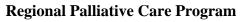


REGIONAL PALLIATIVE CARE PROGRAM

ANNUAL REPORT

APRIL 1, 1999 - MARCH 31, 2000



Grey Nuns Community Hospital Room 5211, 1100 Youville Drive West Edmonton, Alberta, T6L 5X8 CANADA Ph. (780) 450-7797/Fx. (780) 450-7640



REGIONAL PALLIATIVE CARE PROGRAM ANNUAL REPORT APRIL 1, 1999 - MARCH 31, 2000

TABLE OF CONTENTS

	Page Number	<u>:r</u>
I	Introduction	
II	Palliative Care/Philosophy/Goals/Objectives	
III	Components	
	A. Regional Palliative Care Office4B. Tertiary Palliative Care Unit10C. Referral Hospitals10D. Palliative Hospices11E. Home Care11F. Cross Cancer Institute12G. Grey Nuns Palliative Care Clinic13	
IV	Clinical Interpretation of Data 14	
V	Financial Interpretation of Data	
VI	Appendices	

I Introduction

The Regional Palliative Care Program (RPCP) is a community based model of palliative care services designed to increase access to high quality, cost effective palliative care services. The program has focused on providing access to palliative care support in the home and in all region health care institutions, while shifting the main area of end-of-life care from acute care, to home and hospice (hospices are in continuing or long term care facilities). As outlined in the objectives below, the program addresses clinical, educational, research and operational areas.

The Regional Palliative Care Program (RPCP) has been in operation since July 1995. Previously, access to palliative care services was inconsistent. Two palliative care units existed, one at the Edmonton General Hospital, and at the Misericordia Hospital. In 1992, 21% (290 patients), of all cancer patients dying in the region had access to these services. Palliative home care was also providing care in the community. In the 1999/2000 reporting year, access to palliative care consultation for cancer patients was 79.4% (Appendix 1). The RPCP has maintained this level of increased access through the community-based model of care every year since the program began. Although access to palliative care is reported for cancer patients, the program also supports patients with other diagnoses. In 1999/2000, ten percent of patients seen (126/1273) were patients with other diagnoses.

In 1992, 78% of oncology patients died in acute care hospitals, with an average of 20,000 patient days per year. In 1999/2000, the number of acute care days was 7639 a decrease of 14979 patient care days (Appendix 2-4). To meet this goal and sustain the decrease of acute care patient days, services were enhanced in the home, hospice and consultation to allow the transfer of care to other settings.

Central to the program is a patient and family focus (Appendix 5), with outcomes outlining the direction of the program. The components of care; home care and family physicians, outpatient clinics, palliative hospice, regional consultants, acute care (referral hospitals) and tertiary palliative care unit are centrally coordinated by the regional office (Appendix 6). The education and research programs are coordinated with the activities of the Division of Palliative Care Medicine, Department of Oncology, University of Alberta. Patients and their families have access to palliative care consultants regardless of the care setting. The program has criteria for admission for each level of care (Appendix 7), assisting in the streamlining of care for patients.

An advisory committee representing stakeholders from the community, home care, continuing care, acute care, Cross Cancer Institute, Alberta Health, and family practitioners provided input into the design and early operation of the program. (Appendix 8). This committee no longer meets, with regional input being accessed as required. Plans are proceeding for a Regional Program Council for Palliative Care.

II Palliative Care/Philosophy/Goals/Objectives

Palliative Care is defined as:

Active total care offered to a patient with progressive disease and their family when it is recognized that the illness is no longer curable, in order to concentrate on the quality of life and the alleviation of distressing symptoms in the framework of a coordinated service. Palliative care neither hastens nor postpones death. It provides relief from pain and other distressing symptoms and integrates the psychological and spiritual aspects of care. In addition, it offers a support system to help relatives and friends cope during the patient's illness and bereavement.

(Medical/Nursing/Midwifery Advisory Committee - United Kingdom)

The philosophy guiding the program is as follows:

Palliative care specialists (physicians and nurses), by offering support to primary caregivers (family doctors, interdisciplinary caregivers in the community and continuing care) and specialists when appropriate, will assist these people to provide quality palliative care through adherence to sound standards of practice.

- Every individual has the right to participate in informed discussions about the health care resource options that may help to optimize the quality of his/her life during the course of living with a life-threatening illness, especially when dying, and to choose the best possible options based on that information.
- Palliative care strives to meet the physical, psychological, social, and spiritual needs of patients
 and families, with sensitivity to their personal, cultural and religious values, beliefs and
 practices, through patient-directed supportive interventions by an interdisciplinary team of
 appropriately trained professionals and volunteers.
- Care should be delivered in a patient-focused, family-centered environment.
- A patient/family-driven program contributes to successful achievement of health care outcomes.
- The program will promote interdependence, with each participating organization having both autonomy and accountability for delivering quality, cost-effective palliative care within a coordinated network of services.

The goal of the program is to provide the highest quality of Palliative Care by the lowest cost provider. Care is provided in the home, in continuing care centres, in acute hospitals, and on a Tertiary (Acute) Palliative Care Unit. The patients/clients will move freely within the various components of the regional program.

The objectives of the program are to:

- Provide quality patient/client/family care through the development and implementation of palliative care standards.
- Provide cost-effective service by decreasing overall cost per case for palliative care.
- Eliminate duplication of service through a clear definition of roles and responsibilities of health care providers.
- Promote transfer of information in a comprehensive, timely and confidential manner through the use of common assessment and documentation processes.
- Prevent unnecessary hospital admissions of palliative patients/clients by assessment and management in the community.
- Promote standard palliative education by coordinating resources and collaborating in the development and implementation of educational programs.
- Promote research-based practice through collaborative efforts.

III Components

A. Regional Palliative Care Office:

The Regional Palliative Care Program office is located at the Grey Nuns Health Centre. The program:

- Coordinates the delivery of care in the region.
- Provides four consult teams (physicians/nurses) to assist primary caregivers in providing care to palliative patients and families at home, in continuing care and other health care institutions in the region with the exception of the Royal Alexandra Hospital, University of Alberta Hospital, and the Cross Cancer Institute.
- Is responsible for the development of standards, and common assessment tools.
- Identifies and advocates for funding needs.
- Provides education in palliative care for professionals and the public.
- Coordinates research with the Division of Palliative Care Medicine.
- Provides education and support for Palliative Care volunteers.
- Identifies, coordinates and encourages development of bereavement services.
- Manages the data and identifies outcomes.
- Identifies and plans for the future direction of the program.

The office liaises closely with the Division of Palliative Care Medicine, Tertiary Palliative Care Unit (Grey Nuns Community Hospital), Referral Centres, Community Hospitals, Palliative Hospices and Continuing Care, Home Care, Family Physicians, and the Cross Cancer Institute (Appendix 6) to meet the goals and objectives of the program.

