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Providing hospice care to children and young adults: A descriptive study of end-of-life organizations

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Abstract

Over the past two decades, end-of-life organizations have served an increasing number of children and young adults and expanded services important to terminally ill youth, and yet we know little about these organizations. The purpose of this study was to describe the characteristics of end-of-life care organizations that admitted children and young adults to hospice care. Using data from the 2007 National Hospice and Palliative Care Organization (NHPCO) Survey, we conducted a descriptive analysis of operational, mission, market, and financial characteristics, and explored a sub-analysis by age group. Our analysis revealed that these organizations had similar profit status, ownership, and payer mix when compared to the hospice industry. However, they differed in agency type, referrals, organizational size, geographic location, team member caseload, and revenues. We also found important differences in organizations that provided hospice care by age groups (infants, toddler, school-age children, and adolescents/young adults) in geographic location, region, agency type, accreditation, and team member caseload. These findings have managerial and policy implications.

Keywords

Hospice Care; Children; Young Adults; Hospices; Health Care Organizations

Hospice plays a critical role in caring for the terminally ill by providing holistic symptom-directed care encompassing the social, spiritual, and psychological needs at end of life.¹ Over the past two decades, hospice organizations have served an increasing number of children and young adults and expanded services important to youths at end-of-life. In 2007, there were 4,700 organizations that provided hospice care in the United States and 64% of them were willing to accept children – up from 18% in 2005.²⁻⁴

Approximately 74,000 deaths of children and young adults occur annually in the United States.⁵ Using the Centers for Disease Control age grouping, 47% of youth deaths involve adolescents/young adults (15 to 24 years old), 9% school-age children (5 to 14 years old), 6% toddlers (1

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to 4 years old), and 38% infants (< 1 year).⁵⁻⁶ The leading causes of infant death are congenital anomalies, short gestation, SIDS, and maternal pregnancy complications; whereas toddlers, school-age children, and adolescents/young adults often die of congenital anomalies, malignant neoplasms, heart disease, and influenza/pneumonia.⁵ Differences in the types of terminal illness and psychosocial development distinguish end-of-life care for children and young adults from that for adults. Caring for youths is often considered by the hospice industry as a specialty care service.

Hospice care has been shown to be effective for children and young adults in managing pain and symptoms⁷, spiritual distress⁸, and family bereavement⁹. Despite the proven benefits of hospice care for children and young adults, research on hospice organizations that provide specialty care to children and young adults is surprisingly scarce. As a result, we know little about the organizational attributes of these organizations. A few studies have investigated issues faced by these organizations, such as human resources¹⁰, referrals¹¹, reimbursement and payer mix.¹²⁻¹⁴ However, an overall description of these organizations is lacking. As more organizations develop care models for children and young adults, and more states explore policy and reimbursement changes for end-of-life care, research that improves our understanding of the organizations that actually care for youths is needed.^{13,15} Expanding our knowledge of provider organizations is an important contribution in improving the quality of end-of-life care for children and young adults with life-threatening illness. Therefore, the purpose of our study was to describe the characteristics of end-of-life care organizations that admitted children and young adults to hospice care.

Dimensions of Hospice Organizations

Consistent with prior relevant studies, our analysis focused on the following dimensions of hospice organizations that admit children and young adults; market characteristics, mission characteristics, operational characteristics, and financial characteristics.¹⁶⁻¹⁷

Market characteristics indicate where the organization provided care. *Geographic* location served by end-of-life organizations was included because their proximity to children's hospitals, typically located in urban settings, may make admitting children and young adults more common than for rural end-of-life organizations.¹³ *Region* was included because hospice admission for children and young adults may be more common in certain areas of the country, where children and young adults have poor overall physical health such as in the West.¹⁸⁻¹⁹

The organization's care philosophy to provide specialty hospice service to youth is captured in the mission characteristics. *Ownership* type was included because independently owned organizations are often not encumbered with corporate or HMO admission rules and regulations, and as such it may be more common for them to admit children and young adults.²⁰ *Agency* type was included because hospital-based organizations might admit terminally ill children and young adults to the hospice side of the business through an internal referral system rather than refer and transfer to an outside, non-affiliated agency.^{13,21} *Accreditation* was included because organizations that are accredited have demonstrated a commitment to meeting standards of care. That commitment to care may be extended to providing specialty care to children and young adults.²² Nonprofit organizations have been shown to admit more patients needing specialty services such as pediatric hospice than for profit organizations, so *tax status* was included in the analysis.²³

