Hospice Component
of the Longitudinal Diversion Study:
Exploration of Hospice Use by Medicaid
and Medicare Consumers in Kansas

Rosemary Chapin, Ph.D.
Mary Zimmerman, Ph.D.
Theresa Gordon, LSCSW
Sarah Terrebonne Landry, LMSW
Pat Oslund, MS
Roxanne Rachlin, MHSA
Ann Hickey, MA
Claire Peng, BA

University of Kansas
School of Social Welfare
Office of Aging and Long Term Care

This research was supported in part
through a contract with the
Kansas Department on Aging and the
Kansas Department of
Social and Rehabilitation Services
Topeka, Kansas 66612
# Table of Contents

Executive Summary ................................................................. 3

I. Purpose of the Hospice Component of the Diversion Study ............... 7
   A). Sections Outline ............................................................. 7
   B). Significance ............................................................... 8

II. Literature Review and National/State Background Information .......... 9
   A). End of Life Literature Review and General Hospice Information .... 9
   B). Patterns of Hospice Use .................................................. 10
   C). Cost Containment in Hospice Care ................................... 11
   D). Challenges to Using Hospice Care .................................. 13

III. Overall Research Design ...................................................... 16

IV. Hospice Utilization Methodology and Analysis ............................. 17
    Summary of Key Findings .................................................. 34

V. CARE Assessor Survey Methodology and Analysis ........................... 36
    Summary of Key Findings .................................................. 44

VI. Qualitative Interviews of Surviving Care Providers ........................ 46
    Summary of Key Findings .................................................. 56

VII. Synthesizing the Results of the Three Study Components ............... 57

VIII. Next Steps ........................................................................ 61

IX. Conclusion ........................................................................... 63

Glossary .................................................................................... 64

References ................................................................................. 66

Appendices .................................................................................. 72
EXECUTIVE SUMMARY

Purpose and Research Questions

The purpose of our study was to examine hospice utilization in Kansas. Specifically, we analyzed the utilization of hospice services by a sample of CARE Assessment customers, differences and similarities between those who use hospice and those who do not, costs and benefits of hospice enrollment to the Medicaid program, and potential barriers to hospice use. The CARE assessment process is required for admission to a nursing facility in Kansas. The CARE assessor is trained to assess the customer’s functioning levels and needs, discuss potential service options, and if the customer approves, make referrals to appropriate providers/professionals who specialize in that service. It is a critical juncture in an older person’s life when they look to health care professionals to inform, educate, and advise them about possible next steps, which may include end of life care.

Our specific research questions were:

1) What is the incidence of hospice use by potentially eligible Kansans 65 and over?
2) What are the differences and similarities between those who use hospice and those who did not?
3) What are the costs and benefits of hospice enrollment to the Medicaid program?
4) What do care providers and CARE assessors perceive as the benefits and potential barriers to hospice use?

Methodology

The methods employed in this study include the following: 1.) a secondary analysis of quantitative data of Diversion Study participants (n=400) in order to identify the incidence of hospice use in potentially hospice eligible Kansans 65 and over; to explore similarities and differences between the individuals who received hospice and those found to be potentially eligible but did not receive hospice services; and to determine the cost and benefits of hospice enrollment to the Medicaid program; 2.) survey of CARE assessors (n=359) to determine the incidence of hospice counseling at the time of the CARE assessment and to identify benefits and potential barriers to hospice use; 3.) a qualitative telephone interview of surviving family care providers (n=18) of consumers from our sample of Diversion Study participants to explore perceptions of benefits and barriers to hospice use in Kansas. Consequently, we triangulated information from all three methods in order to address our specific research questions.

Findings

What is the incidence of hospice use by potentially hospice eligible CARE Assessment customers age 65 and over?
Of the potentially hospice eligible sample, 1/3 (32%) actually received hospice and 2/3 (68%) did not. Among those who received Medicaid 26.5% utilized hospice services and 73.5% did not.

What are some of the similarities and differences between those consumers that used hospice and those that did not?

The two sub-samples, confirmed hospice (n=129) and non-hospice consumers (n=271), were similar on the following variables:

- Over 90% of both sub-samples were White.
- Almost 60% were female in both sub-samples.
- Both sub-samples exhibited similar ADL scores.
- About 90% of both sub-samples had some recent stay in a nursing facility.
- Both sub-samples had a higher rate of completion of end-of-life documents than national averages (20%), however still less than half of each group completed documents.
- Care providers of both groups discussed the importance of being with loved ones at their end-of-life.
- Care providers of both groups felt that the CARE assessment process was very helpful.

Our sub-samples of hospice and non-hospice consumers were significantly different in these areas:

- 56.2% of people who utilized hospice services had a cancer diagnosis compared to only 25.8% of the entire group.
- Individuals who were in the non-hospice group were significantly older than those in the hospice group.
- A larger proportion of consumers in the non-hospice group had multiple serious diagnoses.

Although the difference was not statistically significant, non-hospice recipients were somewhat more likely to live alone and had less than full-time social support. In addition, non-hospice customers were more likely to have completed advanced planning documents, both a financial will and a Durable Power of Attorney for Health Care Decisions at the time of the CARE assessment.

Medicaid-specific differences were also evident. They are:

- Lower hospice utilization rate for all Medicaid customers.
- Medicaid recipients were less likely to have completed a Durable Power of Attorney for health care decisions at the time of the CARE assessment.
- Medicaid hospice recipients were more likely to have multiple diagnoses.
- Medicaid customers were less likely to receive hospice if they lived in an urban area.
Most of the Medicaid customers were in nursing facilities (not diverted) regardless of hospice status.

What are the cost and benefits of hospice to the Medicaid program?

Our study found that after enrolling in hospice, hospice consumers were less likely to be hospitalized or go to the ER than non-hospice consumers.

If half of the potentially hospice eligible Medicaid customers would have used hospice and avoided one ER visit, the potential annual cost savings would be $62,860.

If half of the potentially hospice eligible Medicaid customers would have used hospice and avoided one hospital stay the potential annual cost savings would be $2,100,382. Care providers of hospice consumers reported no monetary costs for care giving during the last six months of their loved one’s life.

Care providers of non-hospice consumers did report monetary costs for care.

Care providers of both those who used hospice services and those who did not reported costs in regard to time spent providing care.

What do CARE assessors and care providers identify as benefits and barriers to hospice use?

Both the CARE Assessor Survey and the care provider interviews reflected the difficulties of talking about death and dying. Particularly, certain dilemmas were mentioned, especially when the discussion should occur, and who should engage in the conversation. Some CARE assessors wrote that they felt that discussing end-of-life issues was “inappropriate”, “not their job”, or “felt that they didn’t know enough about hospice”. Care providers indicated that they didn’t know about hospice availability or the range of services. Therefore, this highlights a key barrier to hospice use in that professionals are not taking the lead in discussing future care.. An additional barrier was the misunderstanding of some CARE assessors and care providers as to accessibility of hospice or hospice services. Given that 21% of the older adults in our sample died within six months of receiving the CARE assessment, these finding are particularly important.

Benefits to hospice use identified by the CARE assessors and care providers:

- 75% of care providers who recalled the CARE assessment process indicated that the CARE assessor was helpful.
- Of the care providers whose loved one used hospice services, 81% reported that hospice was helpful.
- CARE assessors acknowledge the benefit of hospice services for their clients and would like more information and training regarding its services.

Next Steps

Policy efforts that make end-of-life concerns a priority are needed. Discussions with state agency staff, Care assessors, advocates, and customers point to two possible policy innovations.
One is to formulate an educational drive to increase hospice awareness and education on palliative care at end-of-life. The second is to make “tools” available to CARE assessors to help them address hospice counseling.

An educational drive could be directed at consumers as well as professionals and would dovetail well into the plans already begun by Kansas’ Department of Heath and Environment for patient navigator, state supported web-sites, and an informational phone hot line focused on end of life issues.

In addition, many Kansas rural counties have only one hospice serving their area. Further, Medicare payments for hospice costs are less to rural counties than urban counties. Policy makers can explore ways to support rural hospices and to implement plans that are rural-specific to increase awareness of hospice services.

Another recommendation is to address the problem of hospice use in nursing facilities. Hospice services are poorly understood in nursing homes. Policy makers can explore how best to address education on palliative care and hospice care in state surveyed nursing homes.

The Kansas Department on Aging is already taking steps to increase CARE assessor awareness of hospice and its service provisions. Additional plans have been discussed with key KDOA staff about providing Area Agencies on Aging with hospice “toolkits” and one-page informational handouts; partnering with consumer and professional advocacy groups; and additions to the CARE assessor training.

As a follow up to this project, the Office of Aging and Long Term Care is now analyzing CARE assessor educational needs, compiling tool kits and handouts specific to end-of-life care and collaborating with KDHE on linking end-of-life information to their website and hot line development.
Part I. Purpose of the Hospice Component of the Diversion Study

This report presents the results of the Hospice Component of the Longitudinal Study of Customers Diverted through the CARE Program. The overall purpose of the hospice component was to examine the use of hospice services by older Kansans, particularly those receiving Medicaid, in order to determine if hospice utilization can result in increased quality of end-of-life care as well as in state cost savings.

The following research questions were investigated:

1. What is the incidence of hospice use by potentially eligible Kansans 65 and over?
2. What are the differences and similarities between those who use hospice and those who do not?
3. What are the costs and benefits of hospice enrollment to the Medicaid program?
4. What are the benefits and potential barriers to hospice use as perceived by care providers and/or CARE assessors?

This report paints a picture of the state of end-of-life care in Kansas. It provides information for state policy makers, legislators, services providers, and consumers to inform future policy decisions and program development.

Our study methodology incorporated multiple types of data. We drew quantitative data (e.g. extent of hospice use, advanced planning, diagnoses, and so on) from the Diversion study. We examined these areas in further depth by surveying/interviewing key stakeholders in the CARE assessment process (i.e. CARE assessors and surviving family members of CARE consumers). These three subgroups of customers were of particular interest:

- Hospice and non-hospice recipients;
- Medicaid and non-Medicaid recipients; and
- Diverted and non-diverted customers.

This report is organized as follows:

- A summary of relevant literature and hospice general information;
- A review of our overall methodology in selecting the hospice and non-hospice samples;
- An analysis of the three components of the study:
  - The secondary analysis of the Diversion Study participants and summary of key findings;
  - The CARE assessor survey and summary of key findings;
  - The care provider interview qualitative findings and summary.
- A synthesis of the findings from the above components and implications for policy-makers;
- A discussion of the next steps to be taken.
A). Significance

The Longitudinal Study of Customers Diverted through the CARE Program was initially funded in 2000 to examine factors for nursing facility admission, and to investigate how publicly funded community-based services influence community tenure. The results of the study indicated that the death rate within six months of the CARE assessment was 23.2% for diverted (those consumers who remained in the community) consumers and 28.2% for non-diverted (those consumers who moved to nursing facilities) consumers. This finding regarding the overall death rate led to questions regarding hospice utilization and its possible benefits to consumers, their families and the state of Kansas. Consequently, an addition to the Diversion Study was proposed and funded to explore these end-of-life questions.

An additional factor that motivated this study is the awareness that, as our population grows older, more people will need end-of-life care. In the United States between 1900 and 1996, the population of older persons tripled and by 2030, it is projected that 20% of all Americans will be 65 or older (Federal Interagency Forum on Aging-Related Statistics, 2000). In addition, the incidence of a gradual dying process due to chronic disease management is increasing with the result that caregiving costs are increasing. At the turn of the 20th century, disease processes resulted in a quick death. “Within a week of onset of the serious illness, it was not uncommon for the person to have died or recovered” (Bern-Klug, 2004, p.57). Now with the advent of better medical care, drug therapies, and technology, chronic and terminal illnesses may not result in death for many years.

Current services available to dying patients consist of one end-of-life care model funded by the federal government through the Medicare Part A Benefit—the Medicare Hospice Benefit (MHB). This benefit encompasses services to address the physical, emotional, social, and spiritual needs of the ill individual and their families. This holistic approach can afford elderly Medicaid recipients better end-of-life care, reduce the costs of care for the state, and improve quality of life until their death.

For these reasons, it was of particular interest to explore the utilization of the Medicare Hospice Benefit by Medicaid and non-Medicaid consumers and the related cost savings for the state. A glossary is provided at the end of this report that defines terms used in this report. The terms in the glossary are bolded the first time they are used.
Part II. Literature Review and National and State Background Information

A). End-of-Life Literature Review and General Hospice Information

Two significant events converged in the 1970’s and early 1980’s to increase our collective awareness of the need for better care for the dying in the U.S. The synergy of these events resulted in the passage of the Medicare Hospice Benefit (MHB) in 1982. The first significant event arose within the medical community in the context of medical advances. A physician named Elizabeth Kubler-Ross published her landmark work, *On Death and Dying*, in 1968. This book examined the dying process in all its elements: physical, emotional, and spiritual. The dying process was no longer couched in terms of disease and doom. Instead, it was described as a time for potential enrichment and growth, for a celebration of life, for family and friends, and for dignity and meaning (Kubler-Ross, 1968). This resonated within the health community because both medical providers and families were voicing frustration over the hospital setting for terminal patients, the medical preference for aggressive treatment, and the dramatic rise in length of stays in hospitals for dying patients (Stoddard, 1992).

The second significant contributor to the MHB was the rise of the hospice movement and its philosophy of terminal care. Generally thought of as a way to enhance the quality of end-of-life care for the terminally ill who do not respond to or choose curative treatment (Fitch & Pyenson, 2003), hospice care emphasizes palliative care aimed at treating pain and symptoms provided by a multidisciplinary team (Mesler & Miller, 1996). By the 1960s, dying had become increasingly depersonalized, and death was considered costly (Mesler & Miller, 1996). A presentation given in 1963 by the founder of St. Christopher’s Hospice in London, Dr. Cicely Saunders, helped to change the American view of death and dying by providing an alternative by which terminally ill patients could have “pain control, family involvement, and honest dialogue about their condition” (Miller & Mike, 1995, p. 532), and perhaps save money compared to traditional medical care (Fraser et al., 1986). The hospice movement emphasized providing dignity at the end of life (Hickey, 1999), as well as palliation from physical and emotional suffering that accompany terminal illnesses (Lackan et al., 2003).

The backbone of the hospice vision is the idea that there are four guiding principles of care for hospice patients:

- The patient and their family are the unit of care;
- The team approach provides holistic care, supporting patient self-determination and dignity (Miller & Mike 1995, 1996);
- Palliation (comfort care) from physical and emotional suffering is emphasized (Lackan, Freeman & Goodwin, 2003);
- The continuum of care for the bereaved family members persists beyond the death of the person (Jennings, 2003).

Furthermore, patient feelings about the end-of-life reflect the importance of end-of-life issues and are in line with the hospice vision of providing holistic approach. Steinhauser et al.’s (2000a) found that, when patients were asked how they viewed a “good death” or end-of-life, they overwhelmingly endorsed pain and symptom management, preparation for the end-of-life, and completion of unfinished business with family and friends. Further research by Steinhauser
et al. (2000b) reported that, in addition to the above-mentioned trends, many people at the end-of-life also wanted to contribute to others and be affirmed that they are a whole person.

The Medicare Hospice Benefit promotes a two-prong effort in providing hospice care to terminally-ill patients: first, good quality end-of-life care is emphasized; second, hospice care (versus dying in a hospital setting) is thought to be successful cost containing care for those who are terminally ill. All expenses associated with hospice care are covered 100% under the Medicare Hospice Benefit, including basic hospice services such as nursing visits, doctor consultations, visits from a social worker, visits from a chaplain, help from volunteers, adjunct therapies (physical therapy, occupational therapy, speech therapy), respite care, continuous care, and access to a 24-hour nursing hotline. Basic benefits, such as covering drugs related to the terminal illness, durable medical equipment for comfort and care, and other respite and continuous care are also covered.

Eligibility for hospice care under the Medicare Hospice Benefit is contingent upon four conditions:
- The patient’s physician must certify that a patient is indeed terminally ill, with a life expectancy not exceeding 6 months;
- The patient must choose to receive palliative care and forgo aggressive care;
- Care is provided by a hospice program certified by Medicare;
- The person must be covered by Medicare Part A (Miller & Mike, 1995).

B). Patterns in Hospice Use

National Trends

Hospice use in the United States is growing annually by 10% (Fitch & Pyenson, 2003; Virmig et al., 1999), with 775,000 persons enrolling in a hospice program in 2001 (Lackan et al., 2003). Overall, Medicaid recipients make up 5% (approximately 40,000 people) of all hospice patients (Fitch & Pyenson 2003). According to Fitch and Pyenson, (2003), 64,000 Medicaid recipients die in hospitals annually; nearly two-thirds of whom (approximately 45,000) suffer from typical hospice diagnoses. This illustrates the underutilization of hospice care by potentially eligible patients. This population represents potential cost savings or avoidance of additional costs to the Medicaid program, specifically, and to other service programs such as home-based care, in general.

Another national trend concerning hospice care is the late enrollment by many terminally ill individuals. Studies show that many patients enroll too late to truly maximize the benefits of hospice services (McCarthy et al., 2003; Colias, 2001; Riley & Herboldsheimer, 2001; Shapiro, 1997; Mesler & Miller, 1996). Lamont & Christakis (2002) report that physicians in their study believe that patients should ideally receive hospice care for at least 3 months before death, but the majority only survive 1 month in hospice care, rendering the terminally ill patients unable to maximize hospice services. Underutilization of hospice services remains despite increasing numbers of individuals who enroll in hospice care during the end stage of life. Both trends suggest that a lack of awareness may account in part for this underutilization of hospice care by Medicaid patients.
The largest national coalition promoting quality of end-of-life care, Last Acts, assessed each state on their ability to provide good end of life care to their residents (2002). Last Acts compiled a standard that they felt was best practices in EOL care and used this to rate each state as to how best they met this ideal. These assessments ranged from A - E on nine key indicators with A being the best. No state received consistent “A” or “B” ratings. For example, Arizona received the highest rating by receiving a “B” in hospice utilization. Arizona and Florida ranked high on the indicators overall. Kansas received a low grade (as did the majority of states) for hospice utilization, number of days in hospice, for hospital supported hospices, palliative care programs and advanced directive laws. This report card format was a “call to arms” to policy makers, service providers, and consumers that no state in the nation is providing excellent care; some states are doing very well but most (including Kansas) have room to improve.

Kansas Trends

Utilization of hospice in Kansas follows national trends and is actually slightly higher than the national average of 21.5%. Of those terminally ill individuals over the age of 65 in Kansas, 22.5% used hospice in 2000 (Last Acts Kansas Fact Sheet, 2003). The median length of hospice enrollment in Kansas was approximately 25.4 days in 2001 (Last Acts Kansas Fact Sheet, 2003), similar to the national trend of about one month of hospice enrollment before death. The availability of hospice care in Kansas during 2001 was measured by hospitals reporting they had hospice care programs (14.6%) and hospitals reporting palliative care programs (16.0%) (Last Acts Kansas Fact Sheet, 2003). Kansas numbers are comparable to national trends of hospice availability and utilization.