REGIONAL PALLIATIVE CARE PROGRAM STAFFING - (March 31, 1999)

Title	FTE	Name
Program Director	1.0	Carleen Brenneis
Clinical Director	0.2	Eduardo Bruera
Acting Clinical Director		Robin Fainsinger
Secretary	1.0	Barb Jones
Secretary	0.5	Myrtle Gauld
Data Manager	0.5	Hue Quan
Volunteer & Bereavement Manager	1.0	Paula Brindley
Consult Physician	1.0	Anna Taube
Consult Physician	1.0	Peter Lawlor
Consult Physician	1.0	Jose Pereira
Consult Physician	1.0	Doreen Oneschuk
Consult Physician	0.6	Lemore Alima
Consult Physician	0.4	Tami Shandro
Consult Nurse	1.0	Gary Frank
Consult Nurse	1.0	Sally Turco
Consult Nurse	1.0	Patsy Cantwell
Consult Nurse	1.0	Larissa Podilsky
Consult Nurse	Casual	Bev Frost
Consultant	Casual	Beth Perry
Consultant	Casual	Linda Read-Paul
Consultant	Casual	Jacquie Peden

Staff Changes:

July 1, 1999 -Eduardo Bruera resigned. Robin Fainsinger appointed acting director September 1999 -Jose Pereira on leave of absence to become acting director of tertiary

palliative care unit.

August 12, 1999 -Lemore Alima and Tami Shandro hired as physician consultants.

Consultation:

The regional office coordinates palliative consultation teams who travel to see referred patients in the Community, Palliative Hospice, Continuing Care and other health care institutions with the exception of the Royal Alexandra Hospital, University of Alberta Hospital, and the Cross Cancer Institute. Referrals to the consultants are from the patient's primary physician, for consultation on symptom management and/or access to palliative hospice beds. The consult teams provide on call coverage 24 hours a day, 7 days per week to provide support to the primary caregivers. The teams have access to an emergency drug box, which can be sent to a home if required. Use of the drug box remains modest, due to the 24-hour access of pharmacies in the region. The guidelines and procedure for the emergency response kit have been updated and involve collaboration between home care, pharmacy, family physicians, tertiary unit and RPCP consult team.

Consult nurses will initially assess the patient for all hospice referrals and sometimes for symptom management. Based on information from attending physicians, the consult physicians will do the initial assessment for symptom management, and also asses new patients admitted to the hospices. Patients are contacted to arrange an appointment within 24 hours (Monday – Friday). Urgent referrals are seen as soon a possible any day of the week.

Referrals to the program continue to increase annually (1033 this year, a 4.7% increase) (Appendix 9). The increase of palliative patients based on cancer mortality between 1998 and 1999 in Capital Health was 7% (1511 in 1999 verses 1407 in 1998). Therefore, the continual increase in workload is mostly due to continued growth of the palliative population in this region.

The symptom profile for patients seen on referral remains consistent. The percentage of severe symptom distress, frequency of positive CAGE (22%) an indication of poor coping mechanisms, and incidence of abnormal Mini-mental State Examination (MMSE) suggest that the Regional Consultants continue to be involved in the more complex palliative care problems in the community (Appendix 10-14).

This year 409 distinct physicians referred to the consult team. Of this group, 282 are family physicians, representing approximately 35% of family physicians. A family physician survey was completed this year to identify family physician satisfaction and knowledge about the program in the areas of access to service, role of the consultant, clinical utility of consultation and physician education. The survey was sent to 828 family physicians in the region. Over two mailings, the return rate was 327 (39%). (Appendix 15). When asked if the palliative care physician consultant improves patient care 198/239 (82%) strongly agreed (6 or 7 on a 1-7 likert scale). There was also strong agreement that the consultant helps patients be cared for in their preferred setting (197/239 or 82%). The majority of family physicians (103) see 2 to 5 palliative patients per year.

Education:

Providing palliative care education to patients, caregivers and staff is a primary objective of the RPCP. In the family physician survey, when asked if palliative care is an important area of education for them, only 55% (158/290) identified that it was. However, the knowledge base for palliative care has grown rapidly in the last fifteen years and ongoing education is required. There was a wide variety in preferences to receive education and therefore different methods need to be utilized. Basic and continuing education is provided to a wide range of health professionals in a variety of settings to support them in providing quality palliative care to patients and caregivers. (Appendix 17). In collaboration with the Division of Palliative Medicine, new initiatives have been added to ongoing education:

a) New Initiatives:

- A video about palliative care services for patients and families was completed and circulated to acute care, continuing care (through consultants), and home care. The video "Palliative Care Services: Helping You Find the Right Place" was a joint project of the RPCP, Cross Cancer Institute and Caritas Health Group.
- The family physician handbook, Edmonton Aid to Palliative Care was updated collaboratively with the Alberta Cancer Board and Calgary Regional Health Authority. The Alberta Cancer Board now undertakes to provide it free of charge to all family physicians in Alberta.
- A handbook for family caregivers "A Caregiver's Guide A handbook about end of life care" was completed and is handed out to every palliative care patient at home by palliative home care. The project was a collaborative project between RPCP and Palliative Care Association of Alberta and Order of Lazarus. The handbook is available free of charge to all palliative caregivers in Alberta. The Caregiver Guide will be installed on the website www.albertapalliative.net as part of the Ed Net Project.
- The PallCare EdNet Course online and interdisciplinary, designed by Jose Pereira has completed its pilot and is now running a second course. Both courses are accredited courses for family physicians (Main-Pro C) and pharmacists. Nurses, physicians and interdisciplinary staff from our region are involved as facilitators.
- The first retreat of End of Life care for rural physicians and nurses had 25 participants and was very successful (based on summative evaluation). Further retreats are being planned.
- A clinical placement Main-Pro C course on palliative care was designed (by Anna Taube) and has started training physicians.
- RPCP consult nurse offered half day continuing education sessions to RN's in hospice, and a separate course for Licensed Practical Nurses (LPN) and Nursing Attendants (NA), highlighting palliative care practice for experienced staff. Hospice staff can now attend home care palliative orientations for new staff.

Ongoing Initiatives:

- Handbooks outlining palliative guidelines of care are provided to family physicians, residents (Alberta Palliative Care Resource), nurses (99 common Questions (and answers) About Palliative Care: A Nurses' Handbook) working with palliative care patients.
- The "palliative care tips" are updated and sent to all family physicians in the region on a monthly basis
- The Regional Palliative Care website www.palliative.org contains updates of the journal watch, palliative care "tips", divisional publications, nursing notes, and the assessment tools. Work has begun on the redesign of the website for 2001.
- The Annual Conference, "Palliative Care Education and Research Days" was held in the fall of 1999. Fifty percent of attendees are from other regions and provinces, primarily Western Canada.
- A program of bus rounds continues to be a primary education tool for continuing education
 of physicians and nurses on the delivery of palliative care in the community. The four-hour
 bus rounds take place twice a month and include presentation of cases at home and in
 hospice, discussion of clinical issues, and a number of journal clubs. Bus rounds now include
 family medicine residents and pharmacy.
- A monthly city wide round is held at the Grey Nuns Hospital. This round includes presentations by national and international speakers on education and research aspects of palliative care. Weekly palliative care rounds continue to take place. These rounds focus on the continuing education of palliative care health professionals in the region.
- The quarterly "palliative care newsletter" is a communication tool within the palliative care community. The newsletter is utilized as a wide communication tool to update staff of news, announcements and specific clinical information for the palliative care specialist.
- Family medicine residents attend the Tertiary Palliative Care Unit for a two-week rotation or arrange a community rotation. One nurse practitioner in oncology with an interest in palliative care was precepted by palliative physician consultants.
- The Tertiary Palliative Care Unit and has trained 21 visitors & fellows and 5 trainees (physicians) from all over the world during the year (Appendix 18). Increasingly visitors spend varying amount of time in other areas of the program, (Acute Care, Hospice, Community) depending upon their objectives, providing exposure to a regionalized community based program. Requests for education for nursing are increasing, with the increased interest in regionalized palliative care programs utilizing nursing consultants. This education program is the largest Palliative Care international training initiative in the world.