Operational characteristics demonstrate how an organization provided care. Smaller organizations have fewer financial and human resources to offer expensive and labor-intensive specialty care to children and young adults, so *size* was included.²³⁻²⁴ *Length of stay* was included because hospice admission practices have been shown to be affected by patients with shorter, less profitable lengths of stay.²⁵ In addition, due to physician and parental reluctance

to discontinue curative treatments, children and young adults are often referred to hospice late, so *referral* source was included in the analysis.^{11,13} *Caseload* was included because hospice team members often have greater intensity of work during the times of hospice admission and active dying. When patients have short length of stays, as do children and young adults, hospice care team members may need to maintain a lower caseload in order to provide more intensive care. *Care location* was included because end-of-life care can occur in the home, hospice facility, and hospital. However, youth often prefer to be cared for at home because they are close to family and in familiar surroundings.^{14,26}

The monetary aspects of providing care comprise the financial characteristics. *Payermix* was included because research has shown that non-Medicare payment types such as Medicaid and private insurance are the most common forms of reimbursement for youth hospice care.¹³ Others have reported that younger adults are more likely to receive charity care than persons over the age of 65 years.¹⁹ Research has also shown that providing care to children and young adults can have detrimental effects on organizational revenues and expenses causing the organization either not to offer care to this population or to restructure their payer mix, so *Revenue* and *Expenses* were included in the analysis.^{12,27}

Methods

Design and Sample

Data from the 2007 National Hospice and Palliative Care Organization (NHPCO) Survey were used in this secondary descriptive analysis. A total of 4,700 hospice organizations participated in the FY2007 survey, of which 504 organizations reported age data on their patients. For the purpose of this study, 269 hospice organizations that admitted children and young adults between the ages of <1 to 24 to hospice care during a 12 month period were eligible for inclusion. Age groupings, based on the Centers for Disease Control mortality reporting, included less than 1 year old, 1 to 4 years old, 5 to 14 years old, and 15 to 24 years old. Observations were excluded if the organization was not located in the United States or if the organization was government run. The final sample size was 259 organizations that provided hospice services to children and young adults.

Data Source

The NHPCO data set is a voluntary survey conducted annually with hospice organizations in the United States, Puerto Rico, Guam, and the US Virgin Islands.²⁸ Data are collected electronically based on the organizations' most recent fiscal year. Other data from state hospice associations, state governments, and for-profit hospice chains are included in the data set. Data quality is managed through variable definitions, respondent data verification, and NHPCO staff error checks.²⁸

Measures

Market Characteristics—*Geographic* location was defined as the area served by the organization. Organizations were asked to select the primary location they served -- urban, rural, or mixed rural and urban. *Region* was derived from the Census Bureau's designated areas based on the state in which the organization listed as its main address. Categories included Northeast, Midwest, South, and West.

Mission characteristics—*Ownership* was defined as corporate chain, managed care/HMO, integrated healthcare system, or independent. *Agency* type was measured categorically as freestanding, hospital-based, home health-based (HHA), or nursing home-based. *Accreditation* was defined as the organization being accredited by any one of the following organizations: Accreditation Commission for Health Care, Inc. (ACHC), Community Health

Accreditation Program (CHAP), Joint Commission on the Accreditation of Healthcare Organizations (JCAHO), and other agencies. *Tax status* was measured as either for profit or nonprofit.

Operational characteristics—*Size* was defined as average daily census (total number of patient days/365 days in FY2007).⁴ Organizations were categorized as small (1 to 25 patients/day), medium (26 to 100 patients/day), and large (over 100 patients/day).⁴ *Length of stay* was measured as the median length of patient stay for the organization.⁴

Source of referrals was categorized as physician, hospital, nursing facility, home health agency (HHA), self/family/friend, and other source of referrals. It was measured as referrals per patient. *Caseload* was defined as the number of patients for which a health care team member had responsibility or to which they were assigned. Organizations were asked to provide the number of patients in the average caseload for the following positions: nurse, social worker, home health aide, and chaplain. *Care location* was defined as the proportion of patients receiving inpatient or home care. Inpatient care included days of general inpatient care and inpatient respite care. Home care included days of routine home care and continuous home care.