C). Cost Containment in Hospice Care

From its inception the Medicare Hospice Benefit was conceived as a cost-containment strategy as well as state of the art end-of-life care. In 1983, Medicare regulations changed due to the spiraling costs of health care, particularly hospital care. This resulted in reimbursement by Diagnostic Related Groups (DRGs), a capitated payment system where reasonable and customary fees for treatment are the basis for payment rather than actual hospital costs (Binstock & cuff, 2000). Although not using DRGs, per se, a certification of terminal illness became the “diagnostic group” and the basis for a per diem, capitated reimbursement system. Here also the payment was not tied to actual costs, but a fixed rate. This rate was the projected average per day cost of caring for a dying person.

Under the original hospice vision of the Medicare Hospice Benefit, the goals of the hospice movement were to maximize good quality end-of-life care, as well as to contain costs associated with this end-of-life care. Hospice care is rooted in the belief that an alternative to “impersonal technological intervention” (Fraser et al., 1986, p.141) is both more humane and thought to be potentially cost effective to the patient and to the government through Medicare benefits (Fraser et al., 1986). While hospice care has been proven to improve symptom management and quality of life (McCarthy et al., 2003), an additional incentive (in addition to good end-of-life care) for hospice care versus traditional hospital or nursing facility care at the end-of-life is thought to be the cost savings to Medicare (Fitch & Pyenson, 2003; Shapiro, 1997; Scitovsky, 1994).
National Trends

On a national scale, hospices have the potential to save healthcare dollars (Virnig et al., 1999). Medicare expenditure costs in the last year of life have steadily risen from 30% in 1986 (Fraser et al., 1986), 50% in 1994 (Scitovsky, 1994), to over 60% in 1996 (Buntin & Huskamp, 2002), with a majority of these costs occurring within the last 30 days of life (Scitovsky, 1994). For example, Fitch & Pyenson (2003) found that, without hospice care, the cost of end-of-life care in hospitals would rise to $228 million, the cost of drug treatments would rise to $41 million, and the cost of nursing facility placement would rise to $13 million. There exists a financial incentive for HMOs and other insurance groups to encourage their terminally ill to enroll in hospice care, because medical care expenses in the last months of life tend to be very high (Riley & Herboldsheimer, 2001).

Studies have reported a range of actual cost savings from the use of hospice care at the end-of-life from 0-68%, with the average being around 10%, or $10 billion/year. The wide ranges of savings based on different studies are due to differences in methodologies (Emanuel et al., 1996). Medicare saves $1.52 for every $1 spent on hospice patients during the last year of life (Shapiro, 1997). Cost containment efforts have focused on the cost of pain management, out-of-pocket costs for services, labor costs of caregiver services, and labor costs of family members (Dalton et al., 1998). The managed care element of hospice serves to address pain management, prescription drugs and other care needs. Moreover, hospice policy relies on families to take on the responsibility for caring for their terminally ill loved ones at the end of life (Miller & Mike, 1995), thus contributing to the cost savings of end-of-life care. Familial participation in this care is part of the original hospice vision not only as a cost containment strategy but also to enhance quality of life and conform to patient preferences.

Cost benefits of hospice care are also changing. Currently, hospice utilization is benefiting from increased hospice access due to expanded definitions of covered benefits. Hospices are not reimbursed by Medicare for aggressive treatments but can be reimbursed for palliative treatments. Palliative radiation, palliative chemotherapy, palliative blood transfusions, and other treatment options are acceptable to CMS as hospice charges. However, certifying whether a treatment is palliative or aggressive is still problematic, since many treatments have both palliative and aggressive outcomes (Scott Vicars, CMS liaison to the National Hospice and Palliative Care Organization, private communication, August, 16, 2005). Medicare focused medical review teams still do deny reimbursement if they determine that the treatment was more “aggressive” than “palliative”. Increased costs to Medicare for palliative treatments may decrease the cost benefits of hospice care. Future studies around cost benefits will need to be conducted to see if hospice cost benefits continue to be substantial.

Medicaid Specific

National Trends

The National Hospice and Palliative Care Organization (NHPCO) commissioned a study in May, 2003 to explore cost savings to the Medicaid program. Although serving a predominantly young population, the Medicaid program also covers those at risk for a terminal
illness including poor older adults, HIV infected persons, and younger persons suffering from life-threatening illnesses. Hospital discharge data for 2002 suggest that approximately 64,000 Medicaid beneficiaries die annually in hospitals and about 45,000 of these suffered from typical hospice diagnoses. This does not include those Medicaid beneficiaries that die outside of a hospital and who could also be potential hospice patients (Milliman, USA, 2003). Milliman (2003) also estimated that if all states discontinued hospice coverage, national Medicaid spending would increase by about $282 million. The increase in spending would consist of a $228 million added cost for people receiving care in a hospital; a $41 million added cost for prescription drug use; and a $13 million added cost for people who would have been receiving hospice services in nursing facilities.

**Medicaid Specific**

**Kansas Trends**

Information on cost savings through the use of hospice care in Kansas is not readily available; however, we can assume that trends in Kansas would correspond with national trends. Although the exact number of Medicaid deaths is not known, Shireman & Rigler’s (2002) study on health care expenditures for Kansas Medicaid’s aged (65 and older) recipients (9.5% of all older adults in Kansas) showed that costs for nursing facility placement, hospital stays/tests/procedures, and pharmacy/drug costs were increasing. Furthermore, according to the Kansas Elder Count from 2000, 27.3% of older adults had an ICU stay in the last 6 months of life. Hospice care versus traditional hospital care could have lessened this percentage considerably. Studies to date suggest that hospice care is less costly than conventional care (Mor et al.’s 2003). Hospice is aimed at lowering costs during the last year of life; therefore, a savings to the state of Kansas would occur if more Medicaid terminally ill older adults would utilize hospice services.

D). Challenges to Utilizing Hospice Care

- While the population of terminally ill individuals who enroll in hospice care has grown steadily by an annual rate of 10% (Fitch & Pyenson, 2003), there still exist problems with lack of awareness and access to hospice care and other barriers in obtaining hospice care. This may explain why more terminally ill patients do not use hospice care at the end-of-life.

**National Trends**

The literature points to four main issues regarding the challenges to utilizing hospice care:

- Eligibility criteria;
- Lack of awareness and access to hospice services;
- Lack of cultural sensitivity/understanding;
- Physician knowledge and attitude toward hospice care.
The first issue that impedes hospice enrollment is eligibility criteria. Anyone who wishes to enroll in hospice care for their end-of-life care must obtain documentation from their physician that their illness will run its course in a matter of 6 months or less, or the terminally ill individual will not be able to enroll (Fraser et al., 1986). Often, referrals are given too late (Colias, 2001; Massarotto et al., 2000; Johnson & Slaninka, 1999), and the terminally ill individual is unable to utilize hospice services. In addition, even if a patient receives a referral, a majority of the care (between 80-90%) occurs in the home (and the rest in a nursing facility) which requires either an identified primary caregiver or a plan for care when the person becomes unable to care for themselves (NHPCO Legislative Agenda, 2000; Moore, 1998; Miller & Mike, 1995).

The second issue involves lack of awareness and access. When asked about where they would prefer to spend their final days of life, 9 out of 10 Americans responded that they would prefer hospice care to dying in a hospital (Mitchell, 1994). However, overall knowledge about hospice care is lacking in the United States. A study done by the National Hospice Agenda (2000) revealed that 80% of the participants did not know the meaning of hospice, and 44% did not know how hospice was funded. Furthermore, 70% of Medicaid hospital deaths are for conditions that could have benefited from hospice care but did not utilize hospice (Fitch & Pyenson, 2003), and less than 20% of dying patients in 2002 received hospice care (Emanuel et al., 2002). End-of-life care in the United States is still a mystery to many Americans, with only 15 to 20% of the general population having an advance directive or some instruction on how they would like to be cared for at the end of life (Means to a Better End Report, 2002). Additionally, the terminally ill patient may live in a rural area where a Medicare-certified program is not available or easily accessible (Miller & Mike, 1995), or in a community where there is a lack of awareness about hospice care (Gordon, 1995).

The third challenge to enrolling in hospice care concerns the lack of cultural diversity (Buntin & Huskamp, 2002). Minorities are underrepresented in hospice (Lackan et al., 2003; Kidder, 1992), both as recipients and as caregivers (Gordon, 1995). Research shows that current hospice use by African Americans is just 8% versus use by Whites at a rate of 83% (Crawley, 2000). This underutilization may be due to historical problems with medicine and subsequent improper or non-existing care due to ethnic heritage, differing religious and spiritual beliefs concerning death and dying, lack of knowledge among minority physicians, and lack of cultural sensitivity (Crawley, 2000; Gordon, 1995). Moreover, Gordon (1995) found that African Americans and Hispanics might not have access to hospice care due to the requirement of the continuity of care and the [lack of] availability of a primary caregiver. Language and communication differences based on different cultural backgrounds have also been identified as a problem in the utilization of hospice care by Hispanics (Noggle, 1995). Furthermore, hospice care may be in direct conflict with cultural norms, as Noggle (1995) found in the Asian population who utilize hospice care. Problems arising between minority patients and the hospice team could result in the patients being viewed as non-compliant, though it really is an issue concerning cultural diversity (Beechem, 1995).

The fourth challenge has to do with physicians. Several issues involve the relationship between the physician and terminally ill patient, where the physician acts as a gatekeeper to hospice care (Johnson & Slaninka, 1999). First, a physician may overestimate the prognosis of
terminally ill patients, assuming that they will live longer than the 6 month cut-off point for hospice enrollment (Buntin & Huskamp, 2002; Lamont & Christakis, 2002; Miller & Mike, 1995). Second, the communication between a physician and his or her patient may be lacking, and therefore the physician never offers a referral to hospice care (Buntin & Huskamp, 2002). Third, the physician might hold a bias against hospice or have little knowledge about the value of hospice, and therefore does not offer the choice of hospice care to his or her patient (Bradley, 2000; Virnig et al., 1999).

**Kansas Trends**

The same issues of eligibility requirements, lack of access, and concerns about the relationship between patients and physicians that affect other areas of the United States can also be expected to affect hospice use in Kansas. Based on previous research (Shireman & Rigler, 2002), cultural diversity might also be an issue due to the fact that those who utilize services are more likely to be white (though this might also be an issue of the specific racial makeup of Kansas). Other research found that people living in areas with fewer hospital beds are more likely to use hospice care (Lackan et al., 2003), but this is based on the assumption that there exist reasonable access to hospice services in rural areas, which may not be true in Kansas. While Kansas is struggling, like many other states, its rural and aging population presents additional challenges.
Part III. Overall Research Design

A.) Design and Study Population

This study was designed to use a variety of research methods, both quantitative and qualitative, to develop a picture of the use of the Medicare Hospice Benefit among Kansans 65 and older. Study participants were drawn from the Longitudinal Study of Customers Diverted through the CARE Program (known as the Diversion Study). Using the Diversion Study data set, we identified 566 deceased Kansans who had died within 182 days (six months) of their CARE assessment. These individuals were selected as the research population for this study.

Following the study research questions, attention was placed on examining:
1) hospice use among Medicaid recipients 65 and older.
2) comparative characteristics of hospice and non-hospice users;
3) possible barriers to hospice use from the perspective of care providers and CARE assessors;
4) cost benefits of hospice use.

B.) Data

The data requirements for this study included information that would allow us to determine eligibility for hospice services, as well as a variety of customer characteristics so that we could compare hospice and non-hospice users. These characteristics included: medical diagnosis, advanced planning activities, social support, days in hospice, hospice costs, ER use, hospital use, Medicaid status and other demographic characteristics. See Appendix A for a detailed listing.

Data were obtained from the Diversion Study, CARE assessment, MDS database, OASIS database and Medicare data files. In addition, we conducted a survey of CARE assessors to investigate referrals to hospice, knowledge of hospice, and perceptions of assessor influence on decision-making. We also asked CARE assessors what resources they needed to better address end-of-life issues. Finally, we interviewed a small sample of family members of deceased CARE assessed individuals in order to explore their end-of-life experiences. A more complete explanation of these data sources can be found in Appendix B.
Part IV. Hospice Utilization Methodology and Analysis

The first component of our study focused on hospice utilization among CARE customers who died within 182 days of the CARE assessment. To estimate which of the 566 deceased individuals in our study population would have been eligible to receive hospice services, we applied standard criteria for hospice appropriateness (payer source, diagnosis, rejection of aggressive treatment) in a sequential procedure (see diagram below). For a complete description of the estimation process, see Appendix C.

Diagram 1: Step-wise Methodology to Confirm Hospice Eligibility

566 deceased CARE customers who died within 6 months of CARE Assessment

6 customers younger than 65; Sample reduced to 560

44 customers had neither Medicaid nor Medicare; Sample reduced to 516

85 customers did not have Hospice-qualifying diagnoses; Sample reduced to 431

157 confirmed hospice recipients; HOSPICE SAMPLE=157

274 confirmed non-hospice recipients; NON HOSPICE SAMPLE=274

28 customers receiving hospice at time of CARE assessment; Sample reduced to 129

3 customers receiving aggressive treatments; Sample reduced to 271

129 confirmed hospice recipients who received hospice services post CARE assessment (32%)

271 non-hospice individuals eligible due to proxy who did not receive aggressive treatment (68%)

Total Sample for Study: n=400 (129 hospice/271 non hospice recipients)
This process gave us a group of customers whom we could consider as “hospice eligible”. Then, we determined the actual utilization rate of either Medicare or Medicaid hospice services. We divided the hospice eligible customers according to who actually used hospice services and who did not. The utilization rate (32%) was calculated by dividing the number of hospice users (129) by the total number of hospice eligible (400).

Two additional steps were taken to validate the determination of hospice eligibility. First, we examined Activities of Daily Living (ADL) scores. ADL scores can range from independent functioning to total dependence on others. Among hospice users (n=129), the ADL mean score was 17.01 and among the non-hospice group (n=271) the ADL mean score was 16.57. Looking specifically at Medicaid recipients, their ADL mean scores were also very similar. The Medicaid hospice group (n=22) had a score of 16.45 and the Medicaid non-hospice group (n=61) had a score of 16.43. T-tests showed no significant differences. This suggests that both the hospice and non-hospice deceased customers were similar in functional impairment. We also looked for confirmation of hospice eligibility by determining customer’s end stage disease status. However, the MDS and OASIS data showed so few end stage classifications that we determined these data to be unreliable on this measure. Appendix C contains a detailed account of our literature review of issues related to barriers to determining hospice eligibility.

Based on our procedures for determining hospice eligibility, we identified 400 deceased customers as having been hospice eligible. Of these 129 were determined to be hospice recipients and 271 non-hospice customers.

Comparing Hospice and Non-Hospice Users

The second stage of our methodology was an investigation of the factors that distinguished eligible customers who used hospice from those who did not. This analysis was comprised of a statistical comparison of hospice and non-hospice groups on the basis of selected demographic, environmental, social and health status factors (see Appendix A). The analyses that we conducted included descriptive statistics, t-tests, and chi-square tests. Significance levels were reported if they were at .05 level or below.

Cost Benefit Analysis

This analysis was conducted to compare actual hospice costs on variables we defined as “high cost health care”. These variables are hospitalization costs and emergency room costs. The data from Medicare also listed the actual costs of the hospice services and we reported the mean as well as ranges. Since we did not have the actual costs for the non-hospice group, we examined national data from Medicare (CMS) to provide a comparison set.

A). Findings: Comparison of Hospice and Non-Hospice Customers

1). Demographic Variables and Living Arrangements

   Ethnicity, Gender, Age, and Urban/Rural Classification

The hospice and non-hospice samples have many similarities. These samples are very homogeneous in regard to ethnicity. Both samples are predominantly white (95%) and both have
4-5% persons of African-American or Hispanic origin. They are not significantly different in regard to gender (both samples have 59% female customers). Age is significantly different between the hospice and non-hospice groups but both groups are relatively old and have similar age ranges. The mean age of the hospice group is 82.8 years and ages range from 66-98; the non-hospice groups mean age is 85.16 and a range from 65-102. The non-hospice group is actually older and both groups are similarly impaired (based on ADL scores). Some discrepancies are evident between these two groups. The hospice group is less likely to live alone and less likely to live in a rural area. Table 1 summarizes these demographic characteristics.

### Table 1: Demographic Characteristics of Hospice and Non-Hospice Customers (N=400)

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Hospice (n=129)</th>
<th>Non-Hospice (n=271)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number (%)</td>
<td>Number (%)</td>
</tr>
<tr>
<td><strong>Age (years)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>65 to 74</td>
<td>18 (14.0%)</td>
<td>20 (7.4%)</td>
</tr>
<tr>
<td>75 to 84</td>
<td>54 (41.9%)</td>
<td>98 (36.2%)</td>
</tr>
<tr>
<td>85 &amp; older</td>
<td>57 (44.2%)</td>
<td>153 (56.5%)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>51 (39.5%)</td>
<td>110 (40.6%)</td>
</tr>
<tr>
<td>Female</td>
<td>77 (59.7%)</td>
<td>161 (59.4%)</td>
</tr>
<tr>
<td>Missing</td>
<td>1 (.8%)</td>
<td>0 (.0%)</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>124 (96.1%)</td>
<td>156 (94.5%)</td>
</tr>
<tr>
<td>African American</td>
<td>4 (.3%)</td>
<td>14 (5.2%)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>1 (.8%)</td>
<td>1 (.4%)</td>
</tr>
<tr>
<td><strong>Living Arrangements</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lived alone</td>
<td>47 (36.4%)</td>
<td>132 (48.7%)</td>
</tr>
<tr>
<td>Did not live alone</td>
<td>82 (63.6%)</td>
<td>138 (50.9%)</td>
</tr>
<tr>
<td>Missing</td>
<td></td>
<td>1 (.4%)</td>
</tr>
<tr>
<td><strong>Urban Rural Classification</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urban counties:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Metro or county with 250,000 or more</td>
<td>68 (52.7%)</td>
<td>115 (44.0%)</td>
</tr>
<tr>
<td>County with 20,000 to 250,000</td>
<td>32 (24.8%)</td>
<td>60 (22.9%)</td>
</tr>
<tr>
<td>Rural Counties:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>County with 2,500 to 20,000</td>
<td>19 (14.7%)</td>
<td>67 (25.6%)</td>
</tr>
<tr>
<td>County with 2,500 or less</td>
<td>10 (7.7%)</td>
<td>19 (7.2%)</td>
</tr>
</tbody>
</table>

Further analysis indicated:

- Among people in the non-hospice group there was a slightly higher percentage of people that did not live alone. However, among all the people who lived alone a much higher percent (74%) did not use hospice. This may indicate that living alone could be a barrier
to hospice use. If a person is ill and possibly socially isolated, they may find it harder to advocate for themselves or even inquire about possible service options.

