



Comprehensive
**CANCER
CONTROL**
SOUTH DAKOTA

Palliative and End of Life Care in South Dakota Research Report



Report prepared for:

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Executive Summary: Palliative and End of Life Care in South Dakota

Aims

The purpose of this research project was to aid in the ongoing public health evaluation of the South Dakota Comprehensive Cancer Control Program (SD CCCP). The specific aim was to assess the availability of palliative and end of life (hospice) care in South Dakota (SD). This assessment of services explored whether SD healthcare facilities had: (a) a point of contact for palliative care, hospice services, and advance directives; (b) healthcare providers with specialized training in palliative and hospice care; and (c) a facility-based process for facilitating advance directives and advance care planning.

Methods

Trained research assistants conducted a brief telephone survey to identify the practice of palliative care and end of life services in the state of SD. Of the 668 healthcare facilities that were eligible to participate, 140 were not reached after multiple contacts and 73 refused. A total of 455 facilities completed the survey for a response rate of 68% (455/668). Diverse types of healthcare facilities participated in the study.

Results

Over one-half of the responding facilities reported not having a specific person as the point of contact for palliative care, end of life services, and advance directives. Across the different types of facilities, nursing homes reported the highest percentage of available points of contact for each of the three services (palliative care, hospice services, and advance directives). Of the participating facilities, 80% reported that there were no staff members who had completed training in palliative care, and 73% identified the same lack of staff members with training in end of life care. Palliative care training was most commonly reported in hospice/home health facilities (45%). Nearly 75% of facilities reported having a process in place for addressing advance directives with patients and slightly over one-half (53%) reported having a process in place for advance care planning.

Summary and Recommendations

The availability of a healthcare and allied healthcare workforce with specialized training in the areas of palliative and end of life care is a clear need in SD and is part of the solution to assuring access to quality care. Three overall recommendations are part of this report, including: (1) Engaging partners in advance care planning discussions, especially the three largest SD health systems, with the intent of establishing patient care model standards by 2015. (2) Promoting involvement from community groups in the advance care planning process by seeking their input in the establishment of patient care expectations. And finally, (3) developing end of life and palliative care training and education for healthcare providers that is accessible to rural and frontier care settings.

Palliative and End of Life Care in South Dakota

Background and Significance

The number of cancer related deaths is expected to increase dramatically as the older adult population grows to 19 million by the year 2050.¹ Nearly 25% of the current Medicare budget is spent on services in the last year of life, close to half of which occurs in the last 30 days.^{2,3} The comorbidities of this aging population translate to an increased need for outpatient and inpatient palliative and end of life care.

Palliative care is defined as “an approach that improves quality of life for patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification, and impeccable assessment and treatment of problems, including physical, psychosocial, and spiritual challenges.”⁴ The National Hospice Palliative Care Organization (NHPCO) adds, “palliative care extends the principles of hospice care to a broader population and ...ideally, would segue into hospice care as the illness progressed.”⁵ National and international support exists for early incorporation of palliative care. Inherent in the incorporation of palliative care are the components of advance care planning and advance directives. The former represents a process one undertakes with health care providers and/or family members in making decisions about future healthcare.⁶ The latter is a written document that serves as a healthcare directive for situations in which the individual is incompetent.⁶ Both advance care planning and advance directives are rooted in the principle of patient autonomy. Hospital palliative care programs are gaining momentum as the Center to Advance Palliative Care (CAPC) recently reported a steady 138.3% increase in these programs between 2000 and 2009.⁷ Full integration of palliative care as a component of comprehensive cancer care is expected by 2020.^{8,9} However, despite ongoing initiatives to promote engagement in advance care planning and completion of advance directives, most end of life decisions occur in the absence of either of these components.¹⁰

Despite the gain in the numbers of available hospital-based palliative care programs, geographical disparities play a significant role in palliative and end of life care access.¹¹ South Dakota (SD) was included in a recent Midwest survey of 52 medical organizations located within the four state region. Findings from this preliminary regional study indicated that 61% of facilities currently provided some form of palliative care.¹² Regional variations in end of life care include disparities related to use of services, actual types of care received, length of stay, number of physician visits, and transfer to hospice services.¹³ A disconnect exists between patient wishes and treatments; for patients with advanced cancer, locale dictates the likelihood of spending the final days of life in an intensive care unit.^{14,15} Rural patients face additional palliative access issues as compared with their urban counterparts, yet these patients prefer to remain in their communities at the end of life.^{16,17}

The increasing need for palliative care services for cancer patients coupled with the access challenges and disparities confronted by rural residents create an urgent need to further quantify the current palliative and hospice care services available throughout the state of SD. This study builds upon the limited and preliminary

evidence of palliative care services by strategically assessing services available from SD health facilities.