Research:

The RPCP in collaboration with the Division of Palliative Medicine continues to be highly productive in research in support of evidenced-based practice. Current publications are listed in Appendix 19.

In February 2000, the Alberta Cancer Board supported a province wide palliative care research initiative with three-year funding. Seven streams for research have been determined: cancer cachexia/anorexia and fatigue, population studies, cognitive impairment, opioids/analgesics, psychosocial/communication, education/clinical practice guidelines, and assessment. Robin Fainsinger has been appointed interim leader. Broad collaborative interest has been established, with new studies, such as "Economic Evaluation of Regional Palliative Care Program for Terminally Ill Cancer Patients" and "Dressing for Subcutaneous Sites: What is Best Practice?" being initiated with adjunct funding agencies.

Volunteers:

This year 122 specially trained volunteers gave 13859 hours of their time to help support patients and families at the Hospices, Tertiary Unit and in the home, as well as in the bereavement Support Program (appendix 20). The 27 hour, three part training program which all Palliative Care Volunteers are required to take continues to be offered on a monthly basis An average of 55 volunteers attended each level of the training (table 1) which is facilitated by staff and volunteers from the program.

Table 1

REGIONAL PALLIATIVE CARE PROGRAM
PALLIATIVE CARE VOLUNTEER TRAINING
ATTENDENCE

	1996/97	1997/98	1998/99	1999/00
SESSION 1	73	68	68	50
SESSION 2	61	56	44	56
SESSION 3	50	35	56	59
TOTAL	<u>184</u>	<u>159</u>	<u>168</u>	<u>165</u>

The challenge to retain trained volunteers in this area continues (appendix 21). However, for the fourth year running the volunteer program has shown an increase in retention (70% since the program began.)

Bereavement:

The Bereavement Support Program operates at all hospices and the Tertiary Palliative Care Unit and is shared with the community. Following on specially developed guidelines it provides initial support and information to recently bereaved family members. Where requested it also facilitates their connection with appropriate program and community resources.

Within seven days of the patient's death, a bereavement package, with a personalized letter, grief information booklet and a bookmark identifying key community and program numbers to call is mailed to the primary bereaved caregiver. Throughout its first complete year of operation 349 such packages were mailed

Additional support and guidance with grief related issues was offered within one month of the mail out of the packages through 89 staff and 184 volunteers follow-up calls to bereaved family members. Additional 264 calls relating to grief and bereavement issues have been received from bereaved family members. To assist in connecting all bereaved persons with appropriate bereavement resources in the region, a bereavement resource list has been developed and mailed to over 200 information and support facilities within the region. The resource list is updated annually.

Grief and bereavement support is provided on an ongoing basis for the patients and their families and friends. Education and support is provided for Hospice and Homecare Staff, Medical Students and Fellows, Family Physician Residents on the Tertiary unit and the volunteers through regular support groups and educational sessions. Education and support is also provided to staff in other community care facilities when requested.

B. Tertiary Palliative Care Unit:

The 14-bed tertiary care unit is located at the Grey Nuns Community Hospital. The role of this Tertiary Unit is to provide care and support for patients and families dealing with the most complex physical and psychosocial issues within Northern Alberta. Patients will be admitted, symptoms addressed, and when appropriate discharged to an alternative setting. The expected length of stay is 15 to 30 days to treat complex problems. The median length of stay is 20 days, within the goals of the unit, and the mean length of stay has increased form 24 to 27 days. (Appendix 22). There continues to be a group of patients where the most appropriate setting for end-of-life care is the tertiary unit, due to the severity of symptoms and psychosocial support needed. This group receives care on the unit for a longer length of time, which does impact the overall length of stay.

Overall the frequency and severity of symptoms continues to be significantly higher in patients admitted to the Tertiary Unit than those admitted elsewhere. The patients are younger (average age is 61 versus 72 in the hospices), with a higher incidence (73%) of Stage 3 pain, indicating a poorer prognosis for pain management (Appendix 23-26). This suggests that the Tertiary Unit is being used appropriately for patients with demographic and clinical indications of higher distress.

C. Referral Hospitals:

The Royal Alexandra and the University of Alberta Hospitals both have full time nurse/physician palliative care consultants. Interdisciplinary support is available at both sites. This year data is available for the Royal Alexandra palliative care program only. The number of referrals continues to increase each year. This year a 17% increase (421 in 1999/2000 versus 361 in 1998/99) was noted. A slight increase in nurse consultant hours (.2fte) has been implemented to adjust to increasing referrals. A significant group of referred patients do not have a cancer diagnosis (12%).

Close to half of these patients do not have a palliative care diagnosis on admission, and were admitted for investigation. In addition, 75% of patients are discharged to an alternative setting, as discharge planning with attending staff, patients and families is an integral and time consuming component of consultations.

Length of stay in this setting remains stable suggesting timely admission to the tertiary palliative care unit and hospice settings, as well as the prevention of unnecessary delay and bed use in the acute care setting. However, the new palliative care diagnosis for many patients as well as the need for patients and families to consider different options, will always been an unavoidable component of providing compassionate care (Appendix 24-28).

D. Palliative Hospices:

Palliative Hospices consist of 57 beds located on four sites:

•	Mel Miller Hospice, Edmonton General Hospital (Caritas)	22 beds
•	Norwood Hospice, Capital Care Norwood	20 beds
•	St. Joseph Hospice, St Joseph Auxiliary Hospital	14 beds
•	Youville Nursing Home	1 bed

Palliative Hospices provide care to patients whose care cannot be managed at home, do not require acute care services and accept a "no code" status. A Registered Nurse provides care in the Hospice 24 hours/day, and interdisciplinary and medication support is enhanced as compared with continuing care staffing. The shorter than expected length of stay of 36 days (median 17), has allowed the hospices to care for 545 patients in the last year. The Palliative Hospices have had an increase each year in patient admissions of between 5-14% since the program began. The occupancy rate of 92%, allows for rapid admissions from home or acute care (Appendix 32). The rapid turnover of patient care involving admissions, family conferences and support needed near death, does impact on workload for palliative hospices that were designed for end of life care for relatively stable patients. Workload will continue to be monitored in relation to acuity.

Access to the Hospices is centralized through the regional office. Assessment is completed wherever the patient is located in the region. The patient is admitted under their family doctor whenever possible. The referring family physician continued to care for the patient in 34% (167) of referrals. When the referring physician is not able provide care in Hospice, a family physician interested in palliative care is approached to transfer care. It was expected that specialists would transfer care to a family physician, and this occurred 31% (154) referrals this year. A further 156 (31%) of family physicians transferred care to another physician. (Data on referring physician was available for 496/545 referrals). In all cases, an initial consult is completed on admission by a palliative physician consultant, with follow-up by the consultants until stable.

