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A Needs Assessment to Determine if There Is a Need for Information/Support Groups for Informal Caregivers Of Terminal Cancer Patients

Keri Bolduan
Augsburg College

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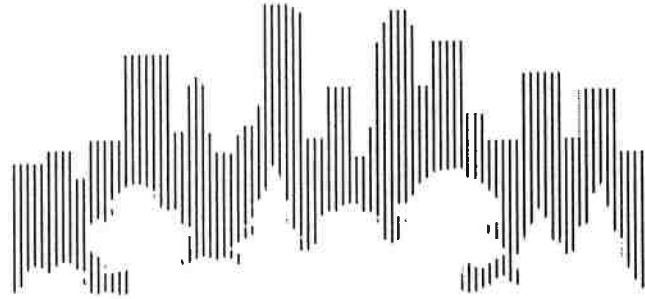
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MASTERS IN SOCIAL WORK THESIS

Keri Bolduan

**A Needs Assessment to Determine if There
Is a Need for Informational/Support
Groups for Informal Caregivers
Of Terminal Cancer Patients**

**MSW
Thesis**

**Thesis
Boldua**

2001

A Needs Assessment to Determine if There is a Need
For Informational/Support Groups for
Informal Caregivers of Terminal Cancer Patients

Keri Bolduan

Submitted in partial fulfillment of
The requirement for the degree of
Master of Social Work

Augsburg, College
Minneapolis, Minnesota

2001

MASTER OF SOCIAL WORK
AUGSBURG COLLEGE
MINNEAPOLIS, MINNESOTA

CERTIFICATE OF APPROVAL

This is to certify that the Master's Thesis of:

Keri Bolduan

Has been approved by the Examining Committee for the thesis requirement for the Master of Social Work Degree.

Date of Oral Presentation: November 2, 2000

Thesis Committee:

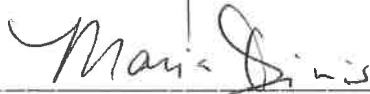
Dr. Sharon Patten

Thesis Advisor



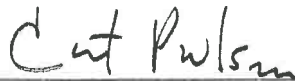
Dr. Maria Dinis

Thesis Reader



Dr. Curt Paulsen

Thesis Reader



**TO THOSE I LOVE AND
THOSE WHO LOVE ME**

When I am gone, release me, let me go--
I have so many things to see and do.
You mustn't tie yourself to me with tears,
Be thankful for our many beautiful years.

I gave to you my love. You can only guess
How much you gave to me in happiness.
I thank you for the love you each have shown,
But now it's time I traveled on alone.

So grieve a while for me, if grieve you must,
Then let your grief be comforted by trust.
It's only for a time that we must part
So bless the memories within your heart.

I won't be far away, for life goes on
So if you need me, call and I will come.
Though you can't see or touch me, I'll be near
And if you listen with your heart, you'll hear
All my love around you soft and clear.

And then, when you must come this way alone,
I'll greet you with a smile, and say--
"Welcome home!"

Author Unknown

HOW CAN I HELP YOU SAY GOODBYE

Through the back window of our '59 wagon
I watched my best friend Jamie slippin' further away
I kept on wavin' till I couldn't see her
And through my tears I asked again why we couldn't stay
Mama whispered softly, "Time will ease your pain.
Life's about changing, nothing ever stays the same," and she said,

How can I help you to say goodbye
It's okay to hurt, and it's okay to cry
Come let me hold you and I will try
How can I help you to say goodbye

I sat on our bed, he packed his suitcase
I held a picture of our wedding day
His hands were trembling, we both were crying
He kissed me gently, and then he quickly walked away
I called up mama, she said "Time will ease your pain.
Life's about changing, nothing ever stays the same," and she said,

How can I help you to say goodbye
It's okay to hurt, and it's okay to cry
Come let me hold you and I will try
How can I help you to say goodbye

Sittin' with mama, alone in her bedroom
She opened her eyes, and then squeezed my hand
She said "I have to go now, my time here is over"
And with her final words she tried to help me understand
Mama whispered softly, "Time will ease your pain.
Life's about changing, nothing ever stays the same," and she said,

How can I help you to say goodbye
It's okay to hurt, and it's okay to cry
Come let me hold you and I will try
How can I help you to say goodbye.

Sung by Patty Loveless
Written by Burton Banks Collins & Karen Taylor-Good

To my husband, Rick,
whose support and understanding
made this possible.
And in loving memory
of my mother,
Phyllis A. McCaffertry
1937-1998

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I would like to thank my family and friends for their patience and understanding through this long journey. I would like to thank my father, Jim and my mother, the late Phyllis, for always believing in me and never letting me doubt myself or my strengths, and for seeing me through all the good and bad times and always supporting me. I love you both so much and I am thankful to have been blessed with such wonderful parents.

ABSTRACT

IS THERE A NEED FOR INFORMATIONAL/SUPPORT GROUPS FOR INFORMAL CAREGIVERS OF TERMINAL CANCER PATIENTS

Needs Assessment

Keri Bolduan

November 2000

This needs assessment was undertaken to determine if Aberdeen, South Dakota is in need of an informational/support group for informal caregivers of terminal cancer patients. A 112 professionals (doctors, nurses, social workers and pastoral care workers) from The Cancer Care Center, Avera St. Lukes Hospital, and it's affiliate, North Plains Hospice were surveyed using both quantitative and qualitative questions. Only 19 of the 112 responded to the survey. The survey focused on the professionals' experience and knowledge of working with terminal cancer patients and informal caregivers as well as resources available to their clients. The findings of this study indicated that 36% perceived a need for informational/support groups of informal caregivers of terminal cancer patients in Aberdeen, South Dakota while 95% perceived a need for additional services, according to professionals who work with informal caregivers and terminal cancer patients on a daily basis. There is a need for more research of informal caregivers of terminal cancer patients. Research found was on caregiving mainly with the elderly but nothing specifically for terminal cancer.

TABLE OF CONTENTS

Certificate of Approval	ii
Poem	iii
Song	iv
Dedication	v
Acknowledgments	vi
Abstract	vii
Table of Contents	viii
I. Chapter 1: THE INTRODUCTION	
A. Statement of the Problem	1
B. Research Question	2
II. Chapter 2: REVIEW OF LITERATURE	
A. Stressors	4
B. Depression	6
C. Grief	6
D. Work	8
E. Hours Spent on Caregiving	9
F. Support Groups	10
G. Summary of Literature	11
III. Chapter 3: THEORETICAL FRAMEWORK	
A. Anticipatory Grief	14
B. Stress Theory	15
IV. Chapter 4: METHODOLOGY	
A. Research Design	17
B. Research Question	17
C. Definitions of Terms	17
D. Characteristics of Study Population	18
E. Sample of Population	18
F. Measurement Issues	19
G. Data Instrument	20
H. Protection of Human Rights	20

V.	Chapter 5: PRESENTATION OF THE FINDINGS	
	A. Introduction	21
	B. Background Information	22
	C. Assessment of Service Needs	23
VI.	Chapter 6: DISCUSSION	
	A. Introduction	28
	B. Comparison on the Findings to the Literature	28
	C. Theoretical Framework	30
	D. Summary of Qualitative Data	31
	E. Limitations	31
	F. Implications for Practice	33
	G. Recommendations	34
	H. Conclusions	34
	REFERENCES	36
	APPENDICES	
	Appendix A: Cover Letter	39
	Appendix B: Questionnaire	41
	Appendix C: Definitions of Terms	43
	Appendix D: Pie Charts	44

CHAPTER ONE

I. Introduction

**“To listen to another’s soul in a condition of disclosure and discovery may be almost the greatest service that any human being ever performs for another”
(Author Unknown).**

A. Statement of the Problem

This research project involved a needs assessment. It attempted to determine if professionals working with terminal cancer patients see a need for informational/support groups for informal caregivers in Aberdeen, SD.

The elderly, people with disabilities, or terminally ill often are dependent on others for basic needs and care. The assistance provided by an informal caregiver can enable the person in need to remain at home (Rubenstein, Kilbride, & Nagy, 1992). Approximately 80% of all long term care in the United States is provided by family members (Stone, Cafferata, & Sange, 1987). Disrupting roles and requiring role reversals, shattering future plans and goals, depleting financial resources and permanently changing and requiring adjustments in lifestyle of all members of the family are certain ways terminal cancer can affect the entire family (Schachter, 1992).