Purpose and Aims

The purpose of this research project was to aid in the ongoing public health evaluation of the SD Comprehensive Cancer Control Program (SD CCCP). In 2011, a new SD CCCP five year plan was designed with the primary intention to reduce the burden of cancer for the residents of the state. Specific strategies to increase palliative care services throughout the state are identified within the plan; however, there is a critical need for baseline measurement of end of life and palliative care services in order to examine the impact of the SD CCCP. The specific aim of this project was to assess the availability of palliative care and hospice services in SD. This assessment of services explored whether SD healthcare facilities had: (a) a point of contact for palliative care, hospice services, and advance directives; (b) healthcare providers with specialized training in palliative and hospice care; and (c) a facility-based process for facilitating advance directives and advance care planning.

Methods

The intent of this descriptive survey research was to reach all healthcare facilities across the state of SD. The healthcare facility list was compiled from SD DOH resources, including the provider list from the “Get Screened SD” program (focused on colorectal cancer screening),¹⁸ the registered or certified health or allied health service database,¹⁹ and the state vaccine registry.²⁰ To minimize burden, data collection for this project was completed in conjunction with a similar project assessing colorectal cancer screening capacity.

After removal of duplicates from the three SD DOH resources, 747 unique healthcare facilities remained on the compiled list. An additional 79 facilities were identified as ineligible prior to any telephone contact. Ineligibility was due to the following factors: (a) location outside of SD, (b) facility closed, (c) facility did not provide health services (e.g., dictation service or medical laboratories), or (d) facility was an Indian Health Services (IHS) or Tribal Health service site. The study procedures excluded all IHS and Tribal Health facilities because of a concurrent project led by the American Indian Cancer Research Foundation (2013) in the Northern Plains region of the U.S. After these exclusions, the total number of healthcare facilities eligible for participation in the study was 668.

The end of life and palliative care services survey consisted of seven items developed in collaboration with the SD CCCP Quality of Life workgroup (Appendix A). Items were designed to answer the research aims. Trained research assistants conducted the telephone surveys. To assure that consistent information was requested, all calls and e-mails were scripted. Facility managers were identified as the point of telephone contact. Managers were informed about the project and invited to participate. Permission was asked from each facility manager to complete the brief survey over the phone. Healthcare facilities were contacted multiple times via phone and e-mail.

Survey data were entered by the research assistants during the phone interview. Data analysis was completed using *IBM Statistical Package for the Social Sciences (SPSS) Version 21.0* (2013). All data were stored on a secure, password-protected server. Institutional Review Board approval was obtained from South Dakota State University.

Description of Sample

Of the 668 healthcare facilities that were eligible to participate, 140 were not reached after multiple contacts and 73 refused. A total of 455 facilities completed the survey for a response rate of 68% (455/668). Geographic distribution of responding facilities was 30% urban, 46% large rural, and 23% small rural.

Diverse types of healthcare facilities participated in the study. The largest number of participating service sites was from clinics, followed by assisted living facilities, specialty clinic, and both hospice/ home health agencies and hospitals (Table 1).

Table 1. Survey Response by Facility Type

Facility Type	Eligible	Survey Completion
Clinic	224	146 (65%)
Assisted Living	129	102 (79%)
Specialty Clinic	74	45 (61%)
Hospice/ Home Health Provider	58	40 (69%)
Hospital	63	40 (63%)
Nursing Home	46	33 (72%)
Nursing Home/ Assisted Living	49	35 (71%)
Other	25	14 (56%)

Results

Palliative and End of Life Care Services Point of Contact

Over one-half of the responding facilities reported not having a specific person as the point of contact for palliative care, end of life services, and advance directives. Across the different types of facilities, nursing homes reported the highest percentage of available points of contact for each of the three services (palliative care, hospice services, and advance directives). Of those responding facilities that reported an available point of contact, a varying range of health care professionals and other personnel were identified (Table 2).