- Among people who lived in urban counties there were a higher proportion of people who received hospice services. Thirty-six percent of people in urban areas **did use** hospice services compared to a 25% hospice utilization rate of the rural sample. The discrepancy in the proportion of hospice users among urban and rural areas raises a question of availability/access to hospice services in rural areas.

**Medicaid**

Incidence of hospice use among Medicaid recipients is important due to potential savings to the Medicaid program. Therefore, we analyzed hospice utilization among Medicaid recipients in our sample. There are 83 (21%) Medicaid customers in our sample, 22 used hospice and 61 did not. The hospice utilization rate although lower for Medicaid recipients (26.5%) is not statistically significant when compared to the non-Medicaid utilization rate (30.3%).

Hospice cost savings are possible both with community-based and nursing facility residents. For individuals living in the community, hospice covers all personal visits (nursing, home health, social worker, chaplain and auxiliary therapies), prescription drugs, and supplies and equipment related to comfort care. Hospice services could impact this group either by reducing the costs of the nursing facility care, or even preventing entrance into the nursing facility by providing more care in the home. Although hospice care is not continuous, 24-hour care, hospice workers often visit daily and have 24-hour on-call services which may allow a person to stay at home.

Medicaid costs for nursing facilities are high because they cover facility room/board and care, prescription drugs, medical supplies, and durable medical equipment needs. Although hospice services would not impact the facility costs, hospice Medicare benefits cover at 100% the above listed costs related to keeping them comfortable and to their primary diagnosis. The Medicaid program would experience cost savings through the utilization of hospice with both the community-based and nursing facility-based recipients, since these costs would be covered by Medicare.

Overall, Medicaid receipt was disproportionately concentrated in the non-hospice, non-diverted (nursing facility) group. Table 2 displays the utilization of hospice services according to Medicaid status. The table shows that people who were receiving Medicaid were **less likely** to receive hospice services than those not on Medicaid. The diversion rate for the customers in our sample who received Medicaid is only 8% compared to a 17% diversion rate of those who received Medicaid in the Longitudinal Study of Customers Diverted through the CARE Program (Chapin et al, 2001). Therefore, in our study Medicaid customers who were potentially hospice eligible were more likely to be in nursing facilities. Ninety-two percent of those who received Medicaid in our sample were non-diverted. Potential cost savings to the Medicaid program could be accrued if those non-diverted customers as well as diverted (community) customers had received hospice services.
Table 2: Hospice Utilization Among Medicaid and Non-Medicaid Customers (n=383)*

<table>
<thead>
<tr>
<th></th>
<th>Hospice n=113 (29.5%)</th>
<th>Non-Hospice n=270 (70.4%)</th>
<th>Total n=383 (100%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicaid</td>
<td>22 (26.5%)</td>
<td>61 (73.5%)</td>
<td>83 (100%)</td>
</tr>
<tr>
<td>Non-Medicaid</td>
<td>91 (30.3%)</td>
<td>209 (69.72%)</td>
<td>300 (100%)</td>
</tr>
</tbody>
</table>

*17 missing data as to Medicaid status.

Demographic information of the Medicaid recipients also shows a predominantly white sample with 11% of the Medicaid recipients African-American. None of the Hispanic customers were Medicaid recipients. The Medicaid recipients were also similar in age. Medicaid recipients were more likely to be female and to live alone than the non-Medicaid recipients. Moreover, in comparing the hospice and non-hospice sample, only one African-American person was a hospice recipient. The non-hospice recipients were younger; and women were more likely to have received hospice services. Table 3 summarizes the demographic information of the Medicaid recipients.

Table 3: Demographic Characteristics of Medicaid Hospice and Non-Hospice Customers (n=83)

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Hospice (n=22)</th>
<th>Non-Hospice (n=61)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (years)</strong></td>
<td>Number (%)</td>
<td>Number (%)</td>
</tr>
<tr>
<td>65 to 74</td>
<td>2 9.1%</td>
<td>7 11.5%</td>
</tr>
<tr>
<td>75 to 84</td>
<td>10 45.5%</td>
<td>24 39.3%</td>
</tr>
<tr>
<td>85 &amp; older</td>
<td>10 45.5%</td>
<td>30 49.2%</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td>Number (%)</td>
<td>Number (%)</td>
</tr>
<tr>
<td>Male</td>
<td>4 18.2%</td>
<td>20 32.8%</td>
</tr>
<tr>
<td>Female</td>
<td>18 81.8%</td>
<td>41 67.2%</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td>Number (%)</td>
<td>Number (%)</td>
</tr>
<tr>
<td>White</td>
<td>21 95.5%</td>
<td>53 86.9%</td>
</tr>
<tr>
<td>African American</td>
<td>1 4.5%</td>
<td>8 13.1%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>0 0%</td>
<td>0 0%</td>
</tr>
<tr>
<td><strong>Living Arrangements</strong></td>
<td>Number (%)</td>
<td>Number (%)</td>
</tr>
<tr>
<td>Lived alone</td>
<td>11 50%</td>
<td>32 52.5%</td>
</tr>
<tr>
<td>Did not live alone</td>
<td>11 50%</td>
<td>29 47.5%</td>
</tr>
</tbody>
</table>

We also examined hospice receipt and whether their type of community (urban or rural) had a differential impact on Medicaid receipt. When considering hospice utilization among Medicaid recipients, there is a lower utilization rate among those living in urban counties compared to rural counties. This suggests that Medicaid recipients, particularly in urban settings, may not have the same access/availability to hospice services as those individuals who do not receive Medicaid. Table 4 displays these findings.
Table 4: Hospice Utilization Among Urban/Rural Medicaid Customers (n=80)*

<table>
<thead>
<tr>
<th>Rurality</th>
<th>Medicaid Hospice</th>
<th>Medicaid Non-Hospice</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n=22 (27.5%)</td>
<td>n=58 (72.5%)</td>
<td>n=80 (100%)</td>
</tr>
<tr>
<td>Urban Counties:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>metro or county with 20,000 or more</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rural Counties:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>county with 20,000 or less</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>13 (25.5%)</td>
<td>38 (74.5%)</td>
<td>51 (100%)</td>
</tr>
<tr>
<td></td>
<td>9 (31.0%)</td>
<td>20 (69.0%)</td>
<td>29 (100%)</td>
</tr>
</tbody>
</table>

*3 missing

2). Hospice Length of Stay

Length of stay is important for two key reasons: timeliness of referrals (are people referred very late in their dying process?); and ability to deliver good end-of-life care (can good end of life care occur in very short stays?). According to Lamont & Christakis (2002), physicians believe that patients should receive hospice care for at least 3 months before death, but most only receive care for 1 month; thus, hospice services are often underutilized due to a short average length of stay. We examined the entire sample of hospice recipients and calculated their length of stay. Although our sample was truncated (we only looked at those people who died within 182 days of the CARE assessment), we found that the sample mean length of stay was 30.16 days with a range of 1-163 days and with a median length of stay to be 18 days. Because of an average length of stay of one month, our findings suggest that hospice services were being underutilized in our sample.

3.) Hospice Use by AAA region

We analyzed hospice use by AAA region. The number of hospice recipients in each AAA region ranges from 1 to 27 hospice recipients. Table 5 displays the location of hospice recipients by AAA region. Of the regions that encompass the urban counties, Region 11 (Johnson County) had the highest proportion of hospice recipients (57.4%). If all AAA regions with an urban county component (Regions 1,2,4,11) were combined, 63% of the hospice recipients would be in these regions. Of the more rural AAAs, Region 9 stands out with a higher proportion (47%) of hospice recipients than the other rural AAAs.
Table 5: Hospice Use and AAA Region (n=400)

<table>
<thead>
<tr>
<th>AAA Region</th>
<th>Hospice (n=129)</th>
<th>Total (n=400)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Wyandotte/Leavenworth</td>
<td>14 (40%)</td>
<td>35 (100%)</td>
</tr>
<tr>
<td>2. Central Plains</td>
<td>26 (25.7%)</td>
<td>101 (100%)</td>
</tr>
<tr>
<td>3. Northwest Kansas</td>
<td>4 (23.5%)</td>
<td>17 (100%)</td>
</tr>
<tr>
<td>4. Jayhawk</td>
<td>14 (42.4%)</td>
<td>33 (100%)</td>
</tr>
<tr>
<td>5. Southeast Kansas</td>
<td>6 (33.3%)</td>
<td>18 (100%)</td>
</tr>
<tr>
<td>6. Southwest Kansas</td>
<td>2 (8.3%)</td>
<td>24 (100%)</td>
</tr>
<tr>
<td>7. East Central Kansas</td>
<td>1 (12.5%)</td>
<td>8 (100%)</td>
</tr>
<tr>
<td>8. North Central/Flint Hills</td>
<td>19 (26.7%)</td>
<td>71 (100%)</td>
</tr>
<tr>
<td>9. Northeast Kansas</td>
<td>8 (47%)</td>
<td>17 (100%)</td>
</tr>
<tr>
<td>10. South Central Kansas</td>
<td>8 (29.6%)</td>
<td>29 (100%)</td>
</tr>
<tr>
<td>11. Johnson County</td>
<td>27 (57.4%)</td>
<td>47 (100%)</td>
</tr>
</tbody>
</table>

4). Medical and Advance Planning Variables

Diagnoses

Diagnoses are critical in determining eligibility for hospice and were a key factor in our stepwise methodology to obtain our eligible sample. We used diagnostic information from all of our sources to confirm eligibility for the study. All of the diagnoses below are potentially end-stage diseases with terminal prognoses. However, we identify the incidence of particular diagnoses and compared them with primary diagnoses for hospice. We also explored the number of diagnoses in order to further investigate the functional disability level of our sample.

National information (CDC, November 7, 2003) has confirmed that the top six diseases that resulted in death for people over 65 are heart disease, cancers, stroke, lung disease (COPD and pneumonia), and diabetes. Our data mirror the national prevalence of these diseases. Within hospice, cancer is and has been the most common disease category (NHPCO, 2002). This is because cancer has a preponderance of data on prognoses and dying trajectories, allowing the physician to clearly substantiate their hospice referral. With non-cancer diagnoses, estimating the length of time a person has left to live is less straightforward. Although non-cancer diseases do have hospice guidelines for qualification, many studies have demonstrated that non-cancer diagnoses are less likely to be referred to hospice (Potter et al, 2003). Our study also confirms this trend. An analysis of the categories of diagnoses found the following to be most prevalent among the entire sample:

- Heart disease (59.8%)
- Diabetes (27.2%)
- Cancer (25.8%)
- COPD (22.2%)
- Renal failure (11.5%)
- Alzheimer’s (9.9%)
- Parkinson’s (3.9%)
- Stroke (17.8%)

We examined the primary diagnosis among the hospice sample in order to determine if a cancer diagnosis was the top disease category for our sample similar to national findings. Although it is not the most prevalent for the entire sample, cancer diagnoses are confirmed to be prevalent in the hospice group. In addition, the other diagnoses are dramatically missing or lessened in the hospice primary diagnoses category. The lack of validation of hospice eligibility
for non-cancer diagnoses acts as a barrier. This reflects issues with both physician awareness and awareness in the general population that hospice is available for people with non-cancer illnesses (Christakis, & Lamont, 2000). Table 6 displays the predominance of cancer diagnoses in our hospice sample.

Table 6: Primary Diagnosis Categories Among Hospice Customers (n=129)

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Hospice (n=129)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heart</td>
<td>20 (15.6%)</td>
</tr>
<tr>
<td>Cancer</td>
<td>73 (56.2%**)</td>
</tr>
<tr>
<td>COPD</td>
<td>14 (10.9%)</td>
</tr>
<tr>
<td>Diabetes</td>
<td>Not listed</td>
</tr>
<tr>
<td>Stroke</td>
<td>6 (4.7%)</td>
</tr>
<tr>
<td>Renal failure</td>
<td>6 (4.7%)</td>
</tr>
<tr>
<td>Alzheimer’s</td>
<td>8 (6.3%)</td>
</tr>
<tr>
<td>Parkinson’s</td>
<td>Not listed</td>
</tr>
<tr>
<td>Other</td>
<td>2 (1.6%)</td>
</tr>
</tbody>
</table>

**42.9% represents the confirmed cancer diagnoses and 13.3% represented unconfirmed masses that are believed to be cancer but have not been biopsied. Many times the mass is known to be cancer by other tests and physician expertise but not biopsied.

Diagnoses categories are important to policy makers in prioritizing educational efforts. Non-cancer diagnoses may not be seen as appropriate for hospice services by consumers. Health care professionals may not be aware of the non-cancer eligibility criteria. In addition, health care professionals may be reluctant to refer people with non-cancer diagnoses due to poor prognosis data. Efforts to encourage better understanding of hospice eligibility and non-cancer diagnoses can reduce barriers to accessing services.

**Multidiagnoses**

Next, we examined the occurrence of multiple diagnoses among hospice customers. We found that in both the hospice and non-hospice group, at least one-half of the customers had two or more serious diagnoses. Table 7 records the incidence of multidiagnoses for the sample. Many of these serious diagnoses are correlated with one another. For example, COPD (chronic obstructive pulmonary disease) negatively impacts heart functioning and can result in congestive heart failure and other heart problems. Also diabetes can result in renal failure. Yet, in comparing the two groups, the non-hospice group unexpectedly had more multiple serious diagnoses than the hospice group. In performing a t-test, this difference proved to be significant at the .002 level. This could be explained in that hospice only needs one primary diagnosis for enrollment and co-morbidities may be coded less often. Another possible explanation is the high incidence of cancer recorded in hospice patients may not be associated with other serious diseases.
Table 7: Number of Diagnoses among Hospice and Non-Hospice Customers (n=399)*

<table>
<thead>
<tr>
<th>Number of Diagnosis</th>
<th>Hospice (n=129)</th>
<th>Non-Hospice (n=270)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>60 (46.5%)</td>
<td>102 (37.8%)</td>
</tr>
<tr>
<td>2</td>
<td>38 (29.5%)</td>
<td>84 (31.1%)</td>
</tr>
<tr>
<td>3</td>
<td>23 (17.8%)</td>
<td>54 (20.0%)</td>
</tr>
<tr>
<td>4</td>
<td>7 (5.4%)</td>
<td>27 (10.0%)</td>
</tr>
<tr>
<td>5</td>
<td>1 (0.8%)</td>
<td>3 (1.1%)</td>
</tr>
</tbody>
</table>

*1 missing

Table 8 describes the differences between the numbers of diagnoses among Medicaid customers. Hospice Medicaid customers were less likely to have just one diagnosis and non-hospice customers were more likely to have only one diagnosis. When comparing tables 7 and 8, it appears that the Medicaid hospice customers may be sicker than the non-Medicaid hospice group and Medicaid non-hospice customers may be less sick than the non-Medicaid non-hospice group. This might suggest disparities in Medicaid recipient’s access to and availability of hospice services.

Table 8: Number of Diagnoses among Medicaid Hospice and Non-Hospice Customers (n=83)

<table>
<thead>
<tr>
<th>Number of Diagnosis</th>
<th>Hospice (n=22)</th>
<th>Non-Hospice (n=61)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>6 (27.3%)</td>
<td>29 (47.5%)</td>
</tr>
<tr>
<td>2</td>
<td>9 (40.9%)</td>
<td>14 (22.9%)</td>
</tr>
<tr>
<td>3</td>
<td>5 (22.7%)</td>
<td>13 (21.3%)</td>
</tr>
<tr>
<td>4</td>
<td>2 (9.1%)</td>
<td>5 (8.2%)</td>
</tr>
</tbody>
</table>

Role of Aggressive Treatment

Another important factor to consider is the use of aggressive treatment with particular diseases and its impact on hospice eligibility. Hospice care and aggressive treatment are mutually exclusive. With some diseases aggressive treatment is more likely. For example, the first interventions for stroke are aggressive in nature; dialysis is routinely offered in renal failure. Furthermore, some cancers have more aggressive treatment options than others. Consequently, a consumer’s choice to pursue aggressive treatments might impact the choice of hospice. From the databases that we examined, only two variables indicate that aggressive treatment was used (rehabilitation and chemotherapy). Few members of our sample were coded as using either of these treatments (we deleted 3 non-hospice persons that had chemotherapy and 2 hospice persons received chemotherapy at one time; no one received rehabilitation). However, we were not able to measure the influence of patient choice on pursuing aggressive treatment with our present data sources.

In summary, the differences between the two groups, hospice and non-hospice, are evident in regard to diagnoses and reflect the known predominance of cancer diagnoses in hospice patients. The incidence of multidiagnoses confirms once again that this population is very ill whether in hospice or not. In fact, on face value the non-hospice group appears to be
“sicker” than the hospice group and the Medicaid hospice population appeared to be “sicker” than the non-Medicaid sample.

**Advanced Planning Activities**

Advanced planning activities are important to consider because they indicate active plans for future care involving self-determination and exercise of choice. Hospice is also an exercise of choice and therefore it is important to examine the incidence of plans for end-of-life care. Advance planning documents are also correlated with decreased high cost health care (hospitalizations, aggressive treatments, and ER visits). If personal choices as to unwanted care are specified, then costs are contained and personal self-determination is honored. Therefore, we operationally defined these activities as having a **financial will**, a **durable power of attorney for health care decisions** (DPOA), a “**living will**”, a “**do not resuscitate**” order (DNR), and a “**do not hospitalize**” order (DNH). These variables are coded in the original CARE assessment, in the MDS database, and/or in the OASIS database.

National averages report that 20% of adults have completed advanced directives (Jenner, Ryndes, D’Onofrio, Baily, 2003a). But even those that are seriously ill do not complete advanced directives at a higher rate than the general population (NHPCO, 2000). In looking at financial wills and DPOAs both the hospice and the non-hospice groups at the time of the CARE assessment had higher than national averages for this end-of-life planning activity.

One explanation for Kansas’ high rate of advanced planning activities may be connected with the medical history of our sample. We know that 96% of our entire sample had some stay in a nursing facility. Therefore these customers would have been exposed to social workers who encouraged or facilitated completing advanced planning documents. This stay may have spurred individuals to complete these documents and account for our higher than expected findings for the overall group. Although the Kansans in our sample had a higher completion rate than national averages, neither group had above a 46% completion rate which indicates a need for more education, more culturally sensitive documents, and more efforts to encourage people to make their wishes known are evident.

We expected to see more planning activities for the hospice group and were surprised when this was not found. Our hospice recipients were not predisposed to advance planning, since they seem to have not completed advanced directives as often as their non-hospice counterparts. At least at the time of the CARE assessment these differences in planning styles seem to be evident.