The results of this study provided data on the need for informational/support groups for informal caregivers of terminal cancer patients in Aberdeen, South Dakota. As a former informal caregiver, the researcher was curious to get the professionals’ assessment on the need of informational/support groups for informal caregivers of terminal cancer patients. The purpose of this study was to determine if Aberdeen, SD is

in need of informational/support groups for informal caregivers of terminal cancer patients.

B. Research Questions

This research study addressed the following research questions: 1) Are informational/support groups beneficial to informal caregivers? 2) Is there a need for informational/support groups for informal caregivers of individuals with terminal cancer in Aberdeen, South Dakota? 3) Is there a need for more resources for informal caregivers of terminal cancer patients?

CHAPTER TWO

II. Review of Literature

The assistance provided by informal caregivers can enable the person in need to remain at home (Rubenstein et al., 1992). There are two types of caregivers. Formal caregivers are usually trained volunteers or paid care providers. Informal caregivers are often untrained, unpaid family members or friends. Approximately 80% of all long term care in the United States is provided by family members (Stone et al. 1987). In this literature review, the focus was on family members who are the informal caregivers.

There were similar definitions of a caregiver found throughout the literature. The definition most used was - a caregiver is a person who provides primary assistance to another person in need. Primary assistance may include but is not limited to cooking, cleaning, bathing, feeding and transporting. Primary assistance is helping another person meet her/his daily needs (Rando, 1984).

It has been observed that caregiving tends to be provided by one family member, who is usually female. Seventy percent (70%) of all informal caregivers are female, while only 30% of them are male. Of those females, those most likely to become caregivers are the wives and the adult female children, respectively (Tully & Sehm, 1994). Barnes and colleagues completed a study that compared spouse caregivers and adult children caregivers for the elderly in order to examine how family relationships affect the caregivers' responses to their caregiver situation. The study found that the

spouse caregivers are at greatest risk for health problems and role overload. It also found that adult children caregivers with siblings are more at risk for feeling overburdened when they first begin their caregiving activities. Those adult children without siblings felt a great role responsibility over time. All the caregivers in this study reported a negative impact on their health, receiving less affective support, increased feelings of abandonment over time, and sleep deprivation (Barnes, Given, & Given, 1992). All family members must agree upon the decision for the terminally ill person to be cared for at home. The primary informal caregiver for the terminally ill loved one may experience several key factors that impact their quality of life, including role reversal which can cause conflict and marital disarray, lack of knowledge and skills needed to perform complicated procedures, lack of privacy, physical exhaustion, stressors, financial burden and the demand of time and energy (Schachter, 1992). Spouses tend to not think of themselves as caregivers of older adults and they often do not seek outside services because they feel it is their duty (Fradkin & Heath, 1992).

Kristjanson (1989) discusses four main concerns for family members of a terminally ill loved one. These main concerns include problems created by symptoms of the disease, fear of the future, waiting, and difficulty obtaining information. She also found in her research that families need assistance with the physical care, need access to information and need a place to discuss their fears.

A. STRESSORS

A stressor is a life event that requires changes and adjustments in an individual's daily life (Lechner, 1993). McCallion, Toseland and Diehl (1994) listed eight factors that

influence caregiver stress: shared versus independent living arrangements, family values and interaction processes, type of illness, length of caregiving, the quality of the relationship between caregiver and care receiver, consequences of the caregiver for work, family relationships and finances, the previous coping history of the caregiver, and availability of formal resources and other informal caregivers.

There are two stress reactions: health outcomes and perceived stress. Health outcomes are unwanted changes in physical and mental health. Health outcomes may be long lasting and costly- financially, socially, and personally. Perceived stress may contribute to health outcomes and may consist of feelings of emotional, financial, relationship and work-family strains (Lechner, 1993).

Caregivers of the elderly and those who care for their parents experience stress due to the multiple roles they take on (Olson, 1994; Spaid & Barusch, 1991; Brody, 1990). Caregivers are not the only ones who experience stress. The entire family and society as a whole are often bewildered and conflicted about their numerous roles as is the caregiver (Brody, 1990).

Studies have found that caregivers of the elderly report being in poorer health than the general population due to stressors. Daily routines may cause back problems or other physical problems and sleep patterns may be disturbed (McCallion et al. 1994). Those caregivers who have to lift an individual can experience muscle strains and back problems if they are not trained properly in lifting techniques (Fradkin, 1992).

A study was conducted to determine the problems and coping strategies of elderly

spouse caregivers and the results showed that the caregivers were worried about their own health (Barusch, 1988; Farkas, 1980).

B. DEPRESSION

A high incidence of depression among caregivers of the elderly was discovered by researchers (Spaid & Barusch, 1991; Gallagher, Rose, Rivera, Lovett, & Thompson, 1989). Reports of depression range from 27% to 52% of caregivers (McCallion et al. 1994). The most frequently studied psychiatric symptom of caregiving for people with dementia is depression. Studies done on depression levels of caregivers versus noncaregivers indicated that clinical depression among caregivers is three times higher than the general population samples of similar age (Walker & Pomeroy, 1996).

The depression reported by caregivers may in part reflect grief that is comparable to that of people who have suffered a nondeath loss. A study found that caregivers' scores on the Beck Depression Inventory (BDI) showed higher levels of clinical depression than would be expected among their noncaregiving peers (Walker & Pomeroy, 1996).

C. GRIEF

A persistent theme in caregiving literature is anticipatory grief. Anticipatory grief is the grief that the caregiver experiences during the caregiving time. The informal caregiver of dementia patients, as well as the care receiver, experience changes and multiple losses. Studies on anticipatory grief have found that the grief is typically related to the length of time following the diagnosis and death (Walker & Pomeroy, 1996).

People experience grief differently. Feelings of anger, despair, and loneliness are a normal part of the grieving process. The grief caregivers go through can last for long periods. Once it starts to interfere with caregivers' ability to function it becomes a problem. During the grieving process, it is important that feelings are shared. This will help to deal with grief and to allow one to function on a daily basis. Grief has no rules and not everyone will respond the same way. According to McNeil (1995) there is a five step grief process for anyone experiencing grief:

STEP 1) Denial: refusal to believe the news

- normal reaction
- allows time to sink in the news
- Usually is temporary
- Returns at time

STEP 2) Anger: it helps relieve the anguish of the loss

- helplessness may turn to rage
- envy others
- resent others for what they still have
- a) for the person dying: anger comes unexpectedly and is hard to control and it causes guilt feelings
- b) for the people around the dying: may become innocent targets and they find it hard to respond with understanding instead of with anger.

STEP 3) Bargaining: an attempt to postpone death

- usually involves a change in behavior or specific promise in exchange for more time to live
- usually made in secret (often with God)
- setting deadlines and once each deadline is reached, a new one is developed

STEP 4) Depression: occurs when the individual faces the losses that dying brings and begins to mourn for:

- what is already lost and what is still to be lost
- normal part of preparing for a loss or death
- truth has set in

-very painful

STEP 5) Acceptance: it can be reached if the person works through the many conflicts and feelings that dying brings.

- dying person is tired and weak at this point
- time for an emotional calm
- healthy way of coming to terms with reality
- a gradual separation from others
- allowing the world to go on without them
- holding on

Grief is described by McNeil (1995) as the intense feeling or emotional pain felt as a result of a loss. People can gain control over their grief by “learning to 1) accept the reality of death, 2) experience the pain of grief, 3) adjust to their environment, and 4) reinvest emotional energies into getting on with the rest of their lives” (Huber & Gibson, 1990, p. 52).

D. WORK

Lechner (1993) indicated that the worlds of work and family life are no longer separate spheres. One study reported that 23% of all workers had some level of caregiving responsibility that could interfere with their work responsibilities (McCallion et al. 1994). Employed caregivers tend to be conflicted about their performance in each of their roles. The research found in the literature suggests that caregivers experience more absenteeism, lateness, reduction of productivity, unscheduled time off, lack of concentration, and numerous phone calls regarding the caregiving activities. Employed caregivers have choices to make. They can remain full time and use outside assistance (if available), go to part time or quit their jobs altogether. These decisions are not easily made and usually involve more than just the caregiver and the care receiver (Barnes et al.

1995).

Another study found that the caregivers who liked their jobs, had a good relationship with their supervisor, and thought their work places were responsive to the demands of their families reported fewer health complications (Lechner, 1993).