Table 2. Point of Contact for Palliative and End of Life Care Services

Point of Contact Identified: Overall and by Facility Type	Point of Contact		Point of Contact Title/Role
	YES	NO	
Palliative care point of contact (n = 445)	34%	64%	MD, RN, LPN, MSW, PA, Administrator, Navigator, Palliative Care Team
Clinic (n = 146)	14%	86%	
Assisted Living (n = 102)	34%	66%	
Hospice / HH (n= 40)	38%	62%	
Hospital (n=40)	48%	52%	
Nursing Home (n=33)	63%	36%	
Nursing Home/AL (n=35)	57%	43%	
Specialty Clinic (n=45)	22%	75%	
Other (n=14)	9%	78%	
End of life care point of contact (n = 444)	39%	58%	MD, RN, MSW, Administrator, Social Security Director, Referral
Clinic (n = 146)	26%	69%	
Assisted Living (n = 102)	30%	68%	
Hospice / HH (n= 40)	68%	32%	
Hospital (n=40)	50%	50%	
Nursing Home (n=33)	70%	30%	
Nursing Home/AL (n=35)	66%	34%	
Specialty Clinic (n=45)	27%	71%	
Other (n=14)	14%	71%	
Advance directives point of contact (n = 444)	41%	56%	MD, RN, PA, MSW, Receptionist, Business Manager, LPN Manager, Care Coordinator, Referral
Clinic (n = 146)	20%	75%	
Assisted Living (n = 102)	47%	52%	
Hospice / HH (n= 40)	50%	48%	
Hospital (n=40)	48%	52%	
Nursing Home (n=33)	79%	21%	
Nursing Home/AL (n=35)	71%	26%	
Specialty Clinic (n=45)	33%	62%	
Other (n=14)	36%	36%	

Provider Training in Palliative and End of Life Care

Of the participating facilities, 80% reported that there were no staff members who had completed training in palliative care, and 73% identified the same lack of staff members with training in end of life care (Table 3). Palliative care training was most commonly reported in hospice/home health facilities (45%). Primary care and specialty care clinics were least likely to have staff trained in either palliative care or end of life care.

Table 3. Employees Trained in Palliative and End of Life Care by Facility Type

	Trained staff	
	No	Yes
Palliative Care		
Clinic (n=138)	89%	11%
Assisted Living (n=100)	71%	29%
Hospice/Home Health (n=40)	55%	45%
Hospital (n=37)	78%	22%
Nursing Home (n=30)	73%	27%
Nursing Home/AL (n=35)	80%	20%
Specialty Clinic (n=42)	93%	7%
Other (n=14)	93%	7%
Total (n=436)	80%	20%
End of Life Care		
Clinic (n=138)	85%	15%
Assisted Living (n=99)	67%	33%
Hospice/Home Health (n=39)	38%	62%
Hospital (n=37)	81%	19%
Nursing Home (n=29)	59%	41%
Nursing Home/AL (n=35)	63%	37%
Specialty Clinic (n=42)	91%	9%
Other (n=14)	93%	7%
Total (n=433)	73%	27%

Facility Process for Advance Care Planning

Nearly 75% of facilities reported having a process in place for addressing advance directives with patients and slightly over one-half (53%) reported having a process in place for advance care planning. Contacts were asked to describe their advance directives and care planning processes. Open-ended responses included the following statements:

- *[The processes is] completed upon admission and may include the social worker, a notary, an LPN, an RN, the family physician, a receptionist, a quarterly review, or at each care conference.*
- *Patients are given information during a clinic visit or a home visit.*
- *Process includes assistance of a lawyer.*
- *Process completed through the health department.*
- *Process completed during the pre-op phone call.*
- *Only if the patient asks for it.*

- *The electronic health record addresses the process.*
- *The patient is given a choice about full code or no code.*

Descriptions of the advance care planning process included brief answers specifying either the steps or timing of the planning, or which professional directs the process. Responses indicated the process takes place upon admission, when level of care changes, if patient requests information, and as needed. Implementation also varied by professional type including social worker, legal representative, and health care provider.