In looking strictly at the Medicaid recipients, however, we do see that both hospice and non-hospice recipients are planning less for their health care decisions but are planning at the same rate as the rest of the sample population for financial decisions (see Table 9).
Table 9: Legal Planning and Health Care Directive Documents among Hospice and Non-Hospice Customers (n=400)

<table>
<thead>
<tr>
<th></th>
<th>Hospice(n=129)</th>
<th>Non-Hospice(n=271)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Medicaid (22)</td>
<td>Non-Medicaid (107)</td>
</tr>
<tr>
<td>Financial will</td>
<td>8 (36.4%)</td>
<td>40 (37.4%)</td>
</tr>
<tr>
<td>DPOA</td>
<td>7 (31.8%)</td>
<td>37 (34.6%)</td>
</tr>
</tbody>
</table>

Medicaid recipients are completing DPOAs less frequently than those not receiving Medicaid. When the ethnicity of the Medicaid recipients was examined, it was revealed that none of the African-American persons had completed a health care directive. The reluctance for persons of African-American heritage to complete health care advanced directives is well-documented (Last Acts, 2000). Culturally sensitive discussions and advanced directives documents have been advocated as a way to address this difference.

Additional findings regarding DNRs (do not resuscitate orders), provide further evidence that this sample was hospice eligible on the basis of consumer choice. With regard to DNRs, the MDS data set reported that 58.9% of the hospice group and 57.2% of the non-hospice group had completed DNRs. This is very interesting in that DNRs can be seen as not only an exercise in patient self-determination but also a risk management tool for health care facilities and personnel. The high incidence of DNRs in the non-hospice group relates to some awareness of the seriousness of their illness and their choice of no CPR treatment. As discussed earlier choosing palliative over aggressive care is necessary for hospice eligibility. Furthermore, both the hospice and non-hospice groups have similar percentages of completing DNRs supporting the idea that these groups are very similar. This finding offers further evidence that this population was hospice eligible on the basis of choice. Lastly, according to the MDS data no customer had a DNH (do not hospitalize) order. See Appendix D for more information on the lack of DNH orders in our sample.

In summary, our population appears to have made some advanced planning decisions at a higher rate than national averages. Studies have confirmed that ill persons and their families do wish to advance plan and are increasingly more proactive in starting the conversations concerning end-of-life care (Steinhauser et al, 2002; Pierce, 1999). Other studies have also reported the reluctance of health care professionals to address advanced planning (SUPPORT, 1995; Christakis & Iwashyna, 1998). Advanced planning can begin to engage consumers in the process of considering their wants and wishes for end-of-life care. Hospice utilization can be impacted if this process occurs. If professionals are reluctant to assist consumers in this process then it becomes a barrier to hospice use.

5.) Social Support

The impact of social support on hospice use can be seen as either an incentive (families seeing hospice as a “help”) or as a barrier (consumers believing social support is a hospice prerequisite). Therefore, how the two hospice groups differed on this variable was important. At one time, the hospice benefit required that patients name a “primary care giver” (PCG) as a contact resource for hospice personnel. However, this requirement no longer exists and many are not aware of this change. Currently if a hospice recipient does not have a designated
primary caregiver, they agree to work with the hospice to formulate a plan of action when they become unable to care for themselves. By looking at social support we can see if there are any differences between our two groups. Consequently, we considered the data from the CARE assessment that recorded the answers to questions about reported social support and living arrangements. See Appendix E for a complete copy of the CARE assessment.

Our findings showed that the hospice group had more reported social support and were less likely to live alone (refer to Table 1 for living arrangements). Medicaid recipients had roughly the same percentages of people reporting full-time support and living alone as non-Medicaid consumers (see Table 10).

**Table 10: Social Support among Hospice and Non-Hospice Customers (n=399)**

<table>
<thead>
<tr>
<th>Social Support</th>
<th>Hospice (n=129)</th>
<th>Non-Medicaid (107)</th>
<th>Non-Hospice (n=271)</th>
<th>Non-Medicaid (210)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Medicaid (22)</td>
<td>Medicaid (61)</td>
<td>Medicaid (61)</td>
<td>Medicaid (61)</td>
</tr>
<tr>
<td>Full-time</td>
<td>9 (40.9%)</td>
<td>40 (37.7%)</td>
<td>17 (27.9%)</td>
<td>69 (32.9%)</td>
</tr>
<tr>
<td>Less than full time</td>
<td>13 (59.1%)</td>
<td>66 (62.3%)</td>
<td>44 (72.1%)</td>
<td>141 (67.1%)</td>
</tr>
<tr>
<td>Total</td>
<td>22 (100%)</td>
<td>106 (100%)</td>
<td>61 (100%)</td>
<td>210 (100%)</td>
</tr>
</tbody>
</table>

Lack of full-time social support and/or living alone may reflect another barrier to hospice. This barrier may be associated with lack of awareness of hospice PCG requirements, lack of advocates for the ill person to receive hospice care, or general social isolation. However, some discrepancies may be due to the small sample size for our Medicaid customers in comparison to the non-Medicaid group.

B.) Cost Benefit Analysis

1). Hospitalizations and Emergency Room Visits

The next analysis we conducted was to examine the number of hospitalizations and emergency room (ER) visits for hospice and non-hospice customers. These hospital visits are considered high cost health care services. It is presumed that the use of hospice services would lower the number of ER visits and hospitalizations and therefore result in lower costs for the hospice group.

**Hospital Utilization and ER Visits of a Typical Hospice Customer**

The typical customer in our hospice sample enrolled in hospice services 44 days after the CARE Assessment. They lived for 30 days from the time they enrolled in hospice until their death. During the 45 days prior to the CARE Assessment until the time they enrolled in hospice they had approximately 1 hospital visit. After they enrolled in hospice they typically had less than 1 hospital visit prior to their death.
During the 45 days prior to the CARE Assessment and until the time they enrolled in hospice they had, on average, less than one ER visit. After they enrolled in hospice they typically had no ER visits until their death.

Average actual costs for hospice care for a customer in our sample totaled $2906.42 (costs ranged from $101.37 to $16,552.94). Average actual costs for hospice care for a Medicaid recipient in our sample was $2470.01 (costs ranged from $201.74 to $12,854.99).*

*Data obtained from the Hospice Standard Analytic File (Medicare).

For both the hospice and non-hospice group we counted ER and hospital visits from the time frame of 45 days before the CARE Assessment to the time until the customer’s death. For the hospice group we divided this time period into: 1) 45 days before the CARE Assessment plus the number of days until they enrolled in hospice; and 2) the number of days from the date of hospice enrollment until death. This enabled us to compare the number of ER visits and hospitalizations for the hospice group pre and post hospice utilization as well as to the non-hospice group. In order for these comparisons to be valid, we also adjusted to remove differences in the length of time that the hospice and non-hospice customers were observed. This standardization procedure is discussed below.

The data for ER and hospital visits came from the MDS assessment. The question on the MDS collects the number of hospital and ER visits in the last 90 days or since the most recent MDS assessment. Therefore, there are some caveats when considering these data. First, the number of visits for the sample may be overestimated since the look back period of the question may extend prior to when our timeframe began (45 days before the CARE Assessment). Second, capturing visits that occurred after enrollment in hospice took place was difficult since the MDS data do not provide actual dates of hospital and ER visits. We only counted the visits we could be sure occurred after the hospice enrollment date (i.e. if there were 2 MDS assessments completed after the hospice enrollment or if 90 days had passed from the date of hospice enrollment until the MDS Assessment was completed). Finally, for the full sample there may be hospital and ER visits that we did not capture because they took place between the most recent MDS Assessment and the date of death. However, it is possible to use the data to give a very rough estimate of hospital and ER visits for the hospice and non-hospice groups. Because our findings are consistent with national studies that show a decline in hospital and ER use after hospice enrollment, we can say that our data suggests hospice enrollment in Kansas also results in a reduction of hospitalizations and ER visits.

The following table displays the number of hospitalizations and ER visits in our sample. The table displays both the number of visits per group and the rate of visits per 1,000 person days. Person days was used as the denominator in these rates in order to standardize them, thereby removing the effects of the fact that customers in this study were observed for hospital and ER visits over varying lengths of time. Since each group has a different number of persons and varying numbers of days of observation, we calculated our standard denominator by multiplying the number of persons observed by the number of days of observation. Then we multiplied by 1,000 to produce rates (per 1,000 person days) that could be more easily read (i.e. eliminating tiny fractions).
As Table 11 shows, the number and rates of ER and hospital visits decreased substantially in the hospice group after enrollment (from 11.7 to 1.5 visits per 1,000 person days). Further, there was also a substantial difference between the hospital utilization rates of customers enrolled in hospice and non-hospice customers (1.5 versus 8.9 visits per 1,000 person days). Similarly, in terms of the number and rates of ER visits, the post-hospice group had considerably fewer visits than the non-hospice group (0.3 versus 2.5 visits per 1,000 person days).

Table 11: Number and Rates of Hospital and ER Visits by Hospice and Non-Hospice Customers

<table>
<thead>
<tr>
<th></th>
<th>Hospice (n=113)</th>
<th>Non-Hospice (n=270)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Before Enrollment</td>
<td>After Enrollment</td>
</tr>
<tr>
<td>Rate of Hospital visits/1000 person days (number of visits)</td>
<td>11.7 (130)</td>
<td>1.5 (5)</td>
</tr>
<tr>
<td>Rate of ER visits/1000 person days (number of visits)</td>
<td>1.8 (20)</td>
<td>0.3 (1)</td>
</tr>
</tbody>
</table>

In analyzing the ER and hospitalization visits, we found that the hospice group before they enrolled in hospice was using ER at a lower rate than the non-hospice group, but was using hospitalizations slightly more. This could reflect many different things. One possibility is that this group even before enrolling in hospice was less likely to seek some aggressive treatments (ER). That would also dovetail well into a palliative care treatment mode that hospice affords. However, once hospice was involved it appears that these high costs health care treatments decreased within the hospice group as well as in comparison to the non-hospice group.

Medicaid customers who utilized hospice also showed a decrease in both the absolute number and in the utilization rates of hospital and ER visits after hospice enrollment compared to the pre-enrollment period and compared to non-hospice users. (see Table 12.)

Table 12: Number and Rates of Hospital and ER Visits by Medicaid Hospice and Non-Hospice Customers

<table>
<thead>
<tr>
<th></th>
<th>Hospice (n=22)</th>
<th>Non-Hospice (n=61)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Before Enrollment</td>
<td>After Enrollment</td>
</tr>
<tr>
<td>Rate of Hospital visits/1000 person days (number of visits)</td>
<td>9.7 (21)</td>
<td>1.5 (1)</td>
</tr>
<tr>
<td>Rate of ER visits/1000 person days (number of visits)</td>
<td>9.7 (21)</td>
<td>1.5 (1)</td>
</tr>
</tbody>
</table>
2). Costs Associated with Emergency Room and Hospital Visits

It is clear that there are cost savings that can be accrued through utilizing hospice and avoiding ER and hospital visits. Our databases could not supply cost data on emergency room or hospital visits or on the average hospital length of stay. Therefore, the following national data were used in our analyses:

- **Average Cost of Emergency Room Visit:** According to the National Healthcare Disparities Report in 2003 the average cost of an ER visit for someone 65 and older is $687.

- **Average Cost of Hospital Visit:** The average cost of a hospital visit is $22,955 per stay and the average length of stay is 5.7 days (American Hospital Assoc., 2003).

We applied the national averages to the data from our sample and computed the estimated savings under the assumption that half of the potentially eligible customers would have used hospice services and avoided one ER and one hospital visit. Our sample was based on four months of CARE Assessments. Therefore, we extrapolated these figures to give an idea of the annual savings if half of the potentially eligible customers in a year would have used hospice services and avoided one ER and one hospital stay. Tables 13 and 14 below display these calculations.

**Table 13: Potential Cost Savings through Using Hospice Services and Avoiding Emergency Room Visits**

<table>
<thead>
<tr>
<th>(A) Half of the Non-Hospice Group (270 divided by 2)</th>
<th>(B) Number of ER Visits Avoided</th>
<th>(C) Average Cost of ER Visit*</th>
<th>(D) Total Cost of ER Visits Avoided (Multiply Columns B &amp; C)</th>
<th>(E) Total Cost of ER Visits Avoided (Multiply Column D by 3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>135</td>
<td>135</td>
<td>$687</td>
<td>$92,745</td>
<td>$278,235</td>
</tr>
</tbody>
</table>


**Table 14: Potential Cost Savings through Using Hospice Services and Avoiding Hospital Stays**

<table>
<thead>
<tr>
<th>(A) Half of the Non-Hospice Group (270 divided by 2)</th>
<th>(B) Number of Hospital Stays Avoided</th>
<th>(C) Average Cost of Hospital Stay*</th>
<th>(D) Total Cost of Hospital Stays Avoided (Multiply Columns B &amp; C)</th>
<th>(E) Total Cost of ER Visits Avoided (Multiply Column D by 3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>135</td>
<td>135</td>
<td>$22,955</td>
<td>$3,098,925</td>
<td>$9,296,775</td>
</tr>
</tbody>
</table>

*American Hospital Association, 2003
The potential annual cost savings through utilizing hospice and avoiding one ER visit would be $278,235.

The potential annual cost savings through utilizing hospice and avoiding one hospital stay would be $9,296,775.

Since the Medicaid group was utilizing hospice services at an even lower rate (26.5%) compared to the overall sample (32%), we applied the national averages to the Medicaid group in the same way as calculated above. Again, we extrapolated these figures to give an idea of the annual savings if half of the potentially hospice eligible Medicaid customers in a year would have used hospice services and avoided one ER and one hospital stay. Tables 15 and 16 display these calculations.

Table 15: Potential Cost Savings through Using Hospice Services and Avoiding Emergency Room Visits among Medicaid Customers

<table>
<thead>
<tr>
<th>(A) Half of the Non-Hospice Group (61 divided by 2)</th>
<th>(B) Number of ER Visits Avoided</th>
<th>(C) Average Cost of ER Visit*</th>
<th>(D) Total Cost of ER Visits Avoided (Multiply Columns B &amp; C)</th>
<th>(E) Total Annual Cost of ER Visits Avoided (Multiply Column D by 3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>30.5</td>
<td>30.5</td>
<td>$687</td>
<td>$20,953.50</td>
<td>$62,860.50</td>
</tr>
</tbody>
</table>


Table 16: Potential Cost Savings through Using Hospice Services and Avoiding Hospital Stays among Medicaid Customers

<table>
<thead>
<tr>
<th>(A) Half of the Non-Hospice Group (61 divided by 2)</th>
<th>(B) Number of Hospital Stays Avoided</th>
<th>(C) Average Cost of Hospital Stay*</th>
<th>(D) Total Cost of Hospital Stays Avoided (Multiply Columns B &amp; C)</th>
<th>(E) Total Annual Cost of Hospital Stays Avoided (Multiply Column D by 3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>30.5</td>
<td>30.5</td>
<td>$22,955</td>
<td>$700,127.50</td>
<td>$2,100,382.50</td>
</tr>
</tbody>
</table>

*American Hospital Association, 2003

The potential annual cost savings through Medicaid customers utilizing hospice and avoiding one ER visit would be $62,860.5.

The potential annual cost savings through Medicaid customers utilizing hospice and avoiding one hospital stay would be $2,100,382.50.

In summary, there are significant cost savings that can be realized through the use of hospice. The above calculations are based on half of the non-hospice customers using hospice.
and avoiding one hospital stay and one ER visit. This is a conservative approach to calculating potential savings and if hospice were fully used in appropriate cases in Kansas, the savings would likely be much greater. Moreover, in our sample the average length of time in hospice was only thirty days. Some of the hospital and ER visits could likely be avoided through earlier enrollment in hospice and further savings could be realized.
Summary of Key Findings

Our research interest was:
- to examine the incidence of hospice use by CARE assessment customers identified through the Diversion Study;
- to compare and contrast the hospice and non-hospice customers on key variables;
- to explore the ramifications of the cost data.

This is a summary of our key findings. More detailed information can be found in the body of the report. Parentheses denote the page(s) where this more detailed information can be found.

What is the incidence of hospice use by potentially eligible Kansans 65 and over?

Of our hospice eligible sample, 1/3 (32%) actually received hospice and 2/3 (68%) did not (see page 11). The mean length of stay in hospice for our sample was 30 days with a median length of stay of 18 days (see page 16).

What are the difference and similarities between those who use hospice and those who do not?

1. The confirmed hospice and non-hospice comparison samples were similar in functional disability, gender, and ethnicity. They differed in that the non-hospice group was older by a little over two years (see pages 12-13).
2. Discussions around future health care plans and financial plans occurred more often than would be expected based on national data in both groups (see pages 20-21).
3. Few African-Americans completed DPOAs but did complete financial wills at the same rate as the other ethnicities (see page 21).
4. Of the persons who received hospice, the highest proportion lived in urban counties. (see pages 13-14).
5. Both samples had similar impairments with multiple serious diagnoses and functional disabilities (see pages 17-19).
6. Hospice recipients reported more full time social support and were less likely to live alone (see page 21-22).
7. Both the hospice group and the non-hospice group had some stay in a nursing facility 45 days before the CARE assessment until the time of their deaths (see page 20 and Appendix B)

Medicaid-specific comparisons

1. Medicaid receipt was concentrated in the non-diverted (nursing facility) group in both the hospice and non-hospice categories (see page 14).
2. Medicaid recipients had a lower proportion of hospice utilization than non-Medicaid recipients (see page 14).
3. The Medicaid group was similar in age, ADLS, and gender, but had a disproportionate number of African-Americans who did not use hospice. (see page 15).
4). Completion of Durable Power of Attorneys for Health Care Decisions occurred significantly less often among Medicaid recipients (see page 21).

5). Medicaid hospice recipients were more likely to have multiple diagnoses (see page 19).

6). The urban Medicaid recipients had a lower utilization rate of hospice than the non-Medicaid recipients (see pages 15-16).

7). Compared to the overall group there was a smaller proportion of Medicaid hospice users who lived with someone; a smaller proportion of men; and a smaller proportion of urban dwellers (see page 15).

**What are the cost benefits of hospice enrollment?**

1). Costly health care as defined as hospital stays and ER visits were more likely incurred by the non-hospice group (see pages 22-24).

2). The hospice group even before hospice enrollment was using ER services at a lower rate than the non-hospice group, but were using hospital stays more than the non-hospice group (see page 24).

3). If national averages for ER visits and hospital stays are used as benchmarks, potential annual cost savings through utilizing hospice and avoiding one (1) emergency room visit would be $378,325.00 and for avoiding one hospital stay would be $9,296,775.00 (see page 25).

**Medicaid specific cost information**

1). Costly health care was incurred by the hospice Medicaid recipients at a lower rate than the non-hospice group (see page 24).

2). After enrollment in hospice, the Medicaid recipients visited emergency rooms or had hospital stays significantly less than the non-hospice group (see page 24).