Another study compared the effects of employment on daughters who are informal caregivers of their elderly dependent relatives. The study participants were 118 daughters who were identified as informal, primary caregivers for their elderly dependent relatives. Of the 118 study participants, 49.2% (n=58) were employed daughters; 26.3% (n=31) were unemployed while caretaking; and 24.6% (n=29) were daughters who terminated their employment to provide care. Findings of this study indicate that daughters who had terminated employment were more involved with the activities of daily living than were the employed daughters. Also, those daughters who terminated their employment to caregive were more involved with the activities of health care than the other two caregiver groups. The last finding showed that never employed daughters used informal services more frequently than the employed daughters (Barnes et al, 1992).

E. HOURS SPENT ON CAREGIVING

A study concerning support strategies for caregivers found it difficult to obtain a sample population of caregivers because the caregiver usually only seeks assistance or services when they have reached a crisis point. In this study, the number of hours spent on certain tasks were calculated. It showed that approximately 8 hours per week were spent on personal tasks (bathing, dressing and toileting); approximately 15 hours per

week on shopping (clothes, groceries), meal preparing and clean up; approximately 3 hours per week attending legal matters, banking and check writing (paying bills); and approximately 7 hours per week on transportation tasks such as doctor appointments and errands. The study found that these hours were not the same for adult children and spouse caregivers. Spouse caregivers spent approximately 14 more hours doing household tasks (Montgomery & Borgatta, 1989).

F. SUPPORT GROUPS

Caregiver support groups have been in existence for about the past three decades (Fradkin & Heath, 1992). Caregiver support groups have two primary objectives for the group. The first objective is problem solving. During this time, caregivers are given resources, tips on improving caregiver tasks and ideas on how to solve problems associated with caregiving. The second objective is emotional support. During this time, members are encouraged to share emotions and self-perceptions. By sharing information about caregiving and personal reactions to specific problems, one can lower stress (Toseland, Rossiter, & Labrecque, 1989).

The following issues are critical in order to structure an effective self-help group for caregivers: 1) information pertaining to all aspects of the aging process (biological, social and psychological) should be addressed; 2) information on resources available; and 3) encouragement and development of the concept of empowerment for the caregiver- which gives the caregiver a sense of gaining control (Bass, 1990).

Overall findings of Biegel, Sales and Schulz (1991) showed that those who

participated in caregiver support groups were satisfied with their experiences and felt they received numerous benefits through support group participation. Some of the benefits reported were realizing that they are not alone with concerns, problems and pressures; receiving encouragement and understanding; gaining ability to understand and communicate feelings about caregiving; and sharing resources. Getzel (1983) reported finding the same benefits for support groups as did Biegel, Sales and Schulz (1991).

One study found that the use of vignette methodology was beneficial. Vignettes are stories of specified circumstances that use hypothetical characters. This study was done in order to determine whether there was a consensus about the conflicting situations and the preferred coping strategies in caring relationships and what the participants did or would do if they were in similar situations. This study used the application form of fixed-choice responses plus one open-ended question. This study found that the majority of the caregivers felt helpless and resented the fact that their lives were so tied up in caregiving. It was also found that caregivers would not live with the care receiver if other options were available. In addition, the majority of caregivers were sympathetic to the hypothetical characters because the vignette resembled their situation. The use of vignette methodology has been found to be a powerful tool for exploring complex and sensitive issues (Rahman, 1996).

G. SUMMARY OF LITERATURE

There are more than 25 million caregivers in America and they provide approximately $\frac{3}{4}$ of all home care services (Saltz & Schaefer, 1996). The American

healthcare system is based on an acute care model that deals well with crisis and is driven toward finding cures. But a significant and growing minority of Americans must deal with issues of chronic illness and disability and these are not well addressed by our society or our healthcare providers. Unfortunately, although the caregiver population is increasing, services and education for caregivers is not increasing proportionally (McCallion et al. 1994).

According to Rossman (1977) there have rarely been enough studies or attention paid to the problems faced by family members who have a terminally ill loved one in their lives to help the family cope with such problems. Families need counseling- not only does the terminally ill person, but the whole family does as well. In a family system, when crisis strikes one person, ultimately the whole family is affected.

There is a definite need for research on informal caregivers of individuals with terminal cancer. Very little was found specifically on these caregivers when doing my literature review. Studies need to look at the informal caregiver and what they go through during their caregiving time and what resources can be utilized to help them during this most difficult time. Also, more research needs to be done on the financial constraints of caregiving. In addition, there needs to be more helping services available from the beginning of the caregiving to well after the caregiving ends.

Research has indicated that informational/support groups are beneficial to caregivers. The study done by Beigel, Sales and Schultz (1991) did show that those who participated in caregiver support groups were satisfied with their experiences and felt they received numerous benefits through support group participation. Due to the

growing number of caregivers in the United States, a study needs to be done to see if different areas around the country need support groups for caregivers.

CHAPTER THREE

III. Theoretical Framework

This study utilized two different theoretical frameworks. The first discussed is anticipatory grief and the last is the stress theory.

A. ANTICIPATORY GRIEF

Anticipatory grief is a persistent theme in literature about families with a terminally ill loved one. "The condition in which one is so concerned about the threat of an approaching loss that he or she experiences the grief reaction before the loss occurs" (p.607) is how Norris and Murrell (1987) define anticipatory grief. Walker and Pomeroy (1996) define anticipatory grief as the grief the family and the terminally ill loved one may experience from the diagnosis until the death of the terminally ill loved one.

Anticipatory grief model is defined as a concept involving the process of "mourning, coping, interaction, planning, psychosocial reorganization that are stimulated and begin in part if the response to the awareness of the impending loss of a loved one and the recognition of associated losses in past, present, and future" (Rando, 1986, p. 24).

According to Rando (1984), anticipatory grief can allow family members to do a number of things before the actual death. These things include: begin to change their assumption about life and identity; resolve any unfinished business with the dying person; and begin to make plans for the future.

Not all the people facing the death of a loved one will experience anticipatory

grief. Of those who do, it may not necessarily be a positive experience. It can be harmful in that it may uncover some ambivalent or negative feelings that may lead to more pronounced or different feelings after the death. It can be helpful in that those who do grieve the loss of a loved one prior to their death may possibly lead to a more bereft grief process following the death (Rando, 1984; Huber & Gibson, 1990). The professionals, such as hospice workers, understanding of the concept of the anticipatory grief model enables them to assist families through the difficult time. Research has shown that hospice workers can assist families with anticipatory grief work which can lead to an easier bereavement process after the death (Huber & Gibson, 1990).

B. STRESS THEORY

Stress process theory proposes that caregivers' negative impacts are the result of an interaction between primary stressors, secondary stressors and mediating factors. Primary stressors are the characteristics of the care recipient's needs and the tasks and time required in meeting those needs. Secondary stressors are factors outside of the caregiving situation such as marriage and employment. Mediating factors are the presence or absence of formal or social supports (Pearlin & Turner, 1987).

According to Schachter (1992), the primary informal caregiver may experience several key factors that impact their quality of life. These factors include: role reversal which can cause conflict and marital disarray; lack of privacy; physical exhaustion; stressors; financial burden; lack of knowledge and skills needed to perform complicated procedures and the demand of time and energy. Also according to Fradkin and Heath

(1992), spouses tend to not think of themselves as caregivers and they often do not seek outside services because they feel it is their duty.

The literature collected has fit directly under the stress theory, which proposes that caregivers' negative impacts are the result of an interaction between primary stressors, secondary stressors and mediating factors.

CHAPTER FOUR

IV. Methodology

A. RESEARCH DESIGN

This research project involved a needs assessment. It attempted to determine if professionals working with terminal cancer patients perceived a need for informational/support groups for informal caregivers in Aberdeen, SD.

B. RESEARCH QUESTIONS

This research study addressed the following research questions: 1) Are informational/support groups beneficial to informal caregivers? 2) Is there a need for informational/support groups for informal caregivers of individuals with terminal cancer? 3) Is there a need for additional resources for informal caregivers of terminal cancer patients? These were determined by the results from a self-administered questionnaire.

C. DEFINITION OF TERMS

The following are definitions of terms:

Caregiver: person who provides primary assistance to another person in need.