The proportion of patients with cognitive impairment as measured by the abnormal MMSE, is highest in Hospice of all settings (46%) on admission (Appendix 33) and is often one of primary reasons for referral to hospice. (Appendix 34-36). The clinical symptoms of patients in hospices as measured by the ESAS remains lower than acute or tertiary care, but will continue to be monitored in relation to acuity.

Transfers from Palliative Hospice to acute care remain low (2%), suggesting the Palliative Hospice staff and consultants continue to deal with symptom issues proactively in Hospice setting.

E. Home Care:

Palliative Home Care is available to clients and their families 24 hours per day, seven days per week. Care is provided collaboratively with the family physician, with consultants available upon request of the physician. The expected length of stay is 3 to 4 months (Appendix 37), with clients expected to be requiring symptom management and psychosocial support. The same palliative assessment tools are utilized by home care staff to provide proactive assessment for clients.

The goals of care are directed by the client and the family. The Home Death Assessment Tool (HDAT) assists case managers in discussion in determining whether or not a home death is desired by the client, caregiver. The HDAT is a set of questions asking client and caregivers wishes for a home death, and also identifies if the family physician is supportive of a home death. (Appendix 38). Resource allocation is guided by the client and family desire for a home death and the appropriateness of the home as a site of care. A wide variety of services are available in the home, including case management, professional nursing, rehabilitation services, social work, respiratory therapy, contracted support services (LPN and personal care). Treatment for hypercalcemia, delirium with treatments such as hypodermoclysis, opioid rotation, and respite support are common practices in the home. There are regional differences within the region on occurrences of home deaths with higher percentages occurring in the south and west. Closer analysis of the data, including the HDAT will be reviewed over the next year.

Home care has appointed a manager responsible for palliative care region wide (August, 1999). This appointment will assist in supporting palliative care within home care and interacting with the program. The southeast and southwest palliative care staff will be amalgamating in April 2000 to assist with 24/7 coverage and increase collaboration.

A home chart has been implemented in the north and south side offices to enhance communication at the site of care. The home chart travels with the client if they attend outpatient clinics, emergency or are admitted to hospice, to assist with continuity of care.

The number of discharges from home care this year was lower than the previous year (862 in 1999/2000 verses 904 in 1998/99). This result is related to our ability to identify and avoid including data on those individuals assessed but not admitted to palliative home care (106). The population size appears stable compared with the previous year. Diagnosis continues to be primarily cancer (Appendix 37). The average length of stay of 101 days is within expected parameters for clients requiring active care to alleviate symptoms.

Data on ESAS and MMSE will be available as the palliative home care database is in the process of being completed. Palliative home care implemented a cost tracking form in September 1999 to relate

professional and support services to ESAS and HDAT scores. This information is included in the database.

F. Cross Cancer Institute:

The RPCP maintains a liaison with the Cross Cancer Institute in three ways:

• Pain & Symptom Control Clinic: This interdisciplinary clinic provides assessment and consultation to cancer patients from any health care region. The clinic continues to deliver tertiary referral consultation to 255 cancer patients with a physician referral (Table 2).

Table 2

CROSS CANCER INSTITUTE – PAIN & SYMPTOM STATISTICS FOR PATIENTS SEEN BETWEEN April 1, 1999- March 31, 2000

New Follow-up		Total	
Clinic	142	113	255
Referral ^a	233	152	385
Total	375	265	640

^a Referrals to Pain & Symptom team seen outside of clinic.

- Internal Consultants: Dr. Watanabe increased her availability to .5 FTE, beginning September 1999, to provide inpatient consultation as well as support the pain & symptom and an oncology clinic. This increased support and visibility most likely accounts for the increased referrals and ability to follow patients until stable (Table 2). The nurse consultant (.8 FTE) and pharmacist (.5FTE) provide consultation, with the support of Dr. Watanabe. Outpatients are followed with telephone calls until stable and are referred to the regional palliative consultants if required.
- Community Liaison Nurse: This nurse provides discharge planning to outpatients who are identified as requiring palliative care (Table 3). This position is instrumental in ensuring patients discharged from the Institute have a family physician, are referred to home care as appropriate and are aware of resources available in the community. A total of 304 referrals to support services (e.g.: home care, new family physician, pain & symptom clinic) were made for 288 patients discharged. The nurse ensures continuity of care by sending a letter to the family physician and home care including an information package **on** symptom assessment, and about palliative care services.

Referrals for Palliative Hospice from the Cross Cancer Institute are completed by the community liaison nurse. The nurse also has available a list of all physicians accepting new palliative patients, to assist patients who do not have or request a change in family physicians. This list is now produced by the family health council, and is utilized by all areas of the Regional Program.

Table 3

COMMUNITY REFERRALS TO PALLIATIVE CARE CROSS CANCER INSTITUTE April 1 1999-March 31, 2000

	In Region	Out of Region	Total
Total	209	79	288
Monthly Average	17.4	6.6	24

G. Grey Nuns Palliative Care Clinic:

Once per week, the staff of the Tertiary Palliative Care Unit support the outpatient clinic for palliative care patients with symptom issues requiring multidisciplinary input. The clinic will book up to three new and two follow-up patients. Last year patients (23 new, 7 follow-up) were seen.

IV Clinical Interpretation Of Data

The availability of clinical and demographic information from the Regional Palliative Care Database allows comment on patient flow, access as well as providing overall clinical information about the various areas of the program. The Tertiary Palliative Care Unit has the highest percentage of patients with severe symptom distress such as pain (57% pain score 5/10 or more) on admission compared with Hospice (37%) or acute care (19%). The clinical profile of patients continues to support that patients with most severe symptoms are cared for on the Tertiary Unit.

Referral sites consult with a more mixed population of palliative care patients, who may be admitted for initial investigation of a palliative diagnosis, or deterioration requiring acute care intervention for investigation, surgery and/or stabilization. Discharge planning is a major role for the palliative care teams.

Hospices short length of stay (36 days) with a median of 17 days is much shorter than the expected 60 days. This short length of stay of less than 3 weeks for over half the patients increases the demands on the staff in this setting. The technical requirements for care and acuity of ongoing management and/or potential management of some patients referred to this setting, has also placed an increased burden on an interdisciplinary team with limited resources. These factors as well as the increased cancer incidence and increasing using of hospices by patients with a non-cancer diagnosis will continue to require careful monitoring to determine the need for increased hospice beds.

There is a decrease in the percentage of cancer deaths in the home (Appendix 39) noted (13 % of all cancer patients in 1999/2000 verses 16% in 1998/99) An increase in hospice admissions correlates with a reduction in professional and support services hours provided in the homes of palliative clients for a period of ten months. By January 2000, an increase in resource allocation to palliative clients in the home resulted in a significant decrease in hospice admissions from the home as anticipated. The consistent failure to achieve the projected plan of 40% home care cancer deaths suggests that this outcome requires reevaluation. A more relevant outcome measure for evaluation of the effectiveness

of palliative home care support may be increased duration of care in the home, with a shorter duration of eventual hospice admissions.

This year the Division of Epidemiology provided the number of patients living outside of the region that died in Capital Health (146). These patients are included in the analysis since they do effect clinical workload. (Appendix 39). Patients from out of region are not included in identifying access to palliative care (Appendix 1).