3). If national averages for ER visits and hospital stays are used as benchmarks, potential annual cost savings through utilizing hospice and avoiding one ER visit would be $62,860.5 and for avoiding one hospital stay would be $2,100,382.50 (see page 26-27).
Part V. CARE Assessor Survey Methodology and Analysis

Our fourth research question concerned the benefits and potential barriers to hospice use as perceived by care providers and/or CARE assessors. To obtain the CARE assessors' perspective we surveyed the CARE assessors in Kansas. Four hundred and forty-two CARE assessors responded to our survey. However, 83 CARE assessors had not completed an assessment within the last five years so they were not included in our data. Consequently, 359 surveys were analyzed (see Appendix F).

A). Methodology

The survey sections addressed the following questions:

- What was the rate of reported hospice counseling by the CARE assessors?
- Did the CARE assessors feel that they had “influence” with the CARE customer?
- How did the CARE assessors rate their knowledge of hospice services?
- Was the CARE assessor aware of end of life planning discussions between the CARE customer and their physician?
- What can KDOA do to support CARE assessors in helping consumers discuss end of life issues?

Names of CARE assessors and their addresses were obtained through each of the regional AAAs. One AAA could not supply us with specific names but only agency affiliation and number of CARE assessors per site. This resulted in a target sample size (n) of 1327 CARE assessors. Surveys were mailed to each assessor in the sample according to the following procedures.

- Announcement via the CARE assessor newsletter about the coming survey (early February 2004).
- First wave of surveys sent week of February 22, 2004, the packets included:
  - Cover letter with statement of Human Subject’s Committee—Lawrence (HSCL) approval
  - Survey
  - Stamped self-addressed envelope
  - Token of appreciation
- Postcard reminder sent week of March 8, 2004
- Second wave of survey sent to non-respondents the week of April 5, 2004.

Staff from KDOA, SRS, and the OALTC collaborated on the construction of the survey instrument. The survey itself was comprised of quantitative as well as qualitative questions. Demographic information (age, gender, county of practice, agency affiliation, and educational level), experience (length of time as assessor and frequency of assessments), awareness of physician consultation with consumers, and self-assessment of assessor influence and knowledge were collected.
The quantitative questions used a Likert scale format or were short answer. Once returned, the survey data was entered into an SPSS database and all analyses were completed using SPSS. The qualitative questions were examined and grouped according to emerging themes. The survey instrument is included in the Appendix E.

Profile of Care Assessor:

The typical CARE assessor who responded to our survey was white, a woman and 45.9 years old. The majority of the respondents had a Masters of Social Work (35%), a Bachelor of Social Work (16.1%), or a Registered Nurse or Bachelors of Nursing (31.7%). Social work trained CARE assessors comprised roughly one-half of the total (51.1%), with nurse trained (including LPNs) CARE assessors comprising 37.9%. The remaining 11% listed gerontology degrees, liberal arts degrees, and social service designee appointments most frequently. The agencies that employed these assessors included hospitals (198 respondents or 54.1%), nursing facilities (57 or 15.8%), AAA’s (56 or 15.5%), and other agencies, some of which were hospices (42 or 11.6%). Six did not identify their agency affiliation (1.6%). Respondents had been a CARE assessor, on an average, for 5.62 years, although we did have respondents who had been a CARE Assessor for as little as 6 months and as long as over 10 years. Chart 1 graphically represents CARE assessor agency affiliation.

B). Survey Findings

1). What was the rate of hospice counseling by the CARE assessors?

The average number of CARE assessment completed in a month was 2.7 per month. CARE assessors report that they discussed hospice services .997 times (approximately one time) out of the last six assessments. However, on the CARE assessment data, hospice counseling (HPIC) was coded as being discussed only 1.6% or 46 times out of the 2799 assessments analyzed (data was not analyzed from entire diversion sample of 2882 due to missing service
code data in the August wave). In looking at the three waves in which service codes were included, 21 assessments out of 994 included the HPIC code in 1999; in April, 2000, 15 out of 1104 had a HPIC code; and in May, 2000, 10 out of 701 were coded to reflect hospice counseling. Hospice counseling appears to occur infrequently both by self-report of the CARE assessors and by the quantitative data.

2). Did the CARE assessor feel that they had “influence” with the CARE customer?

CARE assessor felt they had between “a little” and “some” influence.

3). How did the CARE assessor rate their knowledge of hospice services?

The average score for the amount of knowledge of hospice by the CARE assessor was “adequate”. Thirty-nine percent of all the CARE assessors who responded stated that they had “very good” knowledge of hospice.

4). Was the CARE assessor aware of en-of-life planning discussions between the CARE customer and their physician?

We included two questions regarding the consumer’s contact with a physician. CARE assessors reported that they perceived their customers had “sometimes” to “often” seen a doctor within the last six months. With regard to future planning with the physician, CARE assessors perceived that planning had occurred “often”.

C). Comparison Analysis

In examining the aggregate data, we looked at variables that might predict differences in CARE assessor responses. Neither, age, gender, length of time as an assessor, nor ethnicity appeared to differentiate the assessors. We explored employment agency (hospital, nursing facility, AAA, and other); and urban/rural setting. Both variables did discriminate. How assessors answered some questions was significantly impacted by where they worked and whether they were rural or urban based. In addition, the NF/community-employed CARE assessors were similar in responses. The nursing facility, AAA, and other assessors showed no significant differences in the responses to the questions on CARE assessor influence, doctor contact and consultation, hospice knowledge, or hospice counseling rates. However, this group did significantly differed in some key responses from the hospital-employed assessors. The following reports these differences. We report those differences below.

1). Hospital-employed and NF/Community-employed CARE Assessors

Based on an initial analysis of the data, which showed significant difference between CARE assessors that were employed in hospitals and those that were not, the CARE assessors were divided into those that work in a hospital setting (n=198) and those that worked at an AAA, nursing facility, or other site (n=155) with six not identifying their agency. Comparing these two groups highlighted both similarities and differences. Table 17 compares and contrasts the hospital-employed and NF/community-employed assessors on our key questions.
In analyzing the significant differences, NF/community-employed CARE assessors appeared to discuss hospice more often than hospital-employed assessors. However, since some of the community assessors are affiliated with hospice agencies this finding may be expected. Also neither of the groups discussed hospice more than 1 time out of the last 6 assessments. Since these customers were ill, declining, and aged, why hospice was so infrequently discussed may point to barriers to hospice use due to the setting or the CARE assessor themselves. Clearly, the assessors believe they have adequate knowledge of hospice. However, it is unclear why they are not informing ill, declining customers of this option. One possible explanation is that there may be a reluctance on the part of hospital-employed assessors to initiate hospice conversations, particularly in hospitals where this task has historically been relegated to physicians.

Hospital-employed CARE assessors felt that they influenced the decision-making process more than the NF/community-employed ones assessors. Lastly, it is understandable that hospital-employed CARE assessors would perceive that their customers had seen their doctors within the last month, whereas NF/community-employed ones would not. However, why hospital-employed assessors would not have scored this question at “always” is puzzling (see Table 17).

Table 17: Comparison of Hospital-employed and NF/Community-employed Assessors

<table>
<thead>
<tr>
<th>Rate of hospice counseling in last six assessments</th>
<th>Hospital-employed</th>
<th>NF/Community-employed</th>
</tr>
</thead>
<tbody>
<tr>
<td>CA influence (2= “some”; 3= “a lot”)</td>
<td>2.82</td>
<td>2.58*</td>
</tr>
<tr>
<td>CA knowledge of hospice (3= “adequate”; 4= “very well”)</td>
<td>3.24</td>
<td>3.2</td>
</tr>
<tr>
<td>Seen doctor within last month (3= “often”; 4 “always”)</td>
<td>3.43**</td>
<td>2.23**</td>
</tr>
<tr>
<td>Future planning with doctor (2= “sometimes”; 3= “often”)</td>
<td>2.63</td>
<td>2.59</td>
</tr>
</tbody>
</table>

* Significant at the .05 level
** Significant at the .001 level

2). Rural and Urban CARE Assessors

There were substantial differences in CARE assessors that responded from urban counties and those that were rural-based. Of the respondents 38% were urban CARE assessors and 60% were rural CARE assessors. Each AAA region was represented with AAA Region 6 having the most respondents (17.5% of the sample and Region 8 having the fewest at 2.3%)

Demographically, the urban CARE assessors were more ethnically diverse (15.7% non-white as opposed to 4.7% white) and had more male assessors (12.5% compared to 4.4% females). Sixty-one percent of the urban and 51% of the rural respondents were hospital-based.

Similarities between the urban and rural assessors were found in variables including experience as a CARE assessor, the report of doctor consultation for future planning, doctor contact, and age. On these variables, the assessor groups were not significantly different. In looking at the remaining variables of interest, differences between the urban and rural assessors did emerge. Although each group discussed hospice in very few of their last CARE assessments
(less that 1.3 times on average), the urban group did discuss hospice at a significantly higher rate than the rural assessors. Finally, the urban assessors rated their knowledge of hospice significantly higher that rural ones. (see Table 18).

Table 18: Comparison of Urban and Rural CARE Assessors

<table>
<thead>
<tr>
<th></th>
<th>Urban</th>
<th>Rural</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rate of hospice counseling in last six assessments</td>
<td>1.33**</td>
<td>.78**</td>
</tr>
<tr>
<td>CA influence (2= “some”; 3= “a lot”)</td>
<td>2.81</td>
<td>2.65</td>
</tr>
<tr>
<td>CA knowledge (3= “adequate”; 4= “very well”)</td>
<td>3.37**</td>
<td>3.13**</td>
</tr>
<tr>
<td>Seen doctor within last month (3= “often”; 4= “always”)</td>
<td>3.06</td>
<td>3.07</td>
</tr>
<tr>
<td>Future planning with doctor (2= “sometimes”; 3= “often”)</td>
<td>2.44</td>
<td>2.47</td>
</tr>
</tbody>
</table>

** Significant at the .001 level

CARE assessors appear to be influenced by their setting whether that is their agency or their county location. Even though community and urban CARE assessors are discussing hospice more it is still very infrequently. Differences in perceptions of knowledge about hospice and influence in the CARE assessment decision-making process may point to barriers to hospice access. Our qualitative findings do address some of these questions about barriers and accessibility.

D). Qualitative Questions

We asked CARE assessors to write their comments, suggestions, and concerns regarding end-of-life issues. We analyzed these results and found these emerging themes.

1). Appropriateness of Hospice Discussion

In regards to the hospice services question we received responses that indicated that CARE assessors did not feel the CARE assessment interview was the appropriate place to discuss hospice. In East Central and Johnson County, for example, 14% of the respondents stated that it was “not appropriate to discuss hospice”. Some of the comments were:

- “I do not feel there is a big connection or need between KDOA and hospice. Physicians need to be addressing hospice…”
- “Physician orders are generally written before hospice referrals are made and discussion happens—TALK to physicians”.
- “Hospice is not appropriate for me to discuss with the patient”.
- “Have never considered providing hospice information at a CARE assessment.”

Hospice fact about appropriate hospice discussions:

Discussing hospice options is not necessarily a referral but an exchange of needed information. Information on community and nursing facility-based services that can enhance the quality of consumer’s lives are important functions of the CARE assessment process. Moreover,
hospice does not need a referral from a physician. The certificate of terminal illness (CTI) must be signed by a physician but the hospice regulations state clearly that referrals can come from the person themselves, concerned family and friends, other health care professionals and so on. Furthermore, hospices will provide an informational visit to prospective consumers at no charge and also contact the person’s physician to discuss appropriateness. The CARE assessor can be the educator and allow the consumer to explore more if they choose.

2). Lack of understanding of hospice availability in nursing facilities

Some assessors’ comments reflected that they did not understand that hospice was available in nursing homes. For example,

- “Most of our CARE assessments are for nursing homes and not for hospice care.”
- “(When) the care assessment is done (it) often is decided that NH is the next appropriate step. If NH is chosen, why would I discuss hospice?”

_Hospice fact about nursing facility availability_

Hospices regard nursing facilities as a person’s home, and therefore provide services in nursing facilities for those who utilize hospice. These services are at the same level of intensity as in a private home. They also can provide support to family and friends and the staff of the nursing facility, plus reduced Medicaid and private costs for end-of-life care.

3). Lack of hospice knowledge

Some assessors remarked they lacked knowledge about hospice.

- “The CARE assessor training includes little to no information (about)…hospice.”
- “Info on exactly what service hospice will provide in nursing home setting will be helpful.”
- “I would like more info on what is offered by hospice—cost, etc. criteria.”

_Hospice fact about information on basic hospice services_

There are a number of short booklets that explain hospice services, including eligibility, diagnoses criteria, costs, benefits etc. There are some available at no cost through the Department of Health and Human Services and there are many at very low cost available through other sources, such as the National Hospice and Palliative Care Organization.

4). Barriers to utilizing hospice

Some assessors identified barriers to getting hospice services. The emerging themes that arose in examining these qualitative questions appeared to represent three distinct areas of concerns.
• “My community does not have a hospice program it can easily use.”
• “We do not have hospice services available at this time.”
• “The problem we have in SW KS is lack of hospice services—either the rep. from the hospice cannot come for several days or not at all.”

_Hospice fact about lack of hospice availability_

Lack of availability and timely response from hospices is a barrier identified in national studies. However, while we did find hospice coverage in all counties in Kansas, one hospice may be covering multiple counties and awareness of their coverage areas may be lacking.

5). Further barriers—End-of-life, palliative care, and hospice conversations

Discussing palliative care and end-of-life issues requires sensitivity and awareness of the tasks of anticipatory grief. Appropriate first questions can open a door for the customer to ask questions and to be as comfortable as possible. The services that hospice can provide may allow a person to stay in their home and may enable caregivers to continue to provide personal care. Discussing hospice is not a “death sentence” but instead is a way to support people with life threatening illness that has been shown to decrease anxiety and increase hospice access. Furthermore, the level of discomfort of CARE assessors feel in discussing end-of-life issues may influence or increase the discomfort level of the older adult. National studies do highlight that some helping professionals find discussing end-of-life issues personally uncomfortable. These studies stress the importance of professional health care workers to become more self-aware and to learn ways to inform and counsel clients on these difficult subjects (Gordon, 1995; Jennings et al, 2003a; Kutner et al, 1999; Mor et al., 2003)

6). Concerns about efficacy of CARE assessment process

Some CARE assessors reported that the CARE assessment process was not efficient.

• “I think the CARE assessment is burdensome and time consuming.”
• “I don’t find the CARE assessment helpful at all, just additional unnecessary paperwork”.
• “Please don’t come up with more meaningless paperwork procedures.”

7). Suggestions for KDOA

a). Requests for information on hospice.

All eleven regions had respondents that requested literature/brochures or more information on hospice. The percentage of respondents requesting this information literature ranged from 9% in AAA Region 4 to 25% in AAA Region 8.
Hospice informational literature

As stated before, there are a number of no-cost or low cost general informational booklets about hospice care. Some are more technical than others. Developing Kansas-specific and CARE assessor-specific resources could also be considered.

b). Training and exploration of “starting a hospice conversation”.

Nine regions had respondents requesting assessor training on end-of-life issues and engaging in a therapeutic discussion with customers around these issues. Regions 1 and 11 had no training requests. The remaining regions ranged from 4% to 38% of the CARE assessors requesting training.

Possible training options

Options for training development could be face-to-face training opportunities or on-line modules. Both could have CEU’s available. Options for topics to be addressed are:

- Hospice and the Medicare Hospice Benefit
- Starting the conversation around end of life choices
- Practitioner anxiety around discussing end of life choices

Our data reflected that CARE assessors in areas with few hospices requested training at a higher rate than assessors in areas with many available hospices. This may reflect that in the high hospice areas, assessors have had more contact and more chances to obtain first hand knowledge about hospice.
Summary of Key Findings:

What is the incidence of hospice counseling at the time of the CARE assessment?

Hospice counseling was only coded in 1.6% of the 2882 CARE assessments analyzed for the Diversion Study (see page 31).

What was the rate of hospice counseling by the CARE assessors?

CARE assessors report that the average number of times that hospice was discussed during the last six CARE assessments was less than one time (.997). Urban and NF/community-employed CARE assessors discussed hospice at a higher rate than rural and hospital-employed CARE assessors (see pages 31-32).

Did the CARE assessors feel that they had “influence” with the CARE customer?

The average CARE assessors felt they had “some” to “a little” influence. However, hospital-employed CARE assessors felt that they had more influence with their CARE customers than NF/community-employed assessors (see page 32).

How did the CARE assessors rate their overall knowledge of hospice services?

The average CARE assessor rated their hospice knowledge as “adequate” or better. However, urban CARE assessors rated themselves higher than rural assessors. (see pages 32-34)

Was the CARE assessor aware of end of life planning discussions between the CARE customer and their physician?

91.4% of the hospital-employed CARE assessors reported consumers had a consultation with their physician “sometimes” or more (see page 32).

What can KDOA do to support CARE assessors in helping consumers discuss end of life issues?

CARE assessors in all eleven AAA regions requested more written literature on hospice and CARE assessors in nine regions requested training on end-of-life issues (see page 36).

Qualitative findings from the CARE assessor research:

1). Some CARE assessors seemed unaware that hospice services are available in nursing facilities (see pages 34-35).
2). Some assessors were unaware that all Kansas counties are served by at least one hospice (see page 35).
3). Some assessors did not feel that the CARE assessment interview was an appropriate time to discuss hospice and that physicians should be the ones to talk about hospice (see page 34).
Part VI. Qualitative Study of Deceased Customers’ Care Providers (n=18)

This final study segment addressed our 4th research question. Qualitative methods were used since we wanted an in-depth understanding of a specific type of experience. Qualitative methods, such as intensive interviews, produce rich descriptions of both the flow and details of experience in contrast to quantitative methods, which focus on calculating the frequency of discrete bits of experience.

Issues of response rate and sample size are considered important in a quantitative, survey studies, but are not relevant in a qualitative study. The key criterion in qualitative research is that respondents be good "informants" concerning the experience under study and that e enough individuals are interviewed so that repetition in content begins to occur. At that point, "saturation" is achieved and no more participants are needed. There is no set number, but typically saturation occurs after 15-20 people have been interviewed.

Our purpose was to obtain information and gain insight into the perceptions of care providers concerning the benefits and potential barriers to hospice use. A systematic effort was made to conduct intensive interviews with care providers of hospice as well as non-hospice customers (all of whom had died within 6 months of receiving a CARE assessment).

Care providers were defined as those individuals named as “care managers” at the time of the CARE assessment. They were questioned about the following:

- CARE assessment process;
- Awareness of hospice services;
- Decision-making process
- Costs for caregiving
- Rewards for caregiving
- Suggestions for improving the CARE assessment

(see Appendix E for a copy of the interview guide).