Primary Assistance: helping another person meet his/her daily needs. This may include but is not limited to cooking, cleaning, bathing, feeding and transporting.

Informal caregiver: often is unpaid, untrained family members or friends.

Formal caregiver: usually trained volunteers or paid care providers.

Terminal cancer: any type of cancer that limits the life expectancy of someone to one year or less.

Patients: individuals who have terminal cancer and are being seen or have been seen by

Cancer Care Center and/or North Plains Hospice and/or Avera St. Lukes staff in Aberdeen, South Dakota. In previous studies the term patient was not limited to a person with a terminal illness as it is in this research. Also, terminal cancer in this research extended the life expectancy to up to one year. Most other studies had the life expectancy under 6 months.

Stressor: a life event that requires changes and adjustments in an individual's daily life.

D. CHARACTERISTICS OF STUDY POPULATION

The population studied included professionals (doctors, nurses, social workers, and pastoral care workers), who work with terminal cancer patients. The study population was made up of these professionals who work at The Cancer Care Center, Avera St. Lukes Hospital and its affiliate North Plains Hospice in Aberdeen, South Dakota. The unit of analysis was the individual professionals from these three agencies in Aberdeen.

E. SAMPLE OF POPULATION

Since the population is so small, the total population was studied. The sample consisted of 112 professionals from The Cancer Care Center, Avera St. Lukes Hospital and its affiliate, North Plains Hospice in Aberdeen, South Dakota. The Cancer Care Center is a physician's office and laboratory where treatments are administered. North Plains Hospice is an agency that provides support and medical assistance to terminal patients. It is a patient centered relationship including family and friends. The formal caregiver (primary nurse) would provide individualized holistic care in the home. North Plains Hospice is committed to bringing quality care using an interdisciplinary team approach. North Plains Hospice is part of Avera St. Lukes Hospital. Avera St. Lukes is Aberdeen's only hospital. Their social workers, doctors, nurses and pastoral care workers

are involved with terminal cancer patients as a team. According to St. Lukes Hospital mission, their goal is for these professionals to be committed to helping patients and families make informed decisions about health care needs and related concerns. Each agency was contacted by the researcher to get written consent for their agency to participate in this study. If the agency decided to participate, the contact person was asked to provide the researcher with a list of their workers who fall in the above categories of professionals who work with terminal cancer patients. Once the number was derived for each agency, the researcher dropped off the appropriate number of questionnaires, cover letters and self-addressed stamped envelopes to each contact person at their agency. The cover letter explained to each respondent that participation was voluntary. They were allowed two weeks to return the questionnaire, if they chose to participate (see appendix A for full cover letter). The researcher hand delivered the questionnaires to the agencies' contact person on April 29, 1999 and a return date was set for May 14, 1999. As the questionnaires were returned, the researcher began to process the data.

F. MEASUREMENT ISSUES

This research study has limited external validity. The population chosen and the questions asked were geared specifically to Aberdeen, South Dakota so this study is not generalizable.

This research used nominal and ordinal levels of measurement. The variables in this study are discrete. Raw numbers or percentage marginals were used in data

analysis.

G. DATA INSTRUMENT

Self-administered questionnaires, cover letters and self-addressed stamped envelopes were delivered to the contact persons at the three different agencies in Aberdeen, South Dakota. These agencies were the Cancer Care Center, Hospice, and Avera St. Lukes Hospital. There was no pretest. The questionnaire contained 11 questions. Some questions were quantitative; others were qualitative (see appendix B). One question was used to make sure the professional actually qualified for this study. The question asked if they were involved with informal caregivers or terminal cancer patients. This question worked well because it did eliminate three of the returned surveys. Before questionnaires could be delivered to the agencies, the researcher presented her study to the Augsburg Institutional Review Board and received approval for her study.

H. PROTECTION OF HUMAN SUBJECTS

In the cover letter, potential participants was invited to read everything and call the researcher with any questions prior to agreeing to participate in this study. The cover letter stated that this study was voluntary and would in no way affect their relationship with Augsburg College, The Cancer Care Center, Avera St. Lukes Hospital or North Plains Hospice. The cover letter explained that completion and return of the questionnaire would indicate their consent to participate in this study. Each participant had two weeks to fill out the questionnaire and return it to the researcher in the self-

addressed stamped envelope provided (see appendix A).

CHAPTER FIVE

V. Presentation of Findings

A. INTRODUCTION

The research questions being addressed and answered through the presentation of the findings are as follows:

Are informational/support groups beneficial to informal caregivers?

Is there a need for informational/support groups for informal caregivers of individuals with terminal cancer in Aberdeen, South Dakota?

Is there a need for additional resources for informal caregivers of terminal cancer patients?

One hundred and twelve questionnaires were delivered to the contact person at the above listed agencies who distributed them to the possible participants. Of the one hundred and twelve questionnaires sent, twenty three were returned. Of the twenty three returned, one was returned completely blank and three others didn't meet the qualification due to not working with terminal cancer patients or informal caregivers, leaving only 19 to be used for the collection data. This indicates a 16.9% return rate. Several participants left some questions unanswered but responded to the majority of questions. The number of participants who answered each question is represented in the discussion of each question.

Results of the quantitative and qualitative data collected for this research study by way of a self-administered questionnaire are presented in this chapter. The

quantitative data were obtained by using nominal and ordinal levels of questions and have been converted into charts displaying the numbers and percentage response in each category. The qualitative data were obtained through open-ended questions which provided the participants with an opportunity to give suggestions or comments. These comments are presented in summary in this chapter.

B. BACKGROUND INFORMATION

Data was obtained from 19 of the 23 returned questionnaires. The majority, 85% (n=16), of the participants were nurses with the remaining 15% being split equally with doctors (n=1), social workers (n=1) and pastoral care workers (n=1). (See Page 44).

The percentage of participants that reported they have received inquiries about informational/support groups for informal caregivers of terminal cancer patients was 26% (n=5), while 74% (n=14) reported no inquiries at all. Participants were asked if they thought Aberdeen, South Dakota had services available to meet the needs of informal caregivers of terminal cancer patients. 63% (n=12) responded that Aberdeen does have the services available and 37% (n=7) thought that Aberdeen doesn't have the services available, with all participants responding to the question (please see page 47 in Appendix). In regards to the question if the participants thought Aberdeen needed more resources for informal caregivers of terminal cancer patients, of the 19 who responded, 95% (n=18) felt Aberdeen needed more resources while only 5% (n=1) didn't see the need (see page 46 in Appendix). All 19 participants answered the question whether they saw a need for informational/support groups for informal caregivers of terminal

cancer patients in Aberdeen, SD. Of the 19, 18 (95%) participants felt Aberdeen needed this type of group while 1 (5%) participant didn't see the need (Please see page 46 in Appendix).

All 19 participants answered the question as to the number of years they have worked with terminal cancer patients (Please see page 48 in Appendix). The majority, 32% (n=6), have worked with terminal cancer patients between 11 and 15 years. Only 10 % (n=2) of the participants had worked with terminal cancer patients between 21 & 25 years. Those who worked with terminal cancer patients between 1 & 5 years made up 16%. Of the remaining categories, those who worked with terminal cancer patients between 6 & 10 years and 16 & 20 years made up 42 % (n=8) , 21 % (n=3) for each category, respectively.

C. ASSESSMENT OF SERVICE NEEDS

The responses to the open-ended questions are summarized below. When the respondents were asked if there have been any inquiries about informational/support groups of informal caregivers of terminal cancer patients, the following data was obtained.

Of the 6 (26%) who responded yes, 5 specified the inquiry. Three reported inquiries about hospice; 1 reported inquiries about support; 1 reported that they received 1-2 inquiries per year but didn't specify the inquiry; and 1 reported that they receive more inquiries before the individual and family are involved with hospice, but didn't specify the inquiries. Because the participants were allowed to write more than one answer, the number of responses does not equal the number of participants that answered the

question.

Next, participants were asked if they thought Aberdeen has services available to meet the needs of informal caregivers of terminal cancer patients.

Of the 12 (63%) who responded yes, 10 noted the following services: 6 responded that hospice was available; 4 responded that more services are needed; 3 responded that there are support groups; one participant responded respite; one responded social services and one responded parish nurse. Since the participants were allowed to write down more than one answer, the number of responses do not equal the number of participants who listed services (Please see page 45 in Appendix).