Access to palliative care consultation continues to be high at 79.4% (Appendix 1) and is a major goal of the program. The availability of consultation at any site of care allows for this high access and supports patients in their site of care.

V Financial Interpretation of Data

To provide a community based palliative care program, where palliative services are provided in the home and hospice rather than acute care when appropriate, resources must transfer to the community to provide the care. Added costs of the palliative care program are identified in Appendix 40. Significant cost savings still occur to the region from the decrease of acute care patient days after adjusting for the increased resources (Appendix 40). The overall cost decrease per case for palliative care has been achieved by the transfer of patients from acute care beds to Palliative Hospice in particular. Home care may be delaying admission to institutional care, but data to prove this is lacking.

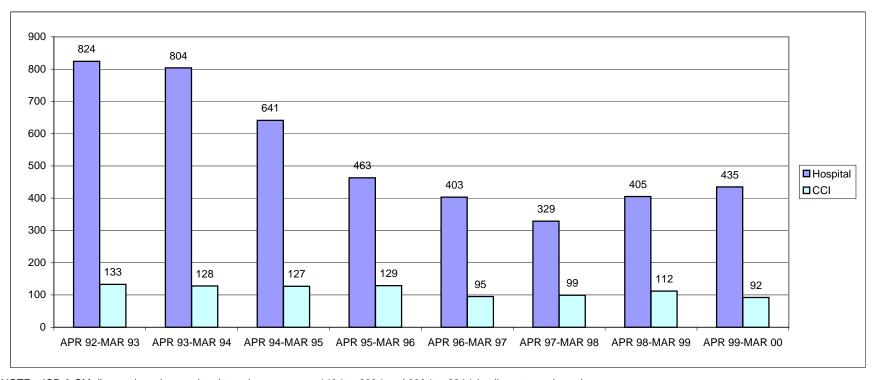
The number of cancer deaths in the Capital Health region is expected to increase by 46% (1513 in 1999 verses 2206 in 2011) over the next 10 to 12 years, according to the Alberta Cancer Board. The increase in the next few years will be approximately fifty patients per year. Therefore, if current trends in where people die continues, it is expected that cancer deaths in acute care will increase next year by 20 (40% of cancer deaths now occur in acute care) resulting in up to 340 more acute care days for final admissions due to cancer. Hospice deaths could increase by 16, adding 496 hospice days and home care days by 656 for patients (6.5) who chose to die at home. This increase has huge implications for the program and highlights the need for planning. It is clear the Regional Palliative Care program needs to prepare for the increasing workload in conjunction with it's many partners. These discussions have begun and will need to increase in the coming months and years.

Review of Patients Receiving Palliative Care Consultation and Actual / Predicted Number of Deaths Due To Cancer

Review of Patients Receiving Palliative Care Consultations

1992	Number of Patients Receiving Palliative Care Services (1)	290	
			21.60%
1992	Actual Number of Deaths Due to Cancer (2)	1341	
NOTE	 Estimate of patients seen in the Acute Palliative Care Unit and at the Misericordia Hospital in1992 Information provided by the Alberta Cancer Board, Epidemiology. Includes Edmonton, St. Albert, and Strathcona County. Subtotals for areas include: Edmonton: 1275 deaths. St.Albert:59 deaths. Strathcona County: 7 deaths 		
Actual / Predicted Num	ber of Deaths Due To Cancer		
1999	Number of Region 10 Cancer Patients Receiving Palliative Care Consultations (3)	1147	70.40/
1999	Predicted Number of Deaths Due to Cancer (4)	1444	79.4%(5)
NOTE	 3- Number of unique admissions/referrals to CHA palliative care consultations from Jan 01,1999 to Dec 31, 1999 INCLUDES: unique Region 10 palliative admissions to the Tertiary Palliative Care Unit and Palliative Hospices, and through referrals to the Palliative Consult teams at the Acute Care Hospitals and the Regional Palliative Care Program. DOES NOT INCLUDE unique patients seen at the Cross Cancer Institute, or Home Care. Source: Palliative Care Information System (Dec 06, 2000) 4-Information provided by the Alberta Cancer Board, Epidemiology. Includes Edmonton, St. Albert, and Strathcona County. The number is provisional as some deaths may be registered in subsequent years as methods of coding on the Alberta Cancer Registry have varied through the years 5-Compares number of patients with consultations from Jan 01,1999 to Dec 31, 1999 		

TOTAL CHA Hospital Deaths with a Most Responsible Diagnosis of Cancer, and Deaths at the Cross Cancer Institute**



NOTE: ICD-9-CM diagnostic codes used to determine cancer are 140.* to 208.* and 230.* to 234.* (malignant neoplasms)

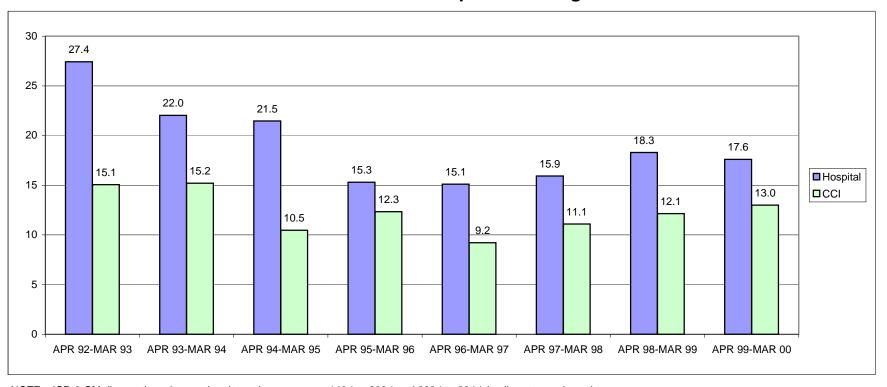
ICD-9-CM diagnostic codes used to determine palliative care, chemotherapy or radiotherapy are V58.0, V58.1 and V58.89 (to 97/03/31) and V66.7 (from 97/04/01) with a secondary diagnosis of 140.* to 208.* and 230.* to 234.*, or V10.* to V10.9*

The numbers provided in the tables are provisional as some cases (or deaths) may be registered in subsequent years.

Methods of coding of cancers on the Alberta Cancer Registry have varied through the years; therefore, caution should be exercised when comparing this data to that of previous years

**Source: Evaluation, Information and Research , for CHA data-July 2000 Cross Cancer Institute data-May 2000

Average Length of Stay- CHA Hospital and Health Centres and Cross Cancer Institute(CCI) Deceased Patients with a Most Responsible Diagnosis of Cancer**



NOTE: ICD-9-CM diagnostic codes used to determine cancer are 140.* to 208.* and 230.* to 234.* (malignant neoplasms)

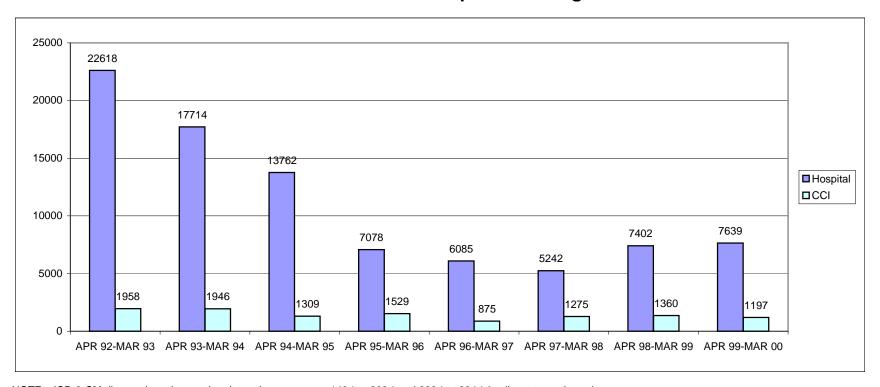
ICD-9-CM diagnostic codes used to determine palliative care, chemotherapy or radiotherapy are V58.0, V58.1 and V58.89 (to 97/03/31) and V66.7 (from 97/04/01) with a secondary diagnosis of 140.* to 208.* and 230.* to 234.*, or V10.* to V10.9*

The numbers provided in the tables are provisional as some cases (or deaths) may be registered in subsequent years.