A). Obtaining the Interview Sample

Deceased CARE assessment customers from our sample who received hospice were identified through the Standard Analytic File database from the Centers for Medicaid and Medicare. A comparison group of non-hospice customers from our sample was identified from CARE assessment data. Chart 2 summarizes the interview group by both diversion (non-diverted customers resided in nursing facilities and diverted customers remained in the community) and hospice status.
The interviewee selection process began with our total hospice eligible study population of 271 non-hospice and 129 hospice customers. A total of 148 letters to participate in the interviews were sent to hospice and non-hospice care providers of both diverted and non-diverted customers. Eleven hospice care providers responded and were surveyed and eight non-hospice care providers responded and seven were surveyed. Table 19 below describes the selection procedures that resulted in the 18 completed interviews.

Table 19: Interviewee Selection Process

<table>
<thead>
<tr>
<th>Care Providers for Hospice Customers</th>
<th>Care Providers for Non-Hospice Customers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Diverted</strong></td>
<td><strong>Diverted</strong></td>
</tr>
<tr>
<td>Of the sixteen diverted CARE assessment customers that received hospice services, seven or 44% did not include complete care manager information. The remaining nine were sent letters inviting them to participate in our study. <strong>Three responded and were interviewed.</strong></td>
<td>With the diverted, non-hospice population, sixteen of the thirty-eight or 42% had incomplete care manager information. Of the remaining twenty-two, all were sent letters of invitation. <strong>Four responded and three were interviewed. One died in the interim.</strong></td>
</tr>
<tr>
<td><strong>Non-diverted</strong></td>
<td><strong>Non-diverted</strong></td>
</tr>
<tr>
<td>Of the one hundred and thirteen non-diverted CARE assessment customers who received hospice services, seventy-five or 66% did not have complete care manager information. Of the remaining thirty-eight, a sample of twenty-six names were randomly selected and invited to participate. <strong>Eight responded and were interviewed.</strong></td>
<td>Finally, with the non-diverted, non-hospice population, 111 out of 233 or 47.6% had missing care manager information. Of the remaining 122, a random sample of ninety-one letters was sent. <strong>Four responded and were interviewed.</strong></td>
</tr>
</tbody>
</table>
B). Interviewee Characteristics

The interviewees included 16 women (4 wives, 10 daughters, 1 daughter-in-law and 1 niece) and 2 men (1 son and 1 son-in-law). This finding is consistent with the literature that estimates that women comprise over 70% of the family caregivers to ill elders (Hooyman & Kiyak, 2002) and that wives, followed by daughters or daughters-in-law typically assume this responsibility (Neal, 1997). Also expected (given the demographics of Kansas) was the fact that all respondents were white. As Table 20 shows, respondents were fairly evenly distributed in terms of rural versus urban residence.

<table>
<thead>
<tr>
<th>Table 20: Customer Diversion Status and Rurality (n=18)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diversion status</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Diverted</td>
</tr>
<tr>
<td>Non-diverted</td>
</tr>
</tbody>
</table>

C). Interview Procedures

Telephone interviews consisting of nine questions were conducted by trained staff of the Office of Aging and Long Term Care (see Appendix E). Since the interviewees included both hospice and non-hospice care providers, some of the questions were specific to each group. Responses were recorded by the interviewer. Respondents were given a $10.00 gift card from Wal-Mart to thank them for their participation.

Notes taken during the interview were reviewed and edited immediately after the interview. These files were then read and analyzed for similarities, differences and emerging themes. These analyses were then read by two other staff members and compared with the original interview notes to cross check for accuracy and completeness. This confirmed the reliability of our analysis.

D). Findings

1) Did you and your loved one ever discuss difficult topics, like what kind of care they wanted at the end of their life?

Similar to some national studies our analysis found that discussions around end-of-life plans did occur between care providers and their loved ones (Pierce, 1999; Steinhauser et al., 2000; Vig, Davenport & Pearlman, 2002). In eleven (61%) out of the 18 interviews at least one discussion occurred about plans. Ten of these eleven stated that these discussions had occurred more than once and over time. Specific topics such as advanced directives, planning for increased disability, and making promises to stay at home were mentioned.

Most of the reported discussions occurred within the non-hospice group. Of the seven respondents in the non-hospice group only two (28.6%) reported no end-of-life discussion. The hospice group reported no end-of-life discussion in five of the eleven surveyed (45.6%). This is
interesting since one would expect that some discussion must have occurred to spur on the choice of hospice. However, all of the non-hospice, non-diverted care managers reported frequent discussions about planning. This is understandable because decisions to enter a nursing facility could be viewed as a key planning opportunity.

Additional analysis found that 6 of the 7 participants who answered “no” to end-of-life planning were also unclear as to whom or what influenced the decision to enter the nursing home or the hospice. This lack of clarity does not necessarily mean that the discussion did not occur but may indicate that the CARE customer used other individuals as resources for discussion or that the stress of the situation impaired their memory. Studies have discussed the difficulty of ill persons discussing end-of-life issues with close family members because they wish “to protect” them from painful issues. Our analysis found that discussions around end of life plans did occur (Ahrens et al. 2003; Schwartz et al, 2002; Seckler et al, 1991). Findings from these studies point to the need for professional third-party facilitators for end-of-life discussions especially around crisis events.

Some comments from the survey:

- A care provider remarked, “Yes, we discussed D.’s wishes many times throughout the last years. D. was a thoughtful person.”
- “Yes, dad went into severe renal failure and we began talking more about his wishes…I felt that having these conversations gave me peace in the end.”
- “Discussing this was hard but I was very happy we had them.”
- “Well, we never had a specific conversation. As long as mom was able to care for herself, we didn’t talk about it.”
- “I don’t think he said. He expected me to take care of him.”

2). Hospice Customer Question:
In your opinion what or whom influenced (the customer’s) decision to enter the hospice?

Non-Hospice Customer Question:
What or whom influenced (the consumer’s) decision to remain in the community or nursing facility and not use hospice services?

Seventy-two percent (13) of all people interviewed were able to identify who influenced their decision to enter hospice, remain in the community, or enter a nursing facility. Of those who were able to identify who influenced their decision, 54% (7) responded that family or the sick individual themselves were the decision maker. The remaining 46% (6) reported different health care and social service providers as influencing their decision such as physicians (3), social workers (1), nursing home personnel (1), and CARE assessor (1). The hospice diverted group had the highest number of “insider” responses, while the entire non-hospice diverted group was "unsure" of who made the decisions.
Both the hospice non-diverted and the non-hospice non-diverted groups identified a mixture of decision makers. This may reflect their more consistent contact with health care professionals and the impact of professional influence on those individuals. For the diverted groups who were in the community, this “constant” was lacking and these individuals may have felt more autonomous. This may reflect that decisions were seen for hospice recipients as in their control and they felt more self-determining than the non-hospice group.

Some comments from the survey are:

- A non-diverted hospice care provider remembers the decision making this way: “The nursing home people made the decision (to call hospice)” and she just agreed. I didn’t even know that hospice would come to the nursing home or even what they would do there.”
- “We decided on hospice together. M discussed it with her doctor and she made the decision.”
- “The doctor came to M and told her she couldn’t go home…we just went along with it.”

3). Was the CARE assessor helpful to (the customer) in learning about services that were available to help care for (them)?

Over 30% of people interviewed could not remember the CARE assessment process, but most who remembered the process found it helpful. We found that both diverted and non-diverted groups recalled the assessment at the same rate. The lack of memory may be attributed to the care provider’s absence at the assessment or the stress or crisis occurring during this time. This is very understandable with the stress of the loved one’s illness, but may also reflect the need for CARE assessors to repeatedly identify themselves or the purpose of the CARE assessment process.

Of those respondents who did recall the CARE assessment process, 75% voiced that the CARE assessor was helpful, 8% found the process confusing, and 17% did not find the process helpful. Specific aspects that were mentioned as helpful included the CARE assessor’s knowledge of nursing home options and costs, and knowledge of where to get medications and supplies. None of the care providers reported that the CARE assessor mentioned hospice services and only one mentioned any community resources other than nursing facility placement.

Some comments from the survey are:

- “The CARE assessor “was very helpful to us and discussed what we would have to do when L. became too much to take care of.”
- “Very helpful”. We talked about costs, locations of homes, things to ask, and all of that. She was very knowledgeable.”
- “No. They wanted her to go to the nursing home and she didn’t want to go and I didn’t want her to go. Felt like M. was pushed to sign the NF admittance papers even though she would have preferred to stay at home.”
“She was asking us questions about things and she really didn’t explain why she was there. Later we learned that C. qualified for a nursing home.”
“(There) was too much going on, I don’t remember who came for what or why.”

4). Was the CARE assessor helpful to you in learning about services that were available to help care for (the person)?

**Non-Hospice group**

None of the non-hospice care providers (7) remember anyone mentioning hospice, either at the time of the CARE assessment or any other time during the person’s illness. Three (43%) did have some foreknowledge of hospice and considered it as a possibility for their loved one. However, two of these non-hospice care providers only wondered about whether their loved one might qualify and did not pursue this further. One non-hospice care provider did request hospice but no one told her that her loved one could have nursing home care and hospice concurrently. Therefore this person did not know until after the person’s death that hospice was a possibility.

In addition, six of the seven non-hospice care providers (86%) and all of the non-hospice, non-diverted care providers (4) remarked that they would have wanted to use hospice care if possible. All six were unsure that their loved one would have “qualified”, but in hindsight wished that “someone” would have told them that hospice was an option. It is possible that none of these ill individuals would have qualified for a terminal diagnosis but it is also telling that all of these care providers relied on other’s knowledge and expertise to direct them. This exemplifies the need for health care professionals to be sure to discuss all options and keep ill persons and their families informed of all services available. Also this emphasizes the need for accurate knowledge of the qualifiers for hospice, so that missed opportunities for desired care can be avoided. Only one of the care providers said that hospice was not needed and only because she perceived that her loved one was not terminal.

Some comments from the survey are:

- “No one really talked about hospice and I wish I had known. C’s sister died two years later and I was her DPOA and she had hospice. They were wonderful and such a help.”
- “I did not know that hospice would go to nursing homes and learned about this last year from friends. Hospice could have helped mom and me. Maybe hospice should advertise so more people know about them. I think the CARE assessor should mention hospice.”
- “Hospice wouldn’t have mattered since M. did not have a terminal diagnosis. The doctor would have told us if she was dying.”

**Hospice group**

None of the hospice care providers (11) discussed hospice services at the time of the CARE assessment, but did discuss hospice at some other point in time. Three (27%) reported that the physician initiated the hospice conversation; three (27%) reported that family members
suggested hospice; four (36%) stated that social workers or other staff brought the subject up; and one (9%) reported that the ill individual themselves requested hospice services. This reflects that fact that numerous individuals from different areas of expertise can introduce a discussion of hospice services. Hospices do require that physicians sign a statement of projected life span called a Certificate of Terminal Illness. However, hospice referrals can and do come from many sources. Anyone can make a hospice referral--ill persons themselves, family members, professionals as social workers, nurses, and so on, and physicians. Hospice staff also provided an informational visit to the person and their family at no cost to discuss hospice services and hospice personnel will contact the physician to discuss hospice appropriateness.

Some comments from the survey are:

- “We knew M. was dying and so did everyone else. I wish that she had known then what I know now about hospice services and wished that M. would have had hospice longer.”
- “We really explored all our options for L. and did our own research on hospice. We then discussed it with all the doctors.”
- “I thought it (hospice) was just for people with cancer. She had emphysema. When the doctor said, ‘D., it is terminal; you should go to a hospice’. I said, ‘But she doesn’t have cancer’. That’s when he told me about hospice.”

5). How did the hospice help (the person) at the end of his or her life?

How did the hospice help you in caring for (the person) at the end of his or her life?

Of the eleven care providers, whose loved ones received hospice, nine (81%) respondents reported that hospice was helpful. Specific areas of support were in personal care needs, availability and accessibility in the home, emotional and spiritual support, after-hours care, and in family support. One respondent stated that the hospice personnel helped her understand “that this time was a gift”. One (9%) felt that the hospice was not helpful due primarily to equipment problems and one (9%) stated that they had hospice services for less than 24 hrs. and was unsure of the benefits of hospice due to the very short length of stay.

Some comments from the survey are:

- “They (hospice) took care of everything. I don’t know what I’d do without them.”
- “They were wonderful. The nurses and caregivers came every day. The nurses gave L. shots and his medications and the caregivers cleaned and bathed L.”
- “Hospice is marvelous. They visited regularly and were very nice. They were on call if we needed anything after hours. And they still call once a year to see how I am doing. My mother-in-law also received hospice services from the same hospice.”
- “They didn’t get the right bed for us and just seemed to always have excuses for not getting the bed.”

6). Hospice Customer Questions:

Can you estimate how much time and/or money you spent caring for (the person)
while they were in hospice? How about before they entered hospice?

Non-Hospice Customer Question:

Can you estimate how much time and/or money you spent caring for (the person) during the last six months of their life?

All groups were asked to estimate the costs, both in time and money, spent during the last six months of their loved one’s life. Time costs were mentioned by all but one of the respondents. Care providers in all groups remarked that they spent a lot of time caring for their loved one regardless of hospice intervention. The range of time spent by the hospice group was “all the time to visiting every day”. For the non-hospice group, the care providers visited “every day” to “a couple of times a week”. Whether the loved ones were in the community or in the nursing home, the care providers visited often, most every day.

Money costs however, did vary. Non-hospice care providers of diverted customers mentioned no monetary costs but all of the four care providers for the non-diverted non-hospice customers reported monetary costs. These costs ranged from “around $11,600 for private duty help” to “about $350 for co-pays for medicines”. Two of the four (50%) care providers for non-diverted customers reported that insurance (LTC) helped with the expenses.

With the care providers for hospice recipients, six (55%) reported no money spent. Three (27%) reported costs before hospice as being about $30,000, $2000 per month and $300 per month respectively and these charges were for medications and caregivers. None of these three care providers reported any costs after hospice became involved. One (9%) reported no difference in costs pre and post- hospice involvement, while one (9%) did not answer. Another of the care providers stated that her loved one “spent about $1200 a month for caregivers during her last six months of life”.

7). Hospice Customer Questions:

What problems or barriers did you experience in caring for (the person) while he or she was in the hospice? Did the hospice help to deal with these problems?

Non-Hospice Customer Questions:

What problems did you experience in caring for (the person) while he or she was in the community or nursing facility? Did someone or some agency help you deal with these problems?

The hospice care providers mentioned few problems. Of the 11, nine (81%) responded “no problems”; one mentioned that the hospice nurse was late showing up, and another mentioned equipment problems. Problems in caregiving were most mentioned by the non-hospice group (both diverted and non-diverted). Three (43%) responded “no problems” but the remaining four mentioned “not knowing who to call for advice”, problems finding private help, problems with the nursing home staff, and problems around caregiving (needing bath help, etc.).

Some comments from the survey are:
- One hospice respondent summarized, “No problems or barriers carrying for L. when hospice was around”.
- A non-hospice respondent said, “He fell out of bed and I had to call 911 for someone to come and help”.
- “It’s very hard, stressful. I’m sandwiched between caring for my daughter and my husband and caring for Dad and having a job. I still feel I should have done more for Dad”.
- “I never trusted the nursing home so I came every day and did a lot of the care. No one really helped me care for R.”.

8). Overall, what was your caregiving experience like in caring for (the person)? How could it have been better?

All of the care providers discussed the last days of their care recipient’s life. Five of the seven (74%) non-hospice care providers described their memories of those last days as positive. One verbalized regrets over not doing more. Another stated that the time was “physically exhausting” and that her health remains precarious due to the strain of the caregiving (this experience was over three years ago). Of the hospice care providers, eight (72%) were positive in their comments and mentioned that this experience was “comforting”, “great”, “very positive”, “loving”, and so on. One mentioned that although it was stressful, it helped her “understand” about life and she is now at “peace”. Another stated that it was a difficult, but “humane”. Another person stated that it was “hard and a lot of work” and a “very sad memory”. None of the respondents voiced any wish to have avoided this end-of-life experience supporting their loved one.

9). Is there anything that you would suggest to CARE Assessors that they might do at the CARE assessment to better serve customers and their families?

As stated before 6 (33%) out of the 18 care providers did not remember the CARE assessment and thus could not give suggestions. Of the remaining providers, four (36%) responded with “no suggestions”. The remaining suggested the following:

- “Talk more slowly and be more patient” (1)
- “Be respectful and understand that caregiving is a tough job” (3)
- “More suggestions to help people stay in their homes” (2)
- “More information especially nursing home costs” (2)
- “Concerns about the need for more care in the hospital” (1)
- “Present the options better and more sensitivity to patient” (1)
- “Suggest hospice services more” (5)
- “Give the person a copy of the CARE assessment so people would be aware of what was on it” (1)
- “How to cope with feelings and help the caregiver understand what was going on with them emotionally” (2)
- “More advice on how to deal with insurance and the health care system” (1)
Summary of Key Findings:

What are the benefits and potential barriers to hospice use as perceived by consumers and/or CARE assessors?

1). End-of-life care planning discussions are happening and they are happening with and without professional input (see pages 42-43).

2). All of the hospice care providers accrued less monetary costs than the non-hospice providers but all viewed end-of-life support as time intensive overall (see pages 46-47).

3). 81% of the hospice care providers were very positive about hospice (see page 46).

4). Both the hospice and non-hospice care providers felt that caregiving for a dying loved one was a positive experience (see page 47).

5). Hospice care providers voiced less problems with caregiving than non-hospice care providers (see page 47).

6). The CARE assessment process was reported as positive and helpful by 75% of the care providers, who recalled the assessment process (see page 44).

7). Some care providers have definite suggestions for CARE assessors. Specific suggestions were respectfulness and sensitivity in the conduct of the interviewer (37%); more informational needs met (32%); and more information on hospice services (27%) (see page 48).
Part VII. Synthesizing the Results of the Three Components of the Study

After completing the three components of the study and analyzing the data, we saw that certain key elements were present in all the studies. With our mixed methodology, we were able to examine data from multiple sources and get strong numerical data with a richer understanding. Our quantitative findings were supplemented by the richer understanding provided by the qualitative data. The following is a summary of the key findings.

- **Hospice is not being discussed by health care professionals at the CARE assessment.**

  Although 32% of the hospice eligible sample actually received hospice, all three components confirmed that hospice as a service option was not being discussed. Hospice counseling at the CARE assessment is recorded only 1.6% of the time in the CARE assessment data. Furthermore, CARE assessors report only discussing hospice about 1 time out of the last six assessments and all of the care provider interviewees stated that hospice was not discussed at the CARE assessment. Moreover, some of the CARE assessors reported that they felt hospice was inappropriate to discuss, whereas many care providers requested that CARE assessors talk about hospice services. In addition, there appeared to be a lack of understanding among care providers and CARE assessors as to the availability of hospice services in nursing facilities. Clearly there is a disjunct between CARE assessor perception of the appropriateness of hospice discussion and care provider requests for hospice information during the assessment which may constitute a possible barrier to hospice services.