When the respondents were asked if they thought there is a need for more resources for informal caregivers of terminal cancer patients, the following responses were given.

Of the 18 (95%) of those who responded yes, 13 noted the following resources: 4 responded that respite care was needed; 2 responded to each of the following: support groups, resources, money for equipment and materials; 1 responded to each of the following: more services is better, need use of equipment, hospice, home health, caregiving information, and mastectomy and colonostomy information.

Because participants were allowed to write down more than one answer, the number of responses do not equal the number of participants who made specifications.

Respondents were asked to list available resources for informal caregivers of terminal cancer patients that Aberdeen has that they know of.

Of the 19 participants, 18 (95%) responded to the above question. Of the resources listed as available: 12 participants listed hospice; 6 listed home health; 4 listed American Cancer Society and 4 listed respite care; 3 listed parish nurses; 2 listed churches, 2 listed survivor groups and 2 listed support groups. Each of the following received one response: library, Internet, friends, social services, oncologist staff, Mersco Medical, United Clinic, private hire and family.

Question # 8 on the questionnaire asked if any of the services they listed in question 7 were strictly for informal caregivers of terminal cancer patients. Only three respondents answered yes. One person circled hospice; another respondent circled hospice and oncologists' staff; and 1 respondent circled the American Cancer Society.

The next open-ended question that respondents were asked was, as a professional, what areas do you think need to be addressed in support groups?

Of the 19 respondents, 14 (74%) of them responded to the question. Each respondent listed different things that they thought should be addressed in a support group. Each area received the following number of responses: grieving process 7, dying process 6, coping issues and emotional support 4, stress management 3, cancer information and resources 2, groups, respite care, self care, techniques in caretaking, enrichment issues, diet information and acceptance issues 1. Due to being an open-ended question, the number of responses does not equal the number of respondents.

The last open-ended question asked for the respondents' additional comments. Of the 19 who returned the questionnaire, only 3 (13 %) commented. The first respondent

stated that support groups have been tried in the past with poor turnout. The next respondent stated that this is an interesting subject. "I didn't give much thought to until this survey. It made me think of families instead of just the patient". The final respondent stated that the public needs a new awareness on death and dying: natural vs. normal vs. "the enemy"; how to help others grieve; and to come to grip with one's own death. The last respondent stated "Avera St. Lukes' ethics conference this year was on death and dying - our hospital is 'primed' for ideas on this topic to educate and involve people."

This study mostly involved nurses who work with terminal cancer patients. It was found that 95% (n=18) saw the need for informational/support groups for informal caregivers of terminal cancer patients in Aberdeen, SD. One respondent stated that this type of service was tried in the past with a very poor turn out. The majority of the respondents (53%) have worked with terminal cancer patients for over 10 years. . Due to the lack of respondents, there is no way to know how other professionals would have answered the survey.

CHAPTER 6

VI. Discussion

A. INTRODUCTION

There were three research questions that needed to be answered. The first question asked if informational/support groups are beneficial to caregivers. The benefits of informational/support groups for informal caregivers were identified through the literature review. The second research question asked if there is a need for informational/support groups for informal caregivers of individuals with terminal cancer in Aberdeen, SD. 95% (n=18) of the participants felt Aberdeen needed this type of group while 5% (n=1) didn't see the need for such a group. The third question asked if there was a need for more resources for informal caregivers of terminal cancer patients.

B. COMPARISON OF THE FINDINGS TO THE LITERATURE

The purpose of this research study was to determine if the professionals who work with terminal cancer patients in Aberdeen, South Dakota saw the need for informational/support groups for informal caregivers of terminal cancer patients, if there is a need for more informational/support groups for informal caregivers of individuals with terminal cancer patients and if informational/support groups are beneficial to informal caregivers in Aberdeen, South Dakota. An analysis of the data collected reveals that 95% (n=18) of the participants thought Aberdeen, South Dakota needed an informational/support group for informal caregivers of terminal cancer patients. 63% (n=12) participants felt Aberdeen, SD had services available to meet the needs of informal caregivers of terminal cancer patients while 37% (n=7) felt Aberdeen didn't

have those services available. Of the 19 participants, 18 (95%) felt Aberdeen, SD needed more resources.

The review of literature for this research study identified several key factors that the primary informal caregiver may experience that impact their quality of life. The factors include: role reversal which can cause conflict and marital disarray; lack of knowledge and skills needed to perform complicated procedures; lack of privacy; physical exhaustion; stressors; financial burden and the demand of time and energy (Schachter, 1992). Spouses tend to not think of themselves as caregivers and they do not often seek outside services because they feel it is their duty (Fradkin & Heath, 1992).

Kristjanson (1989) discusses four main concerns for family members of a terminally ill loved one. The first concern is problems that are created by symptoms or the disease, the second one is the fear of the future, the third concern is waiting, and the last concern is the difficulty in obtaining information. She also found in her research that families need assistance with physical care, need access to information and need a place to discuss their fears.

Overall findings of Beigel, Sales, and Schulz (1991) study showed that those who participated in caregiver support groups were satisfied with their experiences and felt they received numerous benefits through support group participation. Some of the benefits reported were realizing that they are not alone with concerns, problems and pressures; receiving encouragement and understanding; gaining ability to understand and communicate feelings about caregiving; and sharing resources.

When participants were asked: As a professional, what areas do you think need to be addressed in support groups, they listed some of the same concerns and factors as found in the literature. The professionals covered all the areas that were found to be beneficial for informal caregivers from Biegel, Sales, and Schulz (1991) study. Even though 63% (n=12) responded that Aberdeen had services needed for informal caregivers, 95% felt that Aberdeen could use more services to benefit informal caregivers of terminal cancer patients.

C. THEORETICAL FRAMEWORK

According to Rando (1984), anticipatory grief can allow family members to do a number of things before the actual death; begin to change their assumptions about life and identity, resolve any unfinished business with the dying person, and begin to make plans for the future. Research indicated that support groups are beneficial to informal caregivers of terminal cancer patients. Informal caregivers can use the support group to work on anticipatory grief. Other benefits of support groups include realizing that they are not alone with their concerns, problems and pressures; receiving encouragement and understanding; gaining the ability to understand and communicate feelings about caregiving; and sharing resources (Beigel et al. 1991).

Stress process theory proposes that caregivers' negative impacts are the result of an interaction between primary stressors, secondary stressors and mediating factors. Primary stressors are the characteristics of the care recipient's needs and that tasks and time required in meeting those needs. Secondary stressors are factors outside of the caregiving situation such as marriage and employment. Mediating factors are the

presence or absence of formal or social support (Pearlin & Turner, 1987).

D. SUMMARY OF QUALITATIVE DATA

The qualitative data from this study indicated that more resources such as social and emotional support, what is expected, and information on caregiving are needed for informal caregivers of terminal cancer patients in Aberdeen, South Dakota. The common themes among the 63% (n=12) of participants who thought Aberdeen had services available was that of hospice. In addition to hospice being listed the most, home health and respite care were also listed frequently. Due to the definition of terminal cancer which was provided to the participants, hospice would only be available to those terminal ill patients who have less than 6 months to live. Of the 95% (n=18) who felt that Aberdeen needed more services available listed common services such as available list of resources, respite care, and support. Of the 13 (68%) who responded to what should be addressed in a support group the common themes were death and dying, the grief process, information on caregiving, the expectations of the caregiver and care receiver, resources available, stress management and coping skills.

E. LIMITATIONS

Generalizability:

A sample was obtained through a contact person at The Cancer Care Center and Avera St. Lukes Hospital (which included its affiliate, North Plains Hospice). The contact person made a list of all participants who would meet the criteria for the survey. The different criteria for this study were that these professionals work with terminal cancer

patients and/or informal caregivers. Of the respondents, 85% (n=16) were from the profession of nursing. It is uncertain why more from the other professions did not respond. Although study population was fairly large at 112 participants, the response rate was low at 16.9%, and the participants all worked in Aberdeen, South Dakota at one of the above listed agencies. There is no way of knowing how the other 83.1% (n=93) would have responded. Other limitations in this study include population size, geographic location and representation of diverse ethnic groups. Data was not collected from a large cross-section of people representing different cultures or geographic locations. Due to the fact that only Aberdeen, South Dakota was involved in this survey, the results can not be generalized to different cities or states. One major limitation is that the source is limited to professionals. It would have been extremely helpful to survey informal caregivers of terminal cancer patients and the terminal cancer patients themselves.