Methods of coding of cancers on the Alberta Cancer Registry have varied through the years; therefore, caution should be exercised when comparing this data to that of previous years

**Source: Evaluation, Information and Research , for CHA data-July 2000 Cross Cancer Institute data-May 2000

Total Days in Hospital- CHA Hospital and Health Centres and Cross Cancer Institute(CCI) Deceased Patients with a Most Responsible Diagnosis of Cancer**



NOTE: ICD-9-CM diagnostic codes used to determine cancer are 140.* to 208.* and 230.* to 234.* (malignant neoplasms)

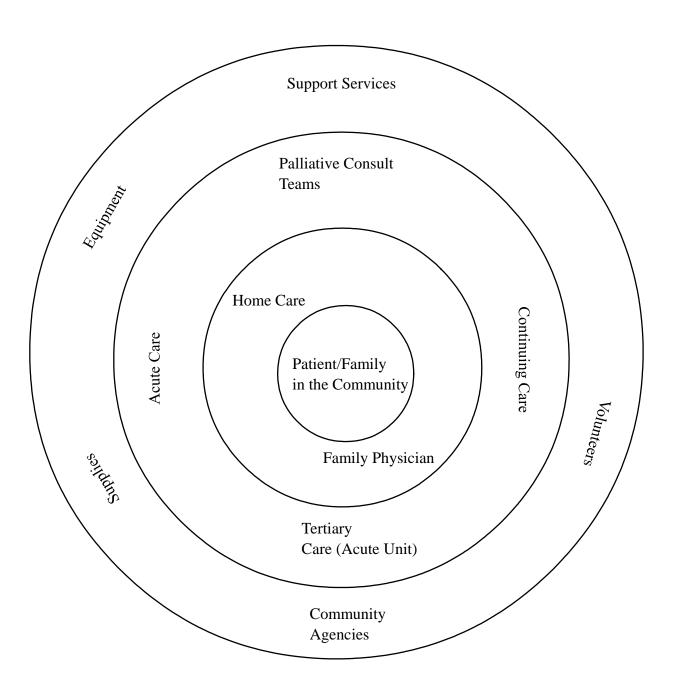
ICD-9-CM diagnostic codes used to determine palliative care, chemotherapy or radiotherapy are V58.0, V58.1 and V58.89 (to 97/03/31) and V66.7 (from 97/04/01) with a secondary diagnosis of 140.* to 208.* and 230.* to 234.*, or V10.* to V10.9*

The numbers provided in the tables are provisional as some cases (or deaths) may be registered in subsequent years.

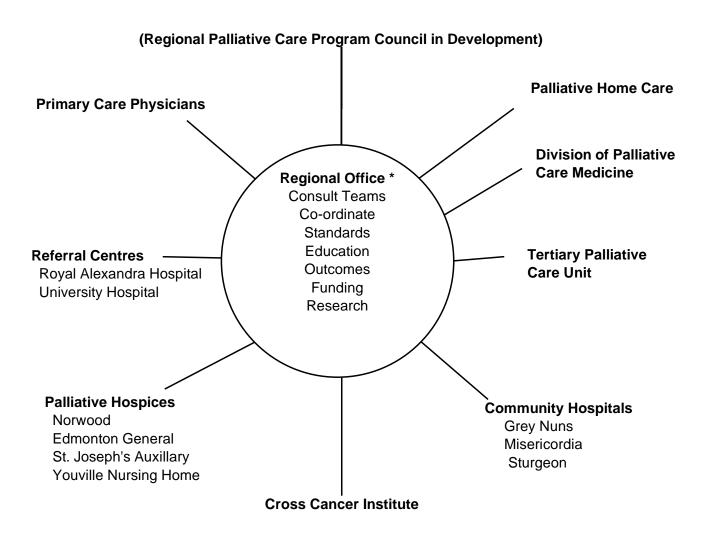
Methods of coding of cancers on the Alberta Cancer Registry have varied through the years; therefore, caution should be exercised when comparing this data to that of previous years

**Source: Evaluation, Information and Research , for CHA data-July 2000 Cross Cancer Institute data-May 2000

REGIONAL PALLIATIVE CARE MODEL



REGIONAL PALLIATIVE CARE PROGRAM PROGRAM STRUCTURE



^{*} The Regional Office maintains a liaison role, in the areas of standards, quidelines, education, research and program outcomes with all areas of the program. The program also liaises with the Alberta cancer Board.

REGIONAL PALLIATIVE CARE PROGRAM CRITERIA FOR ADMISSION

Palliative Care Is:

Active total care offered to a patient with progressive disease and their family when it is recognized that the illness is no longer curable, in order to concentrate on the quality of life and the alleviation of distressing symptoms in the framework of a coordinated service. Palliative Care neither hastens nor postpones death. It provides relief from pain and other distressing symptoms and integrates the psychological and spiritual aspects of care. In addition, it offers a support system to help relatives and friends cope during the patient's illness and bereavement.

(Medical/Nursing/Midwifery Advisory Committee-United Kingdom)

Based upon this definition, all people admitted to the program will:

- be experiencing progressive disease where the focus of care is on comfort, not cure, and improving their quality of life
- require active care to alleviate distressing symptoms related to physical, psychosocial and spiritual needs

Approximately 85-90% of these people will have a cancer diagnosis.