- **The CARE assessment process is an important decision-making opportunity.**

  The CARE assessor survey and care provider interviews confirm that both care providers and CARE assessors see the assessment as an opportunity to exchange information, make decisions, and plan for care needs. Most CARE assessors felt that they had at least “some” influence on the decision-making process with urban assessors rating their influence higher than rural CARE assessors. With hospice discussed so infrequently, the opportunity to exchange information and educate consumers is lost.

- **End-of-life issues are hard to discuss.**

  Both the CARE assessor survey and the care provider interviews reflected the difficulties of talking about death and dying: the dilemma of when the discussion should occur, and who should engage in the conversation. Many of the interviewees indicated that they didn’t know what was available and expected someone else to inform them about hospice. This highlights another barrier to hospice use because **professionals are not taking the lead** in discussing future care plans and **consumers are expecting them to take this lead.** Discussing hospice services allows the consumer to make an informed decision.

  Systemic barriers to hospice use are also evident from the comments of the CARE assessors. Some CARE assessors felt discussing hospice was inappropriate and it is the
physician’s job to discuss end-of-life plans. The assessment process has goals to educate the customer in resources that may allow them to stay in the community. Professionals have a responsibility to not allow their own discomfort to interfere with their ability to communicate information to the older adult. This appears to be another key barrier to hospice utilization.

The quantitative secondary analysis of the Diversion study indirectly addressed the difficulty in making end-of-life plans. Within the context of advanced planning activities (completed financial will, living wills, DPOAs, DNR, DNH), a higher than expected rate of completed plans were reported. However, still only about 46% or less completed these plans. We have much room to improve our support for end-of-life decision-making.

- **Even though difficult, end-of-life plans are being discussed and documents completed.**

Two components of the study reflected more end-of-life discussions than we expected. A higher rate of advanced directives than the national average was documented and the interviews confirmed that this population was discussing and making plans. Medicaid customers, however, are completing end-of-life documents less than non-Medicaid customers.

- **Cultural differences with end-of-life plans exist.**

African American customers are not completing health care preference documents at the same rate as the majority population. Few African American customers were also hospice clients.

- **The non-hospice and hospice samples are very similar.**

When we examined the two samples (confirmed hospice and non-hospice) we were surprised at how similar these two groups are:

- Demographically, they were of similar ethnicity and gender.
- The mean age for both groups was over 82 years of age.
- The total sample population broke down as 1/3 hospice and 2/3 non-hospice.
- The functional impairment (ADL scores) were not significantly different.
- The customers’ life span after the CARE assessment whether hospice or non hospice was not significantly different.
- About 90% of both samples had had some recent stay in a nursing facility.
- At least one-half of both samples had multiple serious diagnoses.
- Both groups completed end-of-life documents at higher rate than national averages.
- Most of the Medicaid customers were in nursing facilities regardless of hospice status.
- Both care provider interview groups discussed the importance of being with loved one’s at their end-of-life.
Both care provider interview groups discussed the importance of CARE assessors being sensitive, respectful, and supportive during the CARE assessment process.

Both care provider interview groups spent a lot of time with their loved ones.

Most of the care providers felt the CARE assessment was helpful.

**Differences between the groups also became evident.**

- Hospice recipients were more likely to have one serious diagnosis and a cancer diagnosis.
- Medicaid customers had a lower hospice utilization rate than the overall group.
- Medicaid hospice recipients were more likely to have multiple diagnoses.
- Non-hospice customers were more likely to have completed both a financial will and a Durable Power of Attorney for Health Care Decisions at the time of the CARE assessment.
- Medicaid recipients were less likely to have completed a Durable Power of Attorney for Health Care Decisions at the time of the CARE assessment.
- Hospice recipients were less likely to live alone and had full-time social support at a higher rate than the non-hospice customers.
- The hospice recipients, even before enrolling in hospice, had less hospital stays and less visits to the ER.
- The hospice recipients were less likely to be hospitalized or go to the ER.
- The non-hospice care providers reported more conversations about end of life planning.
- The hospice care providers reported more discussion about promising to keep the ill person in their own home.
- With decision-making:
  - The diverted hospice group felt that non-professionals had the greatest influence on their decision-making.
  - Both non-diverted hospice and non-hospice recipients identified a mixture of influence from professional and non-professional people.
- Most of the hospice care providers reported no monetary costs for caregiving during the last six months of their loved one’s life. Costs to time and emotions were reported by both groups.
- Most of the non-hospice care providers reported caregiving problems.

**Hospice is cost conserving and decreases high-cost health care expenditures.**

The secondary component of our study reported the range of hospice costs for hospice recipients. The rate of hospital admissions and ER visits for hospice recipients are drastically less than non-hospice recipients. From our data, we were unable to determine if hospice support would have decreased actual nursing facility admissions (another high-cost). However, we know that many care providers wanted to “keep” their loved ones in their homes and hospice services may have provided the needed services to allow this to occur.
• Nursing facilities are key places for cost savings for individuals and the Medicaid system.

The secondary study found that most of the Medicaid recipients regardless of hospice status were in nursing facilities. Many of the care providers reported the greatest costs to them or their loved ones were for these nursing facility costs and in-community personal care costs. Savings to Medicaid or to personal families from the Medicare Hospice Benefit are present even when the recipients are in a nursing facility. These savings include prescription drug costs, personal care costs, equipment/supply costs, and saving from the managed care component of hospice that decreases hospitalizations, ER visits, and so on.

• Barriers to hospice evident in our study are:
  o Little hospice counseling or information sharing at the CARE assessment;
  o Lack of awareness of hospice services by care providers;
  o Evidence of misinformation by both CARE assessors and care providers as to accessibility of hospice or hospice services;
  o Reluctance on the part of CARE assessors to discuss end of life/hospice.
  o Concerns about cultural sensitivity to persons of color and their end-of-life concerns.
  o Customers on Medicaid may not have the same access to hospice as non-Medicaid customers, particularly those in urban areas.
Part VIII. Next Steps

Hospice services and the Medicare Hospice Benefits are still poorly understood. Greater hospice use is cost effective for Medicaid and can improve the quality of life for dying persons. Policy efforts make end of life concerns a priority are needed. Possible policy innovations might be:

- Implementing an informational campaign on end-of-life issues (mirroring the BE WISE IMMUNIZE campaign);
- Distributing information on options to consumers;
- Advocating with policy makers to standardize advance directive documents so that may be easier to complete, more culturally sensitive, and are portable within the state;
- Supporting a Kansas-specific survey addition to the Behavior Risk Factor Surveillance Survey (updating the 2000 survey data and doing more).

Professionals with their clients have the opportunity to discuss with persons the range of end-of-life services and have the obligation to start that conversation. Policy efforts can be made to help professionals feel more comfortable dealing with this hard topic. Training should be developed to help make this happen.

National organizations have developed “tool kits” for professionals and consumers about end-of-life issues and hospice in particular. Efforts can be made to get one of these or a created “tool kit” to every CARE assessor and to make them accessible to consumers.

Many rural counties have only one hospice serving their area. In addition, Medicare payments for hospice costs are less to rural counties than urban counties. Policy makers can explore ways to support rural hospices and to implement plans that are rural-specific to increase awareness of hospice services.

Hospice services are poorly understood in nursing homes. Policy makers can explore how best to address education on palliative care and hospice care in state surveyed nursing homes. In addition, challenges to hospice services in nursing homes have been studied and documented. Wetle et al. (2004) report that “These challenges are apparent in the coordination of billing, staffing and other operations; the integration of clinical car practices across program and staff lines; and the maintenance of consistent and coherent communication at …all levels” (p.10). Although CMS recently published Promising Practices for Implementing the Medicare Hospice Benefit for Nursing Homes, it still does not address how disagreements about care are to be resolved. Consequently professionals and consumers can be crucial in developing guidelines and procedures for resolving these issues.

Kansas specific “Next Steps”

Kansas’ Department on Aging (KDOA) is already taking steps to increase CARE assessor awareness of hospice and its service provisions. Specifically, they have revised the CARE assessment form and hospice services are listed as one of the potential referrals. In addition, they are partnering with the Kansas Department of Health and Environment to
construct a health-specific website to assist consumers to access health care services and hospice general and agency-specific information is to be included. Additional plans have been discussed with key personnel of KDOA concerning “toolkits” on hospice available at the Area Agencies on Aging, one-page informational handouts, and partnering with consumer and professional advocacy groups.
Part IX. Conclusion

Health care professionals provide needed counsel to consumers as they make decisions about their future care needs and hospice as a service option for frail, ill older adults is important to discuss. Hospice use can reduce Medicaid and end-of-life costs to both the families of dying older adults and the state, as well as improve the quality of life for those older adults and their families. Efforts to increase these hospice discussions can benefit both the state and the well-being of the Kansas citizenry. Kansas policy makers are taking the initiative to improve hospice education at the CARE assessment and at other key decision making junctures and to increase both professional and consumer awareness of hospice services.
Advanced Directives—a written document that allows a person to communicate their healthcare preferences if the person has lost the capacity to make or communicate their decisions. The US Supreme Court recognized in 1991 that adults have a constitutional right to direct their own health care, including refusing medical treatment.

CARE Assessment—The CARE assessment gathers information about the person’s potential need for specialized services, functional ability, available support systems, and recent problems and risks at the point they are applying for nursing facility admission. It also provides the older adult with information regarding their LTC options.

Care Provider—For this study, the care provider is the person listed as the care manager on the CARE assessment form.

Diverted—Per the Diversion Study, these customers that did not move permanently to the nursing facility but remained in the community.

Do Not Hospitalize—A written document that is sign by the individual or their agent, witnessed, and co-signed by the person’s physician that states that the person does not want to return to the hospital for aggressive care and wants to remain in the nursing facility to die. The form is used in nursing facilities.

Do Not Resuscitate—a written document that is signed by the individual or their agent, witnessed and co-signed by the person’s physician documenting their choice to not have CPR if their heart stops. This form is used both in the community and nursing facilities.

Durable Power of Attorney for Health Care Decisions—A legal document that allows a person to name another person to make health care decisions for them in the event that they are unable to communicate their wishes. This document may need to be notarized by state law to be in effect.

Financial Will—A legal document declaring how a person wishes his or her possessions to be disposed of after death.

Hospice—A program that provides palliative care and attends to the physical, emotional and spiritual needs of a terminally ill patient at an inpatient facility, nursing facility or at the patient’s home. Hospice receives funding from Medicare through the Medicare Hospice Benefit; from Medicaid through the Medicaid Hospice Benefit; through private insurance; and through private pay. Hospice is also a philosophy of caring for people at the end of their lives that emphasizes quality of life, growing until death, and dying comfortably and with the support of others.

Living Will—A written document that is similar to health care directives. A key difference is that living wills usually apply only when someone is terminally ill and healthcare directives apply whenever someone is unable to make or communicate their wishes.
**Medicare Hospice Benefit**—A program instituted in 1983. This benefit pays for 100% of the physical, emotional, and spiritual care for the dying person. It also covers medication and equipment/supplies to help the person stay comfortable. Medicaid’s benefit mirrors Medicare, but many private insurances have different benefit structures.

**Non-diverted**—Per the Diversion Study, these customers did not remain in the community but moved permanently to a nursing facility.

**Palliative Care**—Comfort care that seeks not to cure but to alleviate pain and other negative symptoms. Palliative care is a cornerstone of hospice care.

**Per Diem Payment**—Hospices throughout the country receive capitated payments from Medicare or Medicaid. The amount of this payment varies as to the location of the ill person. Rural payments are less than urban payments.
References


Steinhauser, K., Christakis, N., Clipp, E., McNeilly, M., McIntyre, L., & Tulsy, J. (2000a) Factors considered important at the end of life by patients, family, physicians, and other health care providers. *JAMA, 284* (19), 2476-2796.

Steinhauser, K., Clipp, E., McNeilly, M., Christakis, N, McIntyre, L., & Tulsy, J. (2000b) In search of a good death: Observation of patients, families, and providers. *Annals of Internal Medicine, 132* (10), 825-832.


APPENDICES
## Table of Contents

I. Appendix A: List of Variables ................................................................. 74  
II. Appendix B: Data Sources ................................................................. 75  
III. Appendix C: Determining Hospice Eligibility ............................... 76  

  Methodology ......................................................................................... 76  

  Validity of Hospice Eligibility Estimation ....................................... 76  

  Methodological Limitations to our Proxy ......................................... 77  
IV. Appendix D: Further Information on DNH Orders ....................... 80  
V. Appendix E: Survey Instruments ...................................................... 81  

  CARE Assessor Survey ........................................................................ 82  

  Hospice Care Provider Telephone Interview Questionnaire .......... 84  

  Non Hospice Care Provider Telephone Interview Questionnaire ..... 85  

  CARE Assessment ............................................................................... 86  
VI. Appendix F: CARE Assessor Survey Return Rate ......................... 88
APPENDIX A

List of Variables

• Diagnosis
• Advanced Planning Activities
  o Financial Planning
  o Health Care Planning
  o Documents
• AAA regions
  o Hospice availability
• Social Support
  o Caregiver access
  o Living alone
• Hospice specific variable
  o Days in hospice
  o Monetary costs
    ▪ Actual hospice costs
    ▪ ER usage
    ▪ Hospital usage
• Medicaid Status
  • Demographic variables:
    o Ethnicity
    o Gender
    o Age
    o Rurality
APPENDIX B

Data Sources

The following data sources were used for each component of this study. For the Secondary Study of Hospice Use with the Longitudinal Study of Customers Diverted through the CARE Program, which is the quantitative exploration of data collected through the Diversion Study. Data was obtained from:

- The Hospice Standard Analytic File from the Centers for Medicare and Medicaid Services, which contains data on Hospice recipients.
- The Longitudinal Study of Customers Diverted through the CARE Program (Diversion Study) conducted by the Office of Aging and Long Term Care and supported by the KS Department on Aging and the KS Department of Social and Rehabilitation Services. This data set includes information obtained in 1999-2000 on a sample of Kansans, who obtained a CARE assessment.
- The MDS database, which is completed on all nursing home residents in the state.
- The OASIS database, which is completed on all home health recipients.

Since so much of our data was being drawn from the OASIS and MDS sources we assessed the percentage of our sample with information contained in these data sources. We looked at all the MDS and OASIS data from 45 days prior to the CARE assessment to time of the customer’s death. Ninety-six percent of the entire sample had data recorded in at least one of these data sets.

For hospice customers:
- 18.6% had data in OASIS
- 87.6% had data in MDS

For non-hospice customers:
- 14% had data in OASIS
- 99.6% had data in MDS

Consequently we analyzed these data sets and their association with our hospice information.

For the CARE Assessor Survey, a survey instrument was created by the researchers at the Office of Aging and Long Term care in 2004 and distributed to CARE assessors in the state. The survey contained both quantitative and qualitative elements.

For the Qualitative Interviews of Surviving Care Providers of Deceased CARE assessment customers, an interview instrument was implemented to explore the end of life experiences of surviving care providers of CARE customers identified in the Diversion Study.

The following section (Appendix C) details the specific methodology and analysis for each of the three components of the project.
APPENDIX C
Determining Hospice Eligibility

A). Methodology

Customers were estimated to have been hospice eligible if they had an appropriate payor source (Medicare or Medicaid) and had a diagnosis that is a possible end stage diagnosis. Actual hospice use was also taken to indicate that a customer was hospice eligible. A sequential screening procedure was adopted as follows.

The first step was to examine payor source and determine how many cases were confirmed as either Medicare or Medicaid. Each of these sources has a hospice benefit and this indicator has become our first “test” for eligibility. Forty-four persons did not have either payor source. This narrowed our sample from 566 individuals to 522.

Second, we examined diagnoses. Hospice provides care for any diagnoses that potentially is life limiting. The most frequent diagnoses for hospice include end-stage diseases in the following areas: cancer, heart disease, diabetes, pulmonary disease, stroke, renal failure, dementias, Parkinson’s disease, and many more. Each disease has a list of clinical variables that indicate severity of illness and its terminality (CMS, 2003). All of the MDS diagnostic categories (except for quadriplegia) and few of OASIS diagnostic categories matched the major hospice diagnoses. In looking at the data for both the MDS and OASIS diagnoses, only individuals with a diagnosis that fit within the list of hospice relevant diagnoses were selected. End stage confirmation was not considered at this point in time. We created a variable (dxappr) to identify those with a potentially hospice appropriate diagnosis. Four hundred and sixty three customers were identified as individuals who had a diagnosis that fit within the relevant diagnoses. Of these, 437 or 84% had a potentially hospice appropriate diagnosis and a confirmed eligible payor source. We also discovered that 28 customers were already receiving hospice at the time of their CARE assessment. Since the focus in this study is hospice access and discussion at the CARE assessment, our study population is limited to those not yet receiving hospice at the time of the CARE assessment. This reduces the number of customers estimated to have been hospice eligible at the time of their CARE assessment to 409. An additional 3 customers opted for aggressive medical treatment (chemotherapy) during this period, signaling that they were not seeking palliative care and, therefore, would not be hospice eligible. Since we wish to be as rigorous as possible, we have chosen to delete the three non-hospice recipients that received chemotherapy from our non-hospice sample (274-3=271). The reduction of our sample by the three chemotherapy recipients really did not impact any of the statistical findings.

Finally, we wanted to limit our study to only those individuals 65 years and older. This would reduce our sample size for the non-hospice group to 271 and for the hospice group to 129. Our entire sample population is 400 and this sample conforms to our proxy and will be the focus of our further analyses. This results in a hospice utilization rate of 32% in a population of eligible users and that 275 or 68% of those eligible did not receive hospice services. See page 12 of our report for our stepwise methodology to confirm hospice eligibility.

B). Validity of Hospice Eligibility Estimation
Several additional steps were taken to validate or confirm the determination of hospice eligibility. First, we explored Activities of Daily Living (ADL) scores. In exploring activities of daily living scores, we were looking for an indicator of debility or decline. Hospice eligibility indicators also use functional assessments of ADLs to assess eligibility for non-cancer diagnoses. Consequently, ADLs were considered a good indicator of severity of illness. The possible ADL score range ranged from independent functioning (6) to total dependence (24) on key activities as toileting, dressing, feeding oneself, and so on. The actual range for all the groups examined (the hospice group and the non-hospice group), was 6-24. All groups had functionally independent to completely dependent persons.

In looking at our hospice users group (n=129) the ADL mean score was 17.0078 and in looking at the non-hospice group (n=271), the ADL mean score was 16.5720. With the Medicaid recipients their ADL mean scores were also very similar. The Medicaid hospice group (n=22) had a score of 16.4545 and the Medicaid non-hospice group’s score was16.4262. After conducting t-tests comparing the means of the hospice group with the non-hospice group and the means of the Medicaid hospice and Medicaid non-hospice groups, no significant difference was found between these groups. This appears to indicate that the both the hospice and non-hospice deceased customers were similar in functional impairment. Moreover, both mean scores of 17.00 (hospice) and 16.57 (non-hospice) represent that most of the customers needed at least supervision or physical assistance in completing their ADLs. This would be understandable since this population needed more care than they were able to provide for themselves and they were considering a nursing home placement—thus triggering the CARE assessment process. However, as a determining factor for the proxy, this variable was not discriminatory since all the groups were basically the same.