Instrument Design:

The data collection tool used for this research study may have some disadvantages which need to be considered as possible limitations. Due to the fact that some of the participants left questions unanswered may indicate that they didn't understand the question. It may also be said that maybe some of the participants didn't understand a question but answered it anyway, which could then produce a false response from that particular participant(s).

Also, questions 5 and 6 appeared to be confusing to the participants. Question 5 asked "Do you think that Aberdeen has services available to meet the needs of informal

caregivers of terminal cancer patients” and question 6 asked “Do you think there is a need for more resources for informal caregivers of terminal cancer patients?” Sixty-three percent (n=12) felt Aberdeen had services available to meet the needs of informal caregivers of terminal cancer patients, but at the same time, 95% (n=18) thought that Aberdeen could use more. It is uncertain what their thinking was because if Aberdeen already has the services to meet their needs, then why do they need more. Another limitation to this study was that no pretest was done. A pretest would have allowed the investigator the opportunity to see how the questionnaire would be seen by a group of similar professionals and would allow for suggestions to improve the survey.

This study provided useful information that helped determine if there is a need for informational/support groups for informal caregivers of terminal cancer patients in Aberdeen, South Dakota, but it is not generalizable to the general population. It is strictly applicable to Aberdeen.

F. IMPLICATIONS FOR PRACTICE

Informal caregivers of terminal cancer patients have many needs during this emotional and stressful time. Research indicates that the use of support groups are beneficial for informal caregivers in many different ways. They can provide informal caregivers information on death and dying, the grieving process, what is expected, what resources are available and support from others who are in the same informal caregiving situation.

The results of this study indicate that Aberdeen, South Dakota is in need of

additional resources for informal caregivers of terminal cancer patients. The professionals who participated did indicate that Aberdeen does have services available, but 95% (n=18) of those participants felt that Aberdeen definitely could use more services. Professionals who work with terminal cancer patients, identified key needs for informational/support groups for informal caregiver in Aberdeen, South Dakota.

The results of the data yielded many valuable suggestions as to what a support group for informal caregivers in Aberdeen, South Dakota should entail to help them through this difficult time. Overall, the responses were very supportive to the need for additional services and offered numerous suggestions as to what those services should be.

G. RECOMMENDATIONS FOR FUTURE RESEARCH

Future research could look more specifically into the needs of informal caregivers of terminal cancer patients. Most research found talked about caregivers for the elderly not to a health related disease. A study that would involve the questionnaire being distributed to informal caregivers instead of the professionals would allow the investigator to get first hand what the informal caregivers see as their needs and if they are being met.

H. CONCLUSION

Due to a number of reasons, 80% of individuals who can no longer care for themselves are receiving help from family members or friends and remaining in their home. The majority of the 80% are elderly. Those informal caregivers are in need of

services to help them provide the best care for the care receiver, themselves and their families. Hospice was developed to help provide support and assistance to the informal caregivers. But hospice has rules and regulations that need to be followed. In order for hospice to become involved, the person who is ill needs to be given six months or less to live by their doctor. The gap in services are in the time the ill person needs the help of the informal caregiver to the time that hospice can get involved.

The purpose of this study was to determine if there was a need for informational/support groups for informal caregivers of terminal cancer patients in Aberdeen, South Dakota. The results suggest that Aberdeen does have services, but could use more to help informal caregivers of terminal cancer patients.

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A
COVER LETTER

April, 1999

To Whom it may concern:

You are invited to be in a research study to determine if there is a need for informational/support groups for informal caregivers of terminal cancer patients. You were selected as a possible participant because of your work with terminal cancer patients and/or informal caregivers. Please read this form and ask any questions you may have before agreeing to be in the study. This study is being conducted by Keri Bolduan for her Thesis at Augsburg College in Minneapolis, MN as partial requirement for a Masters in Social Work Degree.

If you agree to be in this study, I would ask the following things. Please read over the definitions enclosed and then fill out the questionnaire and return it in the self-addressed stamped envelope provided by May 14, 1999. The questionnaire will take about five to ten minutes to complete. You may skip any question and still remain in the study.

There are no direct benefits for participation in this study. The indirect benefit to participation is helping the community of Aberdeen determine if there is a need for informational/support groups for informal caregivers of terminal cancer patients.

The records of this study will be kept private. In any sort of report that might get published, the researcher will not include any information that will make it possible to identify you. Research records will be kept in a locked file, only the researcher will have access to the locked file. In addition to myself, Dr. Sharon Patten will have access to the completed questionnaires throughout the study. The raw data will be destroyed on or before September 30, 1999.

Your decision whether or not to participate will not affect your current or future relationship with Augsburg College, Avera St. Lukes, The Cancer Care Center, or with Aberdeen Hospice Center. If you decide to participate, you are free to withdraw at any time without affecting those relationships. If you chose to participate, your consent to participate will be the returned filled out questionnaire.

The researcher conducting this study is Keri Bolduan. If you have any questions, you may call me at 380-1233 or Dr. Sharon Patten at 612-330-1723. Thank you for your consideration in this matter and I hope to hear from you soon.

Sincerely,

Keri Bolduan
MSW Student

B
QUESTIONNAIRE

Needs Assessment
To Determine If There is a Need for Informational/Support Groups
for Informal Caregivers of Terminal Cancer Patients

1) What is your current role as a professional who works with terminal cancer patients?
(Please check the appropriate choice).

- | | |
|---|--|
| <input type="checkbox"/> Doctor | <input type="checkbox"/> Social Worker |
| <input type="checkbox"/> Nurse | <input type="checkbox"/> Other (specify) _____ |
| <input type="checkbox"/> Pastoral Care Worker | |

2) How long have you been working with terminal cancer patients?
_____.

3) Are you involved with informal caregivers of the terminal cancer patients?
 Yes No

4) Have there been any inquiries about informational/support groups for informal caregivers by the caregivers themselves?
 Yes No

If yes, please specify:

_____.

5) Do you think that Aberdeen has services available to meet the needs of informal caregivers of terminal cancer patients?
 Yes No

If yes please specify:

_____.

6) Do you think that there is a need for more resources for informal caregivers of terminal cancer patients?

Yes No

If yes, please specify:

7) Please list the available resources for informal caregivers of terminal cancer patients that Aberdeen has that you know of.

8) Are any of the resources listed above strictly for informal caregivers of terminal cancer patients?

Yes No

If yes, please circle the ones in the above question.

9) Do you see a need for informational/support groups for informal caregivers of terminal cancer patients?

Yes No

10) As a professional, what areas do you think need to be addressed in support groups?

11) Additional comments:

Thank you for taking the time to complete this survey and to mail it back!!

C **DEFINITION OF TERMS**

Caregiver: person who provides primary assistance to another person in need.

Primary Assistance: helping another person meet his/her daily needs. This may include but is not limited to cooking, cleaning, bathing, feeding, and transporting.

Informal Caregiver: often is unpaid, untrained family member(s) or friend(s).