Admission Criteria to Specific Areas:

Home

- above criteria
- expected length of stay on the program of approximately 3-4 months
- do not require acute/tertiary care
- the ability to provide services within financial resources
- desire for the person/family to be cared for at home

Palliative Hospice

- above criteria
- cannot be managed at home
- do not require acute/tertiary care
- expected length of stay of approximately 2 months
- over 18 years
- accepting of no code status

Acute Care

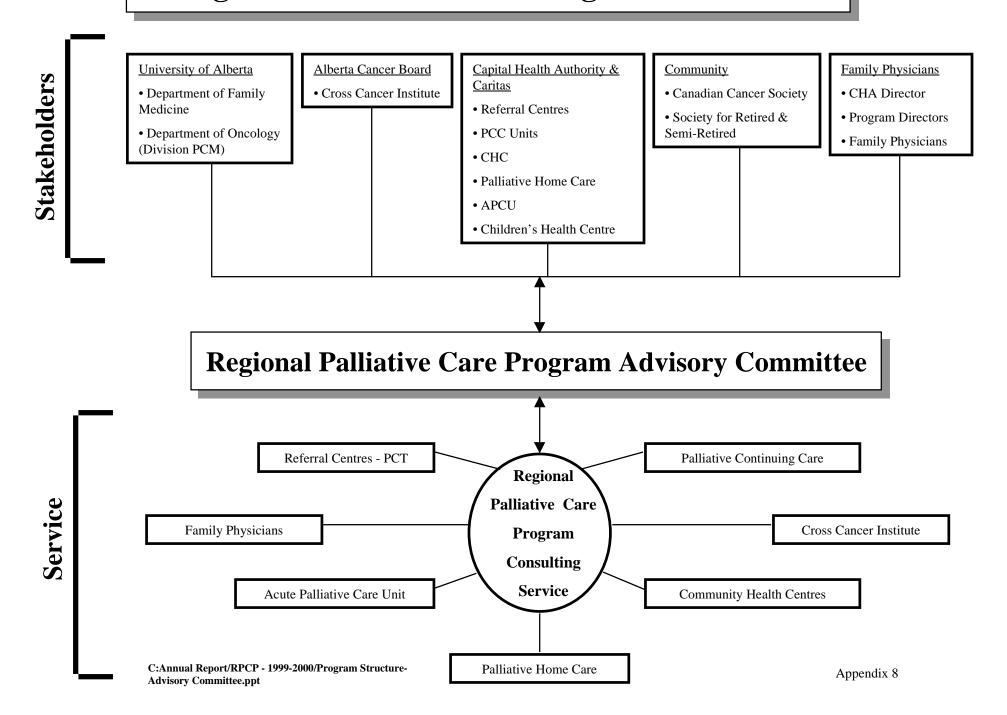
- for management of acute medical problems (i.e. pathological fracture, bleed, acute respiratory distress)
- anticipated short stay

Tertiary Palliative Care Unit

- severe symptom problems for which management has not been successful in any of the other settings, and requiring intensive management
- expected length of stay of approximately 2 weeks
- over 18 years
- accepting of no code status

Appendix 7

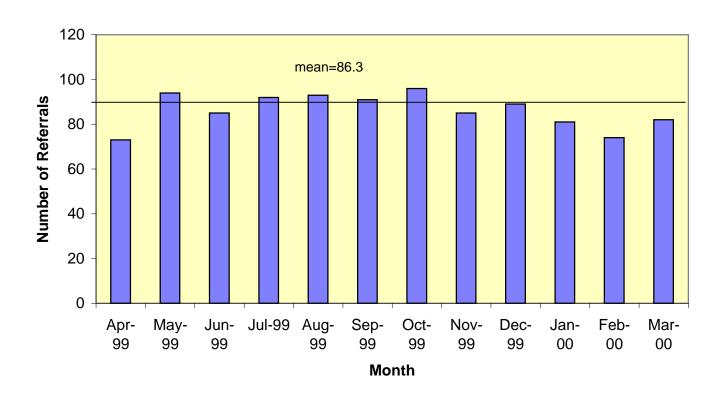
Regional Palliative Care Program Structure



Regional Palliative Care Program Number of Referrals Per Month

For Patients Referred between Apr 01,1999 and Mar 31, 2000

n = 1033



Source: Palliative Care Information System

Date: June 08, 2000 Appendix 9

Regional Palliative Care Program (RPCP) Palliative Consult Team Patient Profile

For Patients Referred between Apr 01,1999 and Mar 31, 2000

n = 1033

Referred From Location *TPCU 3.4% Other 2.2% Acute care 41.9% **Cont.Care 3.3% Cross Cancer Inst 5.3%

AGE at Time of Referral

Mean	69.6
Minimum	25
Maximum	105

Gender

GENDER	PERCENT
Male	49.3%
Female	50.7%
TOTALS	100.0%

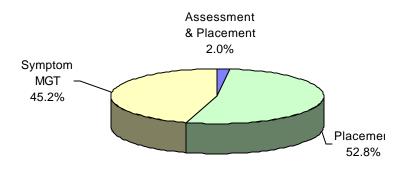
Diagnosis

Diagnosis	Percent
BREAST	8.8%
GASTRO-INT	24.1%
GENITO-URI	15.2%
HEAD&NECK	4.8%
HEMATOLOGY	6.5%
LUNG	25.1%
OTHER CANCER	9.9%
SARCOMA	1.4%
OTHER	3.7%
UNKNOWN	0.6
TOTALS	100.0%

CAGE Scores(n=690)

SCORE	PERCENT
0 to 1	78.3%
2 to 4	21.7%
TOTALS	100.0%

Initial Reason for Referral to RPCP



*TPCU - Tertiary Palliative Care Unit

**Cont. Care - Continuing Care

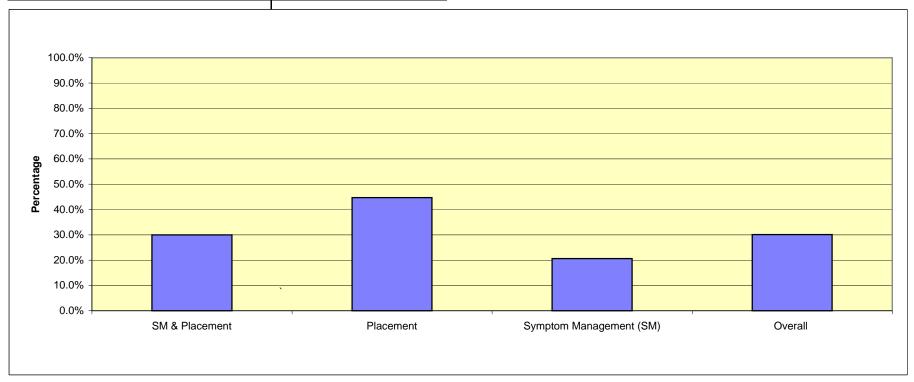
Source: Palliative Care Information System

Date: June 08, 2000

Appendix 10

Regional Palliative Care Program (RPCP) Palliative Consult Team Abnormal MMSE Scores - First Measure by Reason of Referral For Patients Referred between Apr 01,1999 and Mar 31, 2000

	Percent	Count	Total
SM & Placement	30.0%	3	10
Placement	44.7%	102	228
Symptom Management (SM)	20.6%	73	354
Overall	30.1%	178	592



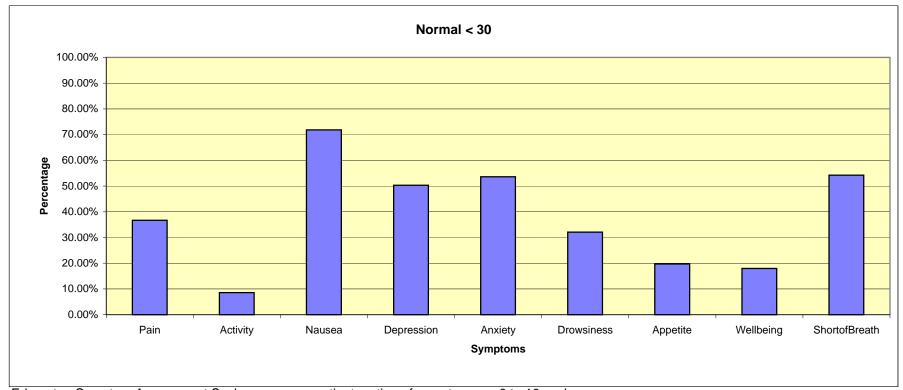
Abnormal Mini Mental State Examination - <80% of answers correct is an indicator for cognitive impairment