Financial Characteristics—*Payermix* was defined as the proportion of patients receiving non-Medicare reimbursement including Medicaid, private insurance, charity, self pay, or other pay type. *Revenue* was measured as revenue per patient.^{23,29} Revenue included hospice revenue, fundraising revenue, and other revenue. *Expenses* was measured as expenses per patient.^{23,29} Expenses included hospice expenses, fundraising expenses, overhead expenses, and other expenses.

Data Analysis

The primary aim of our study was to describe the characteristics of end-of-life organizations that provide hospice care to children and young adults. Descriptive statistics were calculated on operational, mission, market, and financial characteristics, overall as well as by age group of admitted children and young adults. All analyses were conducted using Stata 10.0 software (Statacorp LP, College Station Texas).

Results

In 2007, children and young adults represented 0.67% of total admissions in hospice organizations that served children and young adults. The number of children and young adults admitted ranged from 1 to 101 with an average of 6 and a median of 3. Figure I depicts the percentage of youth admitted to hospice by age grouping. The most common age group was 15 to 24 year olds and the least common was 1 to 4 year olds.

Market Characteristics

Table I summarizes market characteristics of organizations. Although more organizations served a mix of rural and urban location, rural hospices admitted on average more children and young adults than urban or mixed rural and urban organizations. Youth between the ages of 1 and 14 were more often admitted to mixed rural and urban hospices, whereas infants less than 1 year old and adolescents/young adults were admitted to rural hospices. Organizations that admitted youth were most frequently located in the South. However, infants and toddlers were more often admitted in the West, and those ages 5 to 24 in the South.

Mission Characteristics

The mission characteristics of organizations that provided hospice care to children and young adults are displayed in Table II. Most organizations that admitted youth regardless of age category were independently owned. The most common agency type was freestanding hospices. Toddlers and adolescents/young adults were most frequently admitted to freestanding organizations, but infants and school-age children were more often admitted to nursing homes. All organizations were Medicare certified. Although most organizations that admitted youth were accredited, children ages less than 1 and 5 to 14 were admitted by organizations that were not accredited, and ages 1 to 4 and 15 to 24 to those that were accredited. Seventy-eight percent of organizations were nonprofit.

Operational Characteristics

The operational characteristics of organizations are displayed in Table III. Overall, large organizations accepted children and young adults more often than medium or small size organizations. Organizations that admitted school-age children had the highest median length of stay; those that admitted infants had the lowest. In general, organizations that admitted youth received most of their referrals from hospitals and the fewest from home health agencies. Nursing home and self referrals were more common in organizations that admitted infants less than 1 year old. Hospital, home health agencies, and other sources of referral were more common in organizations that admitted toddlers. Chaplains who worked for organizations that admitted children and young adults had the largest caseload and home health aides the smallest caseload. Nurses, social workers, and chaplains working for organizations that admitted infants less than 1 year old had the smallest caseload and organizations that admitted 15 to 24 years had the smallest home health aide average caseload. Social work, home health aide, and chaplain caseloads were the highest in organizations that admitted ages 1 to 4, and nurse caseload was highest in organizations that admitted 5 to 14 year olds. The most common location of care for all age groups was home care compared to inpatient care. Organizations that admitted infants less than 1 year old had the highest homecare and inpatient rates and organizations that admitted 5 to 24 year olds had the lowest homecare and inpatient rates.

Financial Characteristics

Figure II illustrates the non-Medicare payer mix for organizations that admitted children and young adults. For all age groups, organizations were most frequently reimbursed by the non-Medicare sources of private insurance followed by Medicaid and charity care. The least common reimbursement type for all age groups was self pay. Figure III depicts hospice revenue and expenses. Across the board, these organizations had higher revenues than expenses. Although revenues and expenses were very consistent across age groups, organizations that admitted infants had the highest revenues and those that admitted toddlers the lowest revenues. Organizations that admitted toddlers had the highest expenses, and those that admitted adolescents/young adults the lowest.

Discussion

Our study described the characteristics of end-of-life organizations that admitted children and young adults to hospice care. In addition, we sought to describe organizational differences based on admitting age groups.