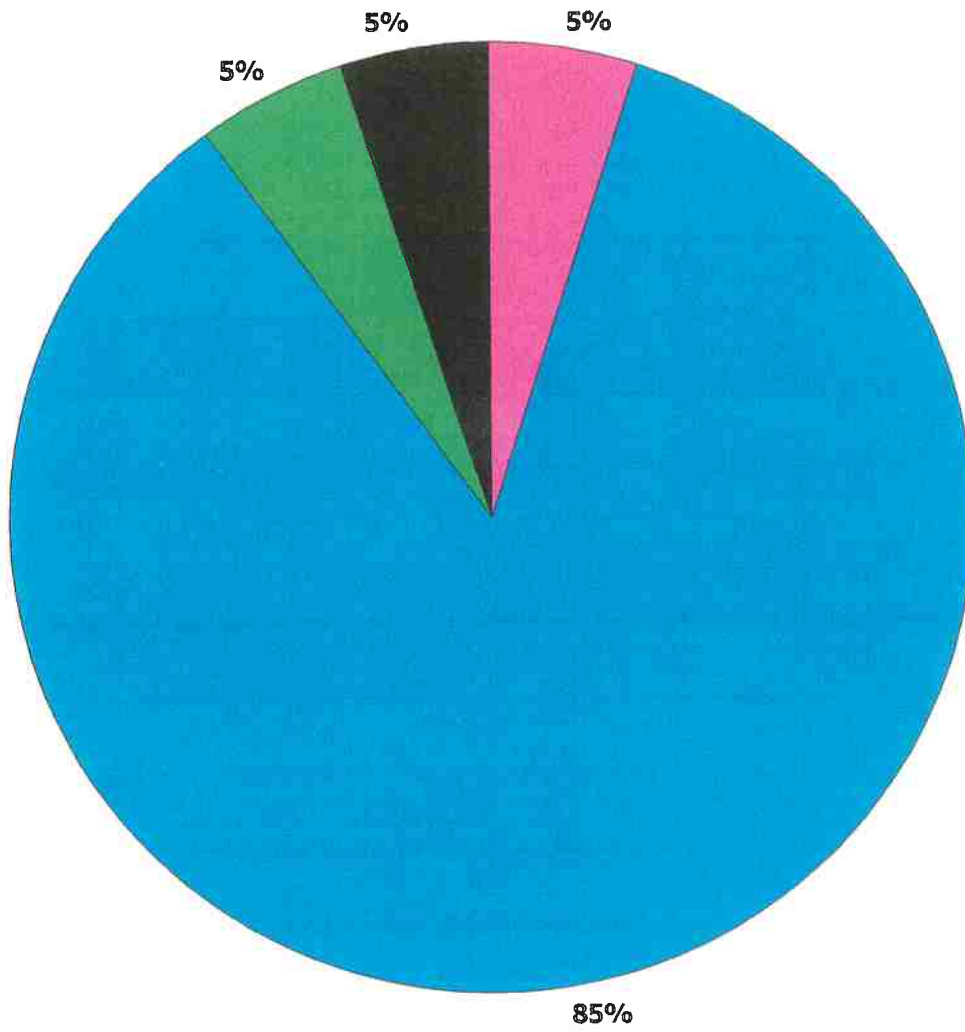
Formal Caregiver: usually trained volunteers or paid care providers.

Terminal Cancer: any type of cancer that limits the life expectancy of someone to one year or less.

Patients: individuals who have terminal cancer and are being seen or have been seen by The Cancer Care Center and/or Avera St. Lukes Hospital and/or North Plains Hospice in Aberdeen, South Dakota. In previous studies the term patient was limited to a person with a terminal illness as it is in this research. Also, terminal cancer in this research extended the life expectancy to up to one year. Most other studies had the life expectancy under 6 months.

Stressor: a life event that requires changes and adjustments in an individual's daily life.