The next step was to look for confirmation of hospice eligibility by determining customer’s end stage disease status. For this, we turned to those variables in the hospice, MDS and OASIS datasets that were an indicator of end stage disease. We know that 129 received hospice due to the Hospice Standard Analytic File and there are no questions as to their end stage disease status. With the 271 persons that did not receive hospice looking at their appropriateness in this area is important to address any questions as to their hospice eligibility. Only 23 of the 271 (8.4%) were classified as having an end stage disease in either MDS or OASIS data sets. This data appears to suggest that few of our sample were end stage disease. However, we also looked at these end stage disease variables in relation to our hospice recipients and found that these indicators are not reliable. Consequently, we were unable to use either the MDS or OASIS end-stage disease codes to further screen our sample.

C.) Methodological Limitations to our Proxy

When we conceptualization our study, we had looked at a four prong approach to substantiate our determination of hospice eligibility. First, the presence of Medicare or Medicaid was necessary since these are the key payor sources for hospice. Second, an hospice appropriate disease diagnosis was needed. Third, functional disability (ADLs) was also seen as a discriminatory variable, since one would assume that dying individuals would have been more functionally impaired than those that were not terminal. Finally, the end stage disease categories (MDS and OASIS) were expected to be further discerning and give us hard data. Unfortunately, what we found is that although our first two proxy determinants did give us important guidance
as to who to include in our sample, the functional disability variable did not discriminate well and the end-stage variable was unreliable.

Consequently, we began looking for other indicators that would shed light on hospice appropriateness. We looked at age and multiple diagnoses (both indicators that might hint at severity of illness and terminality) and we examined the role of patient choice. If a person chose aggressive treatments that could indicate they would not have chosen hospice.

First and foremost this was an aged population, that was frail, had unmet caregiving needs, and died within six months of their CARE assessment. The mean age for the hospice group was 82.80 years and for the non-hospice group was 85.16 years. Mean age was significantly different between these groups (p=.001), but the hospice group was significantly younger than the non-hospice group. Since the prevalence of serious diseases and terminality increases with age, our non-hospice group should have been more at risk for a life-limiting illness not less likely. As stated before these groups were not significantly different on the basis of ADL, both groups were impaired at the same level. Finally, these persons died with in six months of the care assessment. With the non-hospice group 12.9% died within 30 days of the CARE assessment and 5.4% of the hospice group died within 30 days. Hospice clients with a terminal diagnosis actually lived longer those first 30 days after the CARE assessment. From these variables it does not appear that the non-hospice group was any less ill or less likely to die than the hospice group.

An additional finding is that most of these persons had multiple serious diagnoses. With the non-hospice group, 37.6% had one diagnosis recorded; 31% had two and 31% have three or more. Of the hospice group, 46.5% had one diagnosis, 29.5% had two and 24% had three or more. The range of number of diagnoses was also surprising. Each group had individuals who had as many as five diagnoses recorded. This again points to the fact that this population was seriously ill.

Another facet, that might shed light in determining our non-hospice sample hospice appropriateness, concerns patient choice and aggressive treatment concerns. Choice is fundamental to hospice services—customers “elect” to use hospice. Implied here is that this is an informed choice and that people know the facts about hospice and that they choose to forgo aggressive treatment (a hospice benefit requirement). Studies have shown that there are deficiencies in knowledge about hospice services. A survey conducted by the National Hospice Foundation (2001) found that 83% of Americans do not know fundamental facts about hospice care. For example, 90% of Americans do not know that Medicare pays for hospice care and 75% did not know that hospice care can be home-based. This lack of knowledge is not directly addressed in our four databases. However, the CARE assessment service codes list a 1.6% incidence of hospice counseling during the assessment. From this we assume that the CARE assessment process in 1999 and 2000 did not generally dispel this lack of knowledge.

With regard to aggressive treatment concerns, studies have discussed that persons forestall or avoid hospice admissions to complete aggressive treatments (Hanson et al, 1996; McNeilly and Hillary, 1997; Orientlicher, 1992). However, this need to pursue aggressive treatment does not appear to be a major factor in our sample. MDS does have an indicator for
chemotherapy, an aggressive therapy. In examining the incidence of chemotherapy in our sample, we found that two persons prior to hospice admission did have chemotherapy and three non-hospice persons received chemotherapy (the time frame that this indicator reflected is 45 days prior to the CARE assessment up to their death). Another indicator of aggressive treatment is from the OASIS data set and is an indicator of rehabilitation. This indicator was not used by any of the hospice or non-hospice sample 45 days prior to the CARE assessment up to death. In summary, neither of these two variables appears to indicate that the desire for beginning or continuing aggressive treatment was a major consideration in our population of customers.

Since the ADL variable, the end stage variables, and the multiple serious diagnoses did not appear to differentiate between our group but only confirm that these groups appear to be similar, we went back to the findings of other studies to search for any other indicator we might want to include in our proxy. We examined the issue of terminality, national estimations of hospice eligibility rates, and any retrospective studies on hospice choice.

In summary, from what we are able to understand from this data, these CARE assessment customers were ill and needing of additional care, were struggling with serious and many times multiple serious diagnoses and did not pursue aggressive treatment. Consequently, we are assuming that the remaining 271 non-hospice individuals are potentially eligible for hospice services and we will use this as our comparison group.
APPENDIX D

Further information on Do Not Hospitalize Orders

We called three sources to inquire as to why none of our sample had a DNH order. Two of our respondents were social workers in skilled nursing facilities and one was an employee of a long-term care advocacy agency. All stated that people, including many professionals, do not know about DNH and that doctor’s do not discuss this form. The two social workers had been employed at their jobs approximately two years and only one had ever participated in completing a DNH. One of the social workers also stated that she felt two additional issues were occurring. First, that if a person is on hospice it is assumed that they will not return to the hospital and that the form is not necessary. Second, she felt that many times the facility prefers people “to go to the hospital to die” and thus doesn’t actively pursue DNH orders as they do DNR orders (private conversations with SS, MM, and LH, 1-19-05).
APPENDIX E

Survey instruments

Survey development and design was accomplished through consultation with our methodologist, Dr. Mary Zimmerman, our discussions with staff from KDOA and SRS, and feedback from Kathy Moen, Valerie Merrow, and Lana Walsh, as well as consultation with staff and director of the Office of Aging and Long Term Care.
CARE ASSESSOR SURVEY

Please complete each question and return the survey and the consent form in the envelope provided.

1) Have you conducted any CARE assessments within the last five years? (circle) Yes  No

2) How long have you been a CARE assessor? (number of years) ______________

3) How many CARE assessments do you complete in a month approximately? (number) __________

4) a) When you are conducting a CARE assessment, how often do customers state that they have seen their doctor within the last month? (circle)

Never    Sometimes    Often    Always

b) When you are conducting a CARE assessment, how often do customers state that they have had discussions about future care plans with their doctor? (circle)

Never    Sometimes    Often    Always

5) How much influence do you think you have in your customer’s decision-making process about choosing services at the CARE assessment interview? (circle)

None    A little    Some    A lot

6) How well do you feel that you can explain hospice services to customers during the CARE assessment interview? (circle)

Not at all    Poorly    Adequately    Very well

Comments:
__________________________________________________________________________________________
__________________________________________________________________________________________

7) In your last six (6) assessments how many times have you provided information concerning hospice services? (number) ________________

8) What, if anything, can KDOA do to assist you in sharing end-of-life care information and/or making referrals to services for end-of-life care at the CARE assessment?
__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________

Please complete the following section:
Gender: M  F  
Age: ____________  
Ethnicity: ____________________________  
County of practice: ____________

Type of agency (primary affiliation): (circle)  
Hospital, nursing facility, AAA  
Other__________________________  
Other____________________________

Educational level: (circle)  
BSW  MSW  RN

Thank you so much for taking the time to complete this survey. Your input is greatly appreciated and is invaluable.
HOSPICE CARE PROVIDER TELEPHONE INTERVIEW QUESTIONNAIRE

Please follow script.

Please think back to the time when you were the care giver/manager for __________ and answer the following questions:

If at any time you wish to stop this interview, please tell me and we will stop.

1) Did you and __________ ever discuss difficult topics, like what kind of care they wanted at the end of their life?

I would like you to think back to the time when you and your loved one were considering an admission to a nursing facility and a person came to ask you questions about that. The person was a CARE assessor and the form that was filled out was a CARE assessment. So please try to think back to that meeting.

2) Was the CARE assessor helpful to you in learning about services that were available to help care for __________

   If hospice is mentioned check here__________

   If not ask—Do you remember if hospice was mentioned as one of those services?

3) How did you learn about hospice services?

   At the CARE assessment? __________

   Other ________________________________

4) In your opinion what or whom influenced ______’s decision to enter the hospice?

5) How did the hospice help ______ at the end of his or her life?

   How did the hospice help you in caring for _______ at the end of his or her life?

6) Can you estimate how much time and/or money you spent caring for ______ while they were in hospice?

   How about before they entered hospice?

7) What problems or barriers did you experience in caring for ______ while he or she was in the hospice?

   Did the hospice help to deal with these problems?

8) Overall, what was your caregiving experience like in caring for ______ while he or she was in the hospice?

   How could it have been better?

9) Is there anything that you would suggest to CARE Assessors that they might do at the CARE assessment to better serve customers and their families?

Thank you so much for answering our questions. We know that your time is valuable and we would like to send you a small gift certificate to Wal-Mart. Is this your correct address? (verify address) We will be sending out the certificates in about a week.
NON-HOSPICE CARE PROVIDER TELEPHONE INTERVIEW QUESTIONNAIRE
Qualitative questions for primary care givers of deceased customers (telephone survey)
Please follow script.

Please think back to the time when you were the care giver/manager for ___________ and answer the following questions:

If at any time you wish to stop this interview, please tell me and we will stop.

1) Did you and ___________ever discuss difficult topics, like what kind of care they wanted at the end of their life?

I would like you to think back to the time when you and your loved one were considering an admission to a nursing facility and a person came to ask you questions about that. The person was a CARE assessor and the form that was filled out was a CARE assessment. So please try to think back to that meeting.

2) Was the CARE assessor helpful to _______ in learning about services that were available to help care for ______________
   If hospice is mentioned check here_________
   If not ask—Do you remember if hospice was mentioned as one of those services?

3) Did _______ know about the possibility of using hospice services?

4) What or whom influenced ______’s decision to remain in the community or enter a nursing facility and not use hospice services?

5) If you had it to do over again, would you have used ______ hospice care?
   Why or why not?

6) Can you estimate how much time and/or money you spent caring for ______ during the last six months of their life?

7) What problems did you experience in caring for ______ while he or she was in the community or nursing facility?
   Did someone or some agency help you deal with these problems?

8) Overall, what was your caregiving experience like in caring for ______? How could it have been better?

9) Is there anything that you would suggest to CARE Assessors that they might do at the CARE assessment to better serve customers and their families?

Thank you so much for answering our questions. We know that your time is valuable and we would like to send you a small gift certificate to Wal-Mart. Is this your correct address? (verify address) We will be sending out the certificates in about a week.
### CARE ASSESSMENT

**Client Assessment, Referral, and Evaluation**

**I. Identification Information**

<table>
<thead>
<tr>
<th>A. Client Social Security # (optional)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>B. Client Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>Last:</td>
</tr>
<tr>
<td>First:</td>
</tr>
<tr>
<td>Mr.:</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>C. Address</th>
</tr>
</thead>
<tbody>
<tr>
<td>Street:</td>
</tr>
<tr>
<td>City:</td>
</tr>
<tr>
<td>County:</td>
</tr>
<tr>
<td>State:</td>
</tr>
<tr>
<td>ZIP:</td>
</tr>
<tr>
<td>Phone:</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>D. Birth date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Month</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>E. Gender</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Male</td>
</tr>
<tr>
<td>2. Female</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>F. Date of Assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Month</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>G. Assessor ID#</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>H. Primary Language</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. English</td>
</tr>
<tr>
<td>2. German</td>
</tr>
<tr>
<td>3. Spanish</td>
</tr>
<tr>
<td>4. Other</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I. Ethnic Background (code)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Black (non-Hispanic)</td>
</tr>
<tr>
<td>2. White (non-Hispanic)</td>
</tr>
<tr>
<td>3. American Indian/Alaskan Native</td>
</tr>
<tr>
<td>4. Hispanic</td>
</tr>
<tr>
<td>5. Asian/Pacific Islander</td>
</tr>
<tr>
<td>6. Other</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>J. Mental Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. No</td>
</tr>
<tr>
<td>2. Yes</td>
</tr>
</tbody>
</table>

**II. PASARR**

<table>
<thead>
<tr>
<th>A. Have you or anyone else suggested you need to move to a nursing facility?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Yes</td>
</tr>
<tr>
<td>2. No (skip to section III)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>B. MM/MR Screen</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Client has been diagnosed as having a serious mental disorder</td>
</tr>
<tr>
<td>1. Yes</td>
</tr>
<tr>
<td>2. No</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2. What psychiatric treatment has the client received in the past 2 years (check all that apply)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Partial hospitalization</td>
</tr>
<tr>
<td>2. Inpatient hospitalization</td>
</tr>
<tr>
<td>3. Supportive services/Intervention</td>
</tr>
<tr>
<td>4. None</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3. Has the client been diagnosed with one of the following conditions prior to age 22 AND the condition is likely to continue indefinitely? (check all that apply)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Mental retardation</td>
</tr>
<tr>
<td>2. Related condition</td>
</tr>
<tr>
<td>3. None</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4. What resources of information were used for the MM/MR screen (check all that apply)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Client</td>
</tr>
<tr>
<td>2. Family</td>
</tr>
<tr>
<td>3. Health care professional</td>
</tr>
<tr>
<td>4. Clinical record</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>5. Referred for level II assessment?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Yes</td>
</tr>
<tr>
<td>2. No</td>
</tr>
</tbody>
</table>

**III. Functional Assessment**

Enter the code in the box to indicate the client’s level of self performance at the time of the assessment.

<table>
<thead>
<tr>
<th>1. Independent</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Supervision needed</td>
</tr>
<tr>
<td>3. Physical assistance needed</td>
</tr>
<tr>
<td>4. Unable to perform</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>A. Activities for daily living</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Bathing</td>
</tr>
<tr>
<td>2. Dressing</td>
</tr>
<tr>
<td>3. Toileting</td>
</tr>
<tr>
<td>4. Transfer</td>
</tr>
<tr>
<td>5. Walking, mobility</td>
</tr>
<tr>
<td>6. Eating</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>B. Instrumental Activities for daily living</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Meal preparation</td>
</tr>
<tr>
<td>2. Shopping</td>
</tr>
<tr>
<td>3. Money management</td>
</tr>
<tr>
<td>4. Transportation</td>
</tr>
<tr>
<td>5. Use of telephone</td>
</tr>
<tr>
<td>6. Laundry, housekeeping</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>C. Bladder continence (code: current performance for client)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Continent</td>
</tr>
<tr>
<td>2. Usually continent</td>
</tr>
<tr>
<td>3. Occasionally incontinent</td>
</tr>
<tr>
<td>4. Frequently incontinent</td>
</tr>
<tr>
<td>5. Incontinent</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>D. Cognition</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Coma/vegetative state</td>
</tr>
<tr>
<td>2. No</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2. Memory, recall</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Short-term memory</td>
</tr>
<tr>
<td>2. Long-term memory</td>
</tr>
<tr>
<td>3. Memory / recall</td>
</tr>
<tr>
<td>4. Decision making</td>
</tr>
<tr>
<td>5. Total Score</td>
</tr>
</tbody>
</table>

*Continued on next page*
### Communication

1. Expresses information content, however able
   - Understandable
   - Usually understandable
   - Sometimes understandable
   - Rarely or never understandable
2. Ability to understand others verbal information, however able
   - Understands
   - Usually understands
   - Sometimes understands
   - Rarely or never understands

### Current or Recent Problems and Risks

Check all the current or recent problems and risks the patient has had
1. Falls, unsteadiness
2. Impaired vision
3. Impaired hearing
4. Wandering
5. Socially inappropriate, disruptive behavior
6. Self neglect
7. Neglect, abuse, or exploitation experienced
8. None

### Support

A. Lives alone
   - Yes
   - No
B. Support, caregiver available
   - Full time
   - Part time—routine
   - Part time—intermittent
   - Not available

### Possible sources of payment for support services (check all that apply)
1. Self pay
2. Medicare
3. Private insurance
4. VA
5. Medicaid
6. Senior Care Act
7. Other:

### Referral Information

A. These services are needed to assist client to remain in community care

<table>
<thead>
<tr>
<th>Service</th>
<th>Needs</th>
<th>Service</th>
<th>Needs</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

B. Client, family choice for long-term care services (code for correct response)

1. Client's or family member's home without services
2. Client's or family member's home with services
3. Personal, residential, or boarding care
4. Nursing facility
   a. Name of facility:
   
   b. Is the client's stay in the nursing facility anticipated to be less than 3 months?
      1) Yes
      2) No

### Address where client can be contacted for further information and referral services

If different from Section II

<table>
<thead>
<tr>
<th>Field</th>
<th>Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name</td>
<td></td>
</tr>
<tr>
<td>Street</td>
<td></td>
</tr>
<tr>
<td>City</td>
<td></td>
</tr>
<tr>
<td>State</td>
<td>ZIP:</td>
</tr>
<tr>
<td>Phone</td>
<td></td>
</tr>
</tbody>
</table>

Comments:

[Blank space for comments]
APPENDIX F

Information on CARE Assessor survey returns.

Returns

Returned as undeliverable=166
Sample size reduced to 1161 (1327-166=1161).
  Returned completed=448
  Returned unusable=6
  Percentage returned=38%
Sample size reduced to 442 (448-6=442)
  CARE assessor not completed assessment in 5 yrs=83
Sample size reduced to 359 respondents.

Area Return Rates

  Johnson County=19%
  South Central Region=20%
  Jayhawk=27%
  Wyandotte=36%
  East Central Region=36%
  Southeast Region=37%
  Northwest Region=39%
  Northeast=40%
  Central Plains=43%
  Southwest Region=46%
  North Central Region=80%

Missing Values

  Missing values occurred in every variable except “currently doing CARE assessments”. The variables that had the least amount of missing responses were educational level (1), gender (1), years as CARE assessor (3) agency affiliation (6), and age (9). The variables with the greatest amount of missing responses were future planning with doctor (28), doctor visit (25), number of hospice discussions (25), CARE assessor influence (23), and ethnicity (21).