Market Characteristics

We found that most hospice organizations, in our sample, provided care in a mixed rural and urban location, but that infants and adolescents/young adults primarily received care from organizations serving rural areas. Although others have found that hospices are primarily

located in urban areas,²³ our findings suggest that youth may return to their rural communities from urban-based children's hospitals once medical treatments have stopped.^{26,30} In addition, our finding that most organizations were located in the South was consistent with the 2007 hospice industry reports.^{4,31} However, the fact that infants and toddlers were more often admitted to organizations in the West may reflect poorer overall health outcomes in this region.¹⁸ It may also be the result of increased attention and interest in youth end-of-life care because of recent California pediatric palliative care reimbursement legislation (Nick Snow Children's Hospice & Palliative Care Act of 2006).³² Alternatively, people who reside in the West may be more receptive to hospice care, and hospice organizations in the West might be more willing to admit children and young adults. Future research might explore the difference in youth admission rates and prevalence of youth specialty services by region.

Mission Characteristics

Our study showed organizations that admitted youth were most often independently owned, freestanding, accredited, and nonprofit, which was consistent with hospice industry findings.^{4,33} An interesting finding was that more nursing homes cared for infants and school-aged children. Many freestanding hospices only offer home hospice care, so if a family requires inpatient care near their home, a nursing home may be the only type of organization able to provide local hospice care.⁴ Additionally, most organizations that admitted infants and school-age children were not accredited, which may suggest that accreditation has more to do with marketing and/or controlling internal operations than the acceptance practices of hospices. It may also suggest quality concerns with unaccredited organizations. As state and national hospice associations compile industry quality data, further exploration into the relationship between accreditation and quality of youth hospice care is warranted.

Organizational Characteristics

This study revealed organizations that cared for children and young adults were predominantly large. This differed from 2007 industry studies that reported most hospices were small size.⁴ This may suggest that large organizations with more financial and human resources are more capable of caring for specialty populations such as children and young adults.²³ We also found that organizations primarily provided hospice care in the home and had a median length of stay ranging from 19 to 21 days, which was in line with industry reports.^{4,31}

Contrary to other researchers that found physicians the most common source of hospice referral, our study revealed that organizations that admitted youth had hospitals as their primary source of referral.^{23,34-35} As noted earlier, many terminally ill children receive acute care at children's hospital prior to being admitted to hospice care, so it may be more common for the hospital to refer to hospice.

Our caseload findings across age groups were consistent with 2007 hospice industry reports with the exception of chaplain caseload. The Hospice Association of America³¹ reported average caseloads for nurses (13), social workers (25), home health aides (11), and chaplain (13). However, our findings revealed organizations that admitted youths had a chaplain average caseload ranging from 43 to 52, three to four times the national average. It may be that organizations that admit children and young adults have a philosophy that youth are not spiritually developed enough to need additional visits or hours of pastoral care.³⁶ Our findings may also suggest that the quality of spiritual care to youths and their families is compromised when chaplains maintain high caseloads. Feudtner et al.³⁷ found similar spiritual quality issues in children's hospitals the result of inadequate pastoral staffing, inadequate pastoral training, and timing of pastoral care. Thus further investigation into the antecedents and consequences of high pastoral caseloads is recommended.

Another interesting finding in caseload by age grouping was that organizations that admitted infants typically had lower average caseloads for all health care team members compared to organizations that admitted children, adolescents, and young adults. Several researchers have noted that hospice and homecare services have limited experience caring for infants, so in order to compensate for the lack of experience within the organizations, organizations may find it easier to reduce caseload and allow team members more time to care for these infants.³⁸

Financial Characteristics

In our study, the extent of non-Medicare payer mix was consistent with 2007 hospice industry reports of private insurance and Medicaid as the most common sources of reimbursement.^{4, 13,31} However, we found that organizations that admitted youths had average revenue of over \$12,000 per patient which differed from industry reports of \$7,273 per patient.³¹ The difference may be due to the fact that providing hospice care to youths is expensive and often not fully covered by insurance reimbursement. As an example, the average hospice per diem benefit for the California Medicaid program is approximately \$169/day for routine home care.³⁹ The cost of end-of-life care for children and young adults can range from \$33,283 to \$783,953 per youth or between \$182 and \$4296 per day.⁴⁰ Caring for youth in California would cost 1.08 to 25.4 times more than California Medicaid per diem rate for hospice services. Therefore, hospice may increase revenues in profitable sectors of the business to offset the cost of care to children and young adults.²⁷