Percentage of Study Population



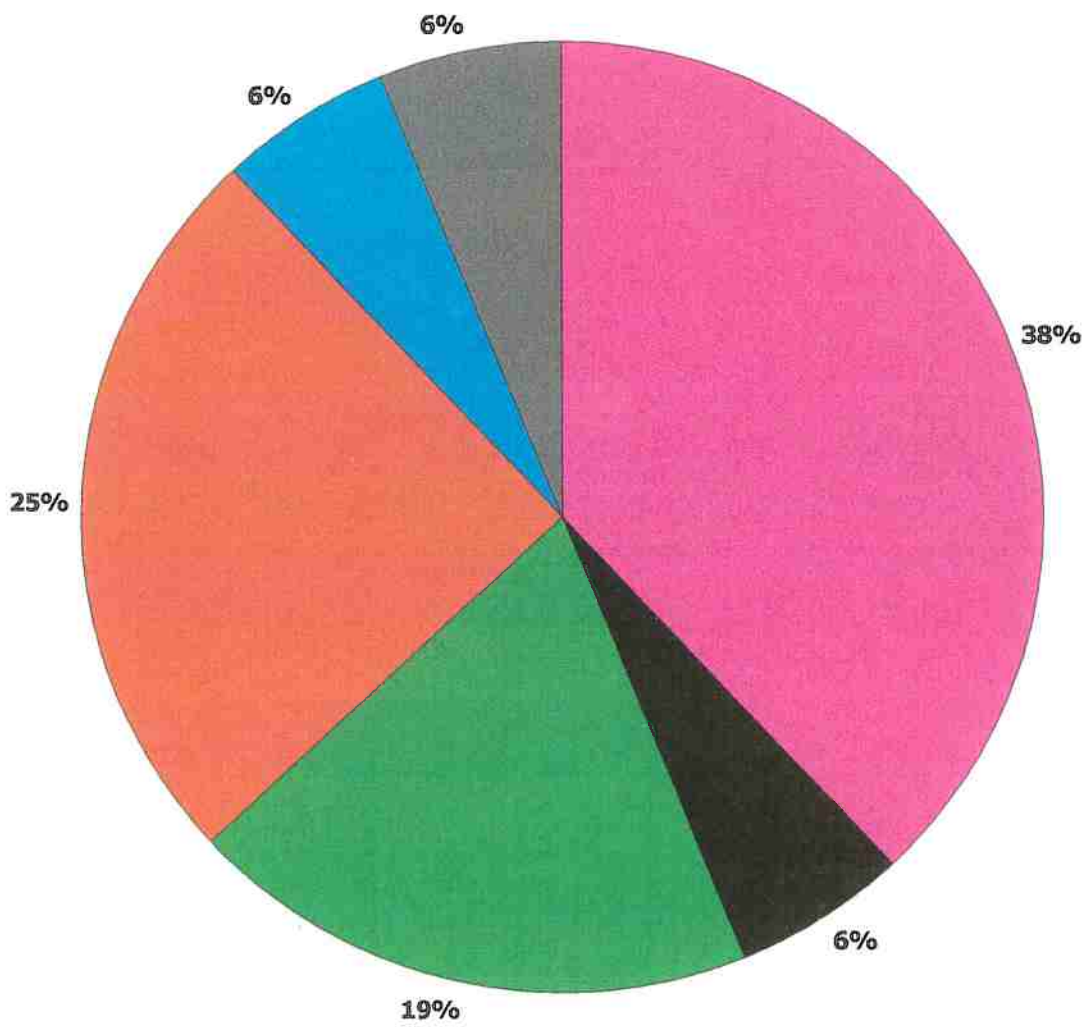
Nurse

Social Worker

Pastoral Care Worker

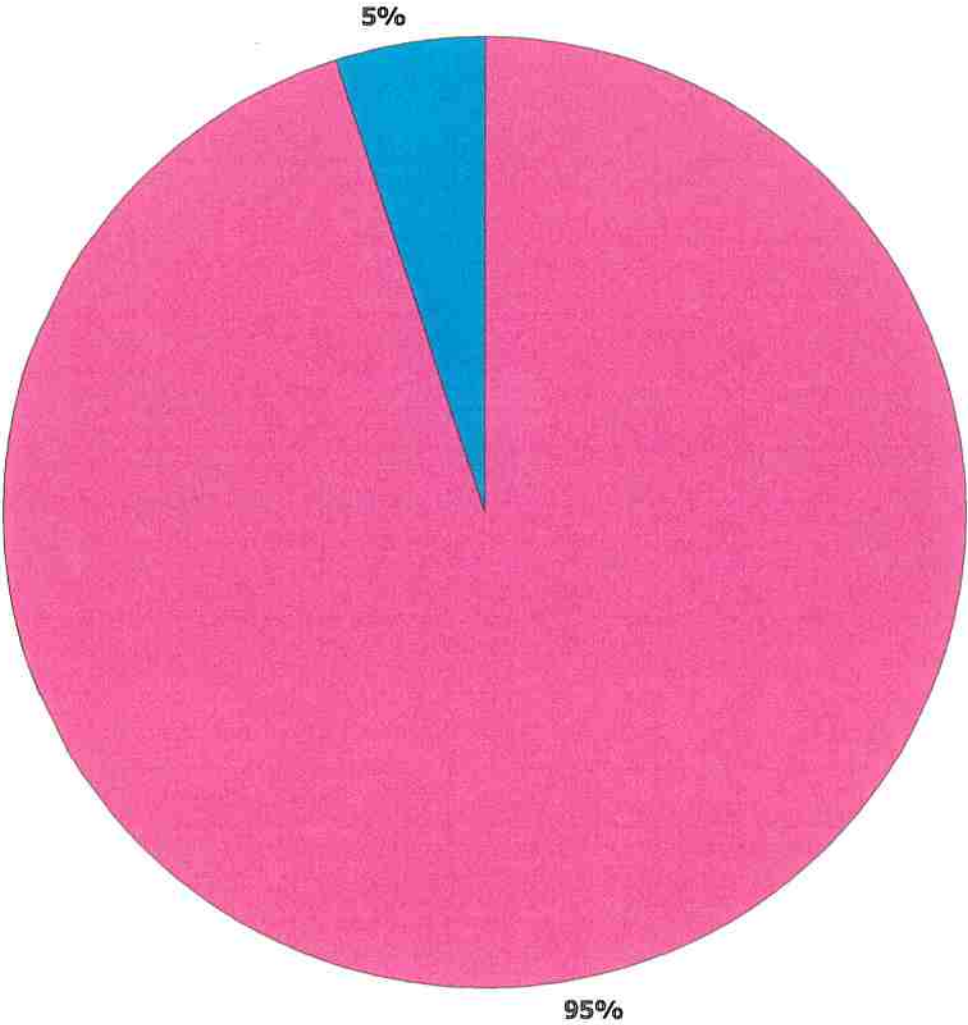
Doctor

Services Available to Meet the Needs



More Needed Support Groups Respite Hospice Parish Nurse Social Services

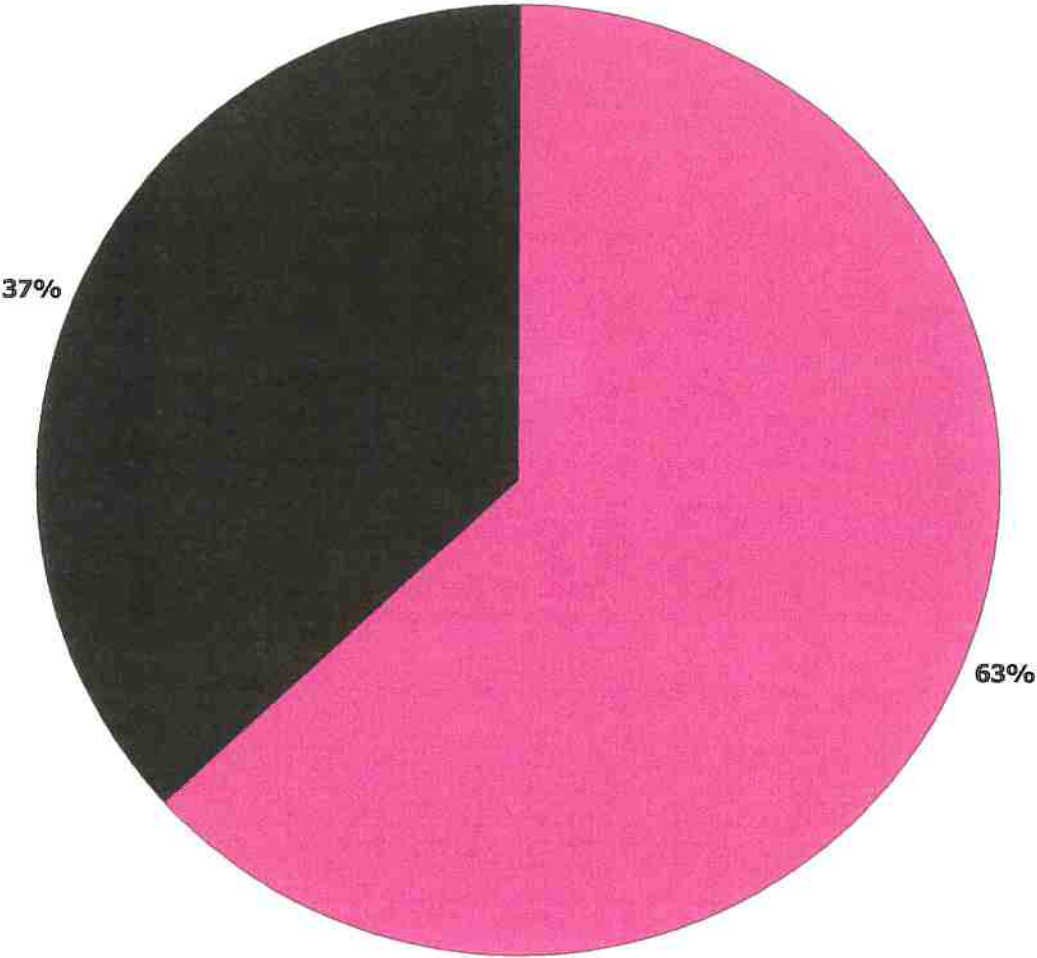
A Need for More Resources



YES

NO

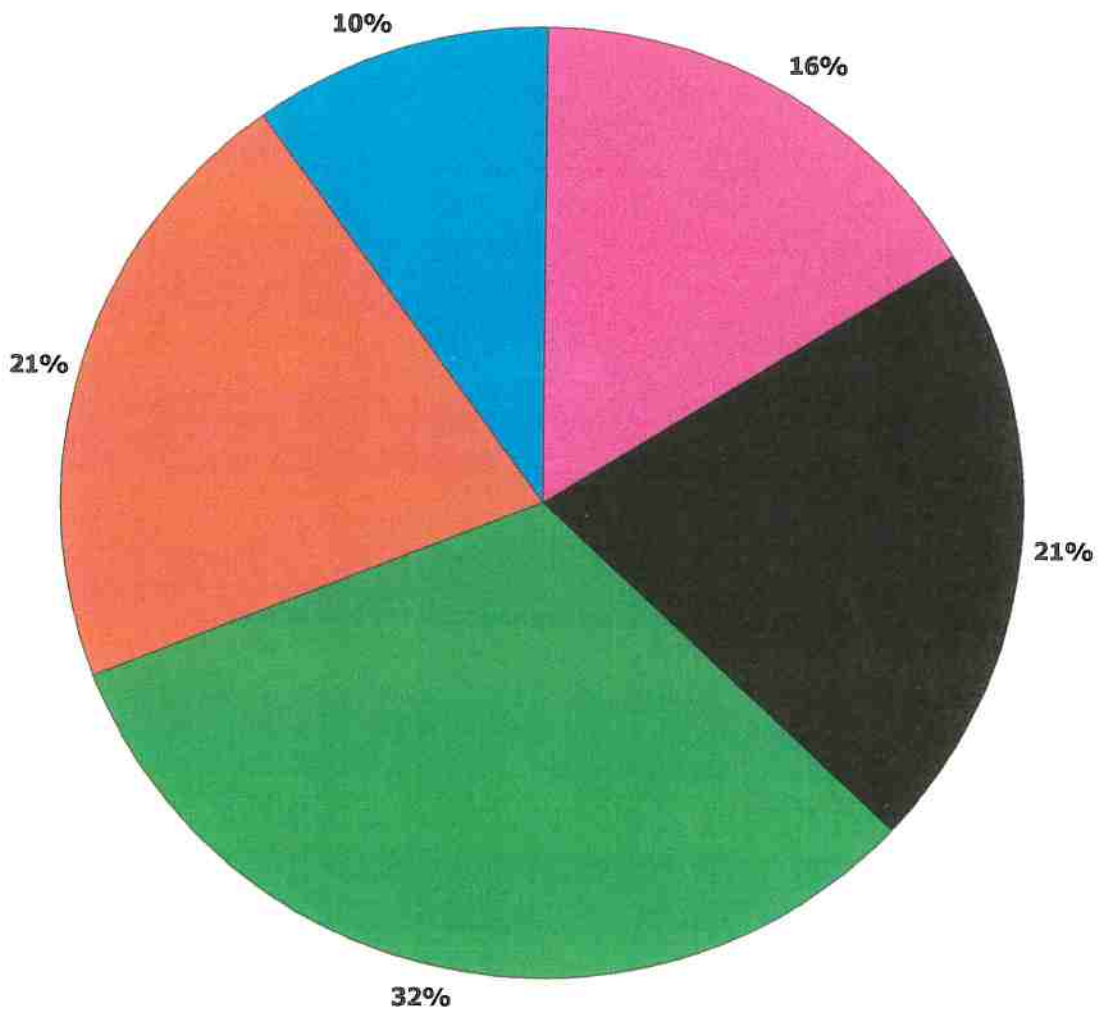
Aberdeen Already has Services Available



YES

NO

Percentage of Years Professionals Worked with Terminal Cancer Patients



1-5 Years 6-10 Years 11-15-Years 16-20 Years 21-25 Years