Discussion

The results of this statewide survey indicate that advance directives and advance care planning mechanisms are in process in many of the responding facilities. There exists, however, a lack of consistency regarding the professional point of contact for these processes. This finding aligns with national data acknowledging the absence of clear direction within the traditional health care system for the basic initiation of the advance care planning discussion.¹⁰

This statewide survey highlights the significant need for health care professionals with specialized training in the areas of palliative and end of life care, a need previously cited in an upper Midwest survey.¹² In SD, approximately 8% of the population spends their final days in nursing homes,²¹ where 73% of facilities have no staff trained with an understanding of palliative care. Elderly South Dakotans account for 40% of all state's hospitalizations,²² and cancer is one of the top conditions for hospitalization among individuals 40 years of age and older,²² yet, 81% of hospitals reported that no staff members are trained in end of life care. Even among hospice/home health care facilities, which provide significant services at end of life, 55% reported no staff with training in palliative care. The complexity of caregiving during end of life is compounded with the fact that 25% to 30% of patients experience frequent transfers across care sites in their final months of life.²³ Provision of quality palliative care and end of life care is a serious concern in SD, given that the vast majority of healthcare staff members are untrained.

Future Directions

Extending the existing partnerships that are committed to quality and accessible end of life and palliative care is needed. Life Circle of South Dakota and the SD CCCP Quality of Life workgroup are two SD entities that lead this effort. These groups engage in monthly dialogue to identify proactive approaches for improving education, research, and delivery of care for SD individuals during cancer survivorship as well as at end of life. The groups include representation from the three major health systems in SD, some of the health professions training programs, as well as rural practitioners. Additional partners that should be explored include the SD parish nurse network, area senior citizen groups, ministerial associations, and health professional organizations.

Specialized training in the areas of palliative and end of life care for healthcare professionals in SD is a clear need based on the survey results. Raising the level of

awareness is crucial for all healthcare workers who interface with patients and families in a variety of health care settings. End of life care and palliative care education is needed across health systems, but especially for hospital and long term care staff and providers. To this end, the Interdisciplinary Palliative Care course which is part of the Sanford School of Medicine curriculum is a valuable source of entry level knowledge for health professions students as well as practitioners with no prior training. South Dakota's numerous nursing education programs need to be engaged for addressing baseline curriculum content for palliative and end of life care providers. Nursing and medical professionals who have participated in train the trainer programs such as the End of Life Nursing Education Consortium (ELNEC)²⁴ and the Education for Physicians on End of Life Care (EPECTM)²⁵ should be tapped for outreach education that is available to rural and frontier sites via distance education technologies.

Additionally, the partners involved in statewide end of life and palliative care leadership should plan for development and dissemination of a systematic approach which engages patients in advance care planning discussions including the completion of the advance directive document. Comprehensive training programs are available (e.g., Respecting Choices^{®26}), but the costs associated with statewide dissemination and implementation are prohibitive. There is a beginning awareness of the necessity to build upon previous initiatives with advance directives to create consistent intentionality about advance care planning throughout SD, e.g., current discussions regarding implementation of the Physician Orders or Sustaining Treatment program (POLST[®]) to streamline communication of patient wishes among care settings.²⁷ The advance planning conversation must be a priority among physicians and supported by members of the interdisciplinary team.

The advance care planning process will ideally incorporate representation from all geographic regions and facilities for education and decision making. This statewide planning and implementation process will most likely require a three to five year process that would ultimately produce a scripted format ensuring a consistent and timely advance care planning approach for patients and families. To begin the process of addressing advance care planning discussions, it is recommended that the SD CCCP Quality of Life workgroup create an informational brochure and instructional video link regarding advance care planning. These materials would be created with the input of SD Life Circle and associated health care professional organizations and would be made available to providers and consumers much the same way as the advance directives brochure is currently utilized. Awareness is the first step, followed by dedicated efforts to assure access to quality end of life and palliative care in the state.

Recommendations

Based on the findings of this study, the following ideas to improve the quality of palliative and end of life care in SD are suggested:

1. Engage partners in advance care planning discussions, especially the three largest SD health systems, with the intent of establishing patient care model standards by 2015.
2. Promote involvement from community groups in the advance care planning process by seeking their input in the establishment of patient care expectations.
3. Develop end of life and palliative care training and education for healthcare providers that is accessible to rural and frontier care settings.

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Appendix A

Palliative and End of Life Care Survey

1. Does your facility have a particular person who is the point of contact for any of the following services?
 - a. Palliative Care Services No/Yes If yes, what is their name and title?
 - b. Hospice Services No/Yes If yes, what is their name and title?
 - c. Advance Directives No/Yes If yes, what is their name and title?
2. Is there a process in your facility to address advance directives with patients?
3. What is the process for advance directives?
4. Is there a process in your facility to address advance care planning with patients?
5. What is the process for advance care planning?
6. How many employees in your facility are specifically trained and/or certified in palliative care?
7. How many employees in your facility are specifically trained and/or certified in end of life care?