There are some limitations in our study. First, a limitation in the survey design was the voluntary nature of the data submission process. There may be response bias because organizations that have an interest in the topic typically respond to the survey. This limits generalizability, so results of this study need to be interpreted with caution. Second, another survey design limitation was the omission of key variables. For example, the hospice survey did not ask respondents what services they provided to patients. As more states explore increasing reimbursement for youth end of life care to include palliative care services, research has shown that patients who receive palliative services face barriers to hospice admissions.⁴¹ Understanding hospice service delivery in relation to youth is important and its omission limits the descriptions of operational characteristics. Third, because the age reporting categories combined adolescents with young adults; it was not possible to report on organizations that provided only pediatric hospice care.

Conclusion

The goal of this study was to improve our understanding of the organizations that admitted children and young adults to hospice care. To our knowledge, this is the first study to investigate organizational characteristics of these hospices. Our analysis showed important similarities and differences between these organizations and the hospice industry in general, and also differences based on the age groups. As administrators assess whether or not to provide specialty hospice care to children and young adults, this information will provide baseline data for their decision making. It provides a starting point for conversations about improvements or modifications in organizational structures for those who admit children and those contemplating the addition of this service. For example, hospices with health team caseloads above the average for hospices that admit youths might need to evaluate the operational feasibility of admitting children and young adults. Those that operate with below average revenue and/or above average expenses might need to assess their financial ability to incorporate a specialty care service to youth.

As policy makers at the state and federal level debate financing of youth end-of-life care, this information will provide baseline data on organizational market, mission, operational, and financial characteristics to consider in policy decisions. It also allows policy makers to target

policy initiatives. For example, based on the low number of small and medium size hospices that admit youth, policies aimed at financially incentivizing small and medium hospices to admit youth might be explored. State hospice associations may want to explore additional training and education for home health agencies in referring children and young adults to hospice.

Based on our initial descriptive findings, further research on organizations that provide hospice care to children and young adults is warranted. Future research might focus on the organizational facilitators and barriers of admitting youth to hospice care, a comparison of organizations that admit youth to those that do not, and the impact of increasing reimbursement for youth end-of-life on organizational characteristics. Continuing this exploration will contribute to the quality of end-of-life care for children and young adults.

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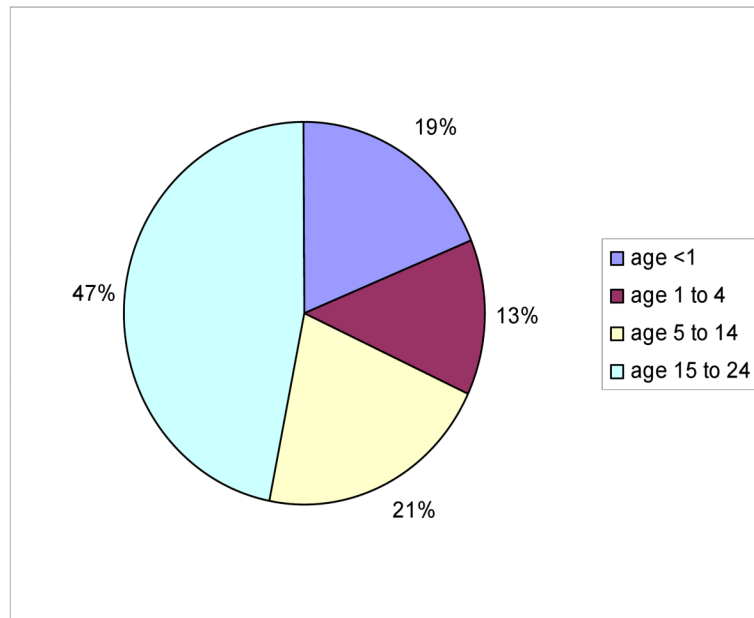


