, A. J. (1983). Social resources and the quality of life. American Journal of Community Psychology, 11, 275-290.

MICHIGAN STATE UNIV. LIBRARIES
31293000708572