Figure 1.
Percent Children by Age Group

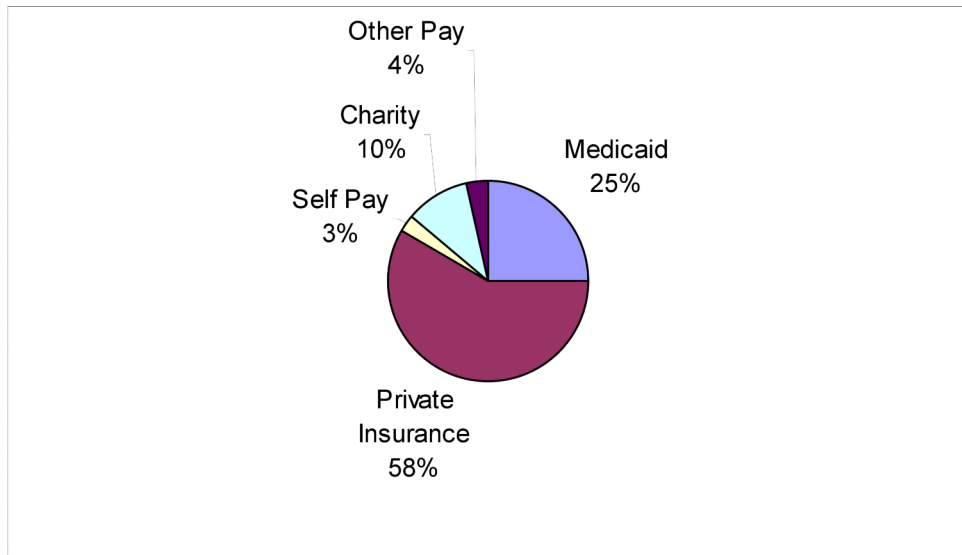


Figure II.
Overall Non-Medicare Payer Mix

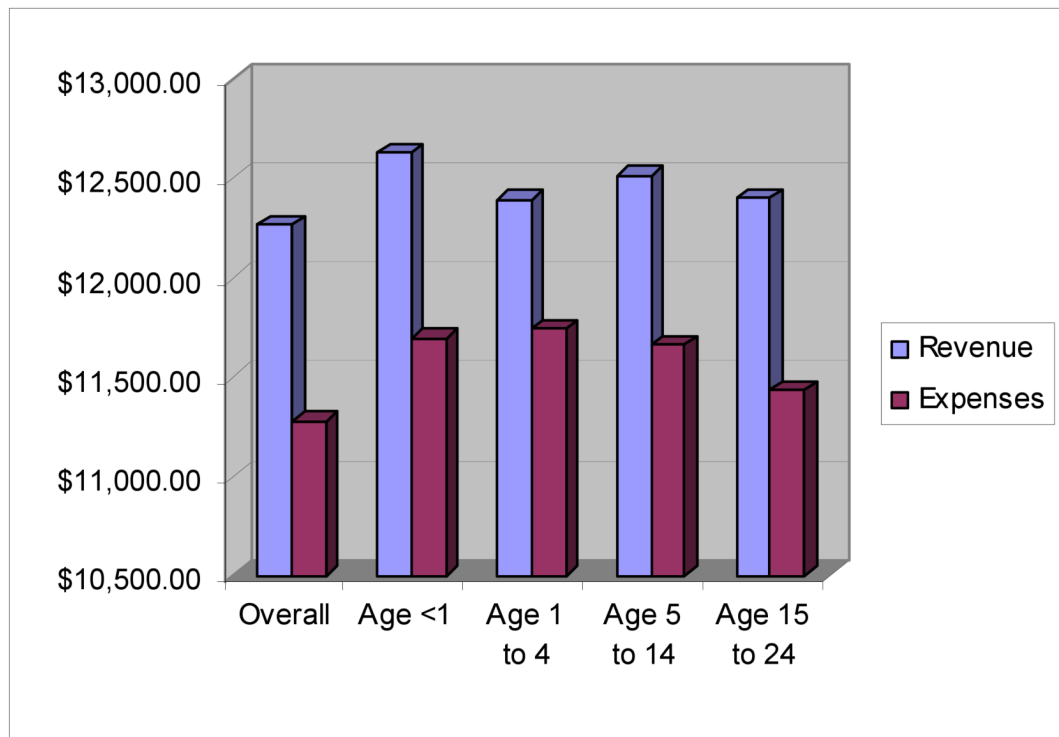


Figure III.
Hospice Revenue and Expenses by Age Group

Table 1

Market Characteristics

Geographic Region	Frequency	Overall		Age <1		Age 1 to 4		Age 5 to 14		Age 15 to 24	
		Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Rural	64	7.63	12.50	2.09	4.03	1.05	2.96	1.61	3.27	2.89	3.40
Urban	49	2.63	4.75	0.57	1.27	0.51	1.14	0.53	1.61	1.02	1.49
Mix	114	7.37	12.78	1.31	2.72	1.34	3.21	1.95	4.35	2.77	4.49
Region											
Northeast	28	4.57	3.44	0.89	1.57	0.75	1.04	0.96	1.37	1.96	1.50
Midwest	59	4.46	5.25	0.71	1.03	0.74	1.88	1.03	2.40	1.97	2.71
South	118	7.18	13.28	1.54	2.93	1.12	3.07	1.81	4.36	2.71	4.63
West	54	6.02	12.46	1.63	4.06	1.13	3.03	1.44	3.21	1.81	2.96

Table II

Mission Characteristics

Ownership	Frequency	Overall		Age <1		Age 1 to 4		Age 5 to 14		Age 15 to 24	
		Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Independent	115	8.22	14.96	1.70	3.74	1.35	3.55	2.07	4.69	3.03	4.85
Integrated	54	4.24	5.40	0.69	1.44	1.00	2.06	0.91	1.42	1.65	2.05
Corp. Chain	37	5.16	6.10	1.27	2.13	0.35	0.89	1.11	2.50	2.42	2.35
Mgd. Care	1	3.00	0.00	1.00	0.00	1.00	0.00	1.00	0.00	0.00	0.00
Agency											
Hospital	42	1.88	1.19	0.31	0.64	0.14	0.35	0.42	0.71	0.98	0.78
Freestanding	184	7.19	12.64	1.62	3.22	1.19	3.03	1.72	3.98	2.67	4.10
HHA	30	4.87	5.34	0.63	1.00	1.13	2.00	1.30	2.69	1.80	2.16
Nurs. Home	4	5.50	7.72	2.00	3.37	0.25	0.50	1.75	2.22	1.50	2.38
Accreditation											
No	104	6.22	13.55	1.46	3.58	0.99	3.21	1.52	4.17	2.25	3.51
Yes	149	5.99	9.03	1.22	2.19	1.00	2.27	1.44	3.06	2.33	3.73
Tax Status											
Profit	56	3.63	4.67	0.92	1.79	0.32	0.86	0.61	1.27	1.77	2.11
Nonprofit	203	6.70	12.09	1.40	1.40	1.18	2.95	1.70	3.88	2.41	3.91

Table III

Operational Characteristics

Size	Overall		Age <1		Age 1 to 4		Age 5 to 14		Age 15 to 24	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Small	1.35	0.59	0.25	0.55	0.20	0.41	0.20	0.41	0.70	0.66
Medium	2.37	1.65	0.46	0.91	0.39	0.86	0.61	0.74	0.90	1.00
Large	8.37	12.43	1.73	2.71	1.31	3.14	2.05	4.31	3.30	4.28
LOS	20.75	12.39	19.39	9.54	19.60	9.05	21.34	14.44	19.42	8.20
Referrals										
Physician	363.64	501.81	445.76	471.96	491.28	605.73	403.26	571.87	427.04	554.39
Hospital	535.60	758.51	816.13	955.35	823.21	1021.02	640.19	913.86	632.95	814.29
N. Home	194.31	264.34	257.97	309.33	256.47	310.65	203.95	307.57	227.72	285.99
HHA	34.73	99.59	43.31	93.84	43.85	105.58	35.62	92.17	40.43	113.12
Self	134.07	200.46	181.18	233.17	158.06	211.58	134.92	194.13	161.49	221.63
Other	87.04	212.94	116.19	215.98	157.32	348.38	123.27	301.03	104.58	204.02
Caseload										
Nurse	13.28	12.82	11.90	4.29	12.97	9.35	13.29	13.30	12.77	8.76
Soc. Work	26.04	17.33	24.17	6.92	26.58	24.04	25.77	12.91	25.04	7.92
Home aide	10.99	10.41	11.11	11.25	12.40	11.75	11.46	10.84	11.01	9.36
Chaplain	44.10	36.79	43.03	24.80	52.00	52.71	44.22	23.76	45.52	24.95
Care Location										
Home	64.95	27.77	67.26	31.34	62.06	24.82	65.70	28.77	64.29	25.66
Inpatient	2.04	2.41	2.38	2.30	2.20	1.87	2.28	2.68	2.10	2.04