Source: Palliative Care Information System

Date: June 08, 2000 Appendix 11

Regional Palliative Care Program (RPCP) Palliative Consult Team ESAS Scores - First Measures For Patients Referred between Apr 01,1999 and Mar 31, 2000

	Pain	Activity	Nausea	Depression	Anxiety	Drowsiness	Appetite	Wellbeing	ShortofBreath	Count
First	36.70%	8.60%	71.80%	50.30%	53.60%	32.10%	19.70%	18.00%	54.20%	726



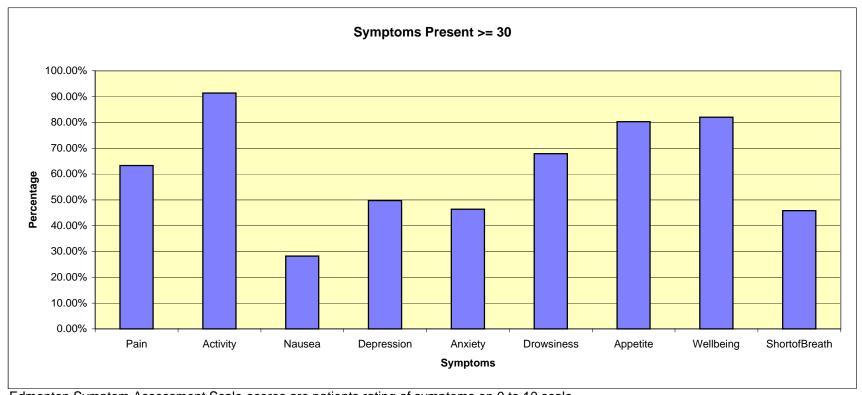
Edmonton Symptom Assessment Scale-scores are patients rating of symptoms on 0 to 10 scale

Source: Palliative Care Information System

Date: June 08, 2000

Regional Palliative Care Program (RPCP) Palliative Consult Team ESAS Scores - First Measures For Patients Referred between Apr 01,1999 and Mar 31, 2000

	Pain	Activity	Nausea	Depression	Anxiety	Drowsiness	Appetite	Wellbeing	ShortofBreath	Count
First	63.30%	91.40%	28.20%	49.70%	46.40%	67.90%	80.30%	82.00%	45.80%	726



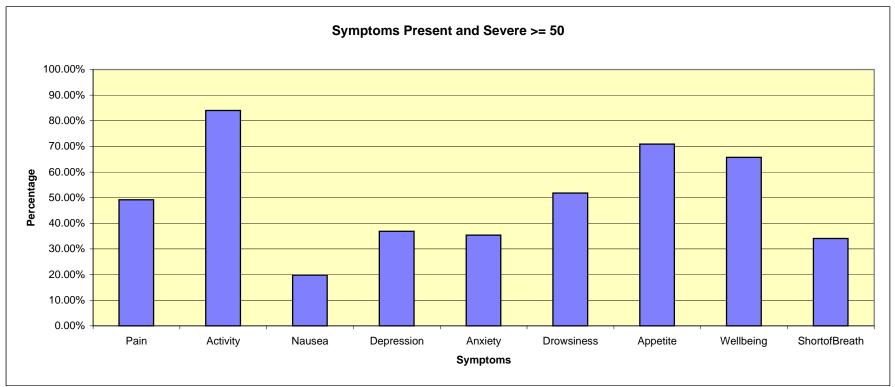
Edmonton Symptom Assessment Scale-scores are patients rating of symptoms on 0 to 10 scale

Source: Palliative Care Information System

Date: June 08, 2000

Regional Palliative Care Program (RPCP) Palliative Consult Team ESAS Scores - First Measures For Patients Referred between Apr 01,1999 and Mar 31, 2000

Ī		Pain	Activity	Nausea	Depression	Anxiety	Drowsiness	Appetite	Wellbeing	ShortofBreath	Count
I	First	49.20%	84.00%	19.80%	36.90%	35.40%	51.80%	70.90%	65.70%	34.10%	726



Edmonton Symptom Assessment Scale-scores are patients rating of symptoms on 0 to 10 scale

Source: Palliative Care Information System

Date: June 08, 2000

PHYSICIAN REFERRALS TO PALLIATIVE CARE CONSULTANTS REGIONAL PALLIATIVE CARE PROGRAM

For the Period Between Apr 01,1999 and Mar 31, 2000

REFERRALS	PHYSICIANS	PATIENTS
1	182	182
2	94	188
3	42	126
4	39	156
5	20	100
6	8	48
7	9	63
8	5	40
9	1	9
10	2	20
11	3	33
12	1	12
16	1	16
19	1	19
21	1	21
Grand Total	409	1033

of the 409 physicians listed above, 282(68.9%) are family physicians

Total	698	100.0%			
Specialists	192	27.5%			
Family Physicians	506	72.5%			
Physicians referring to the program since inception to Mar 31, 2000					

Source: Palliative Care Information System

Date: June 08,1999 Appendix 15

The Interaction Between Family Physicians and the Regional Palliative Care Program: Results of a Survey November, 1999

- The Regional Palliative Care Program (RPCP) is a community-based model of care, where palliative consultants role is to support primary caregivers such as family physicians (fp)
- Purpose of the survey is to identify fp satisfaction and knowledge about the program in the areas of access to service, role of the consultant, clinical utility of consultation, and physician education.
- Survey sent to 828 family physicians in the region. (Mailing list from College of Physicians and Surgeons).
- 327 (39%) return over two mailings.
- Of returned surveys, 234 (72%) stated had referred to the program, and 113 (35%) had cared for a patient in a palliative hospice.
- There was strong agreement (6 or 7 on a 1-7 Likert scale) that the palliative care physician consult improves patient care (82.8%), and helps patients be cared for in their preferred setting (82.4%).
- FP were satisfied with the consultant's promptness (80.5%), usefulness of consultation (82.1%) and respecting the FP role (74.8%).
- Phone calls from the consultant to the FP were considered useful (81.3%), and an acceptable method to communicate (81.7%).
- Letters from the consultant were considered useful (78.2%) and appropriate in content (74.5%) (Letters are detailed in content).
- Timeliness of the letters could be improved upon (31.6% unsure, 1.2 %unsatisfied)
- In the area of Hospices, we asked if the automatic consultation on admission is useful: 82.8% agreed that it was.
- Recommendations made by consultants at interdisciplinary rounds are considered slightly less useful (67.2%) (regular weekly rounds, FP have not asked for input)
- The most acceptable method of sharing interdisciplinary team recommendations was by fax to the FP office (76.5%), with comments to telephone only if urgent.
- When asked if palliative care education is an important area of education for them, 54.5% identified that it was. The majority of FP identified they see 2-5 palliative patients per year.
- One identified area of improvement is in understanding who to call for a consultation. 45% were unsure, and 11% did not know whom to call. Clearly communication in this area with FP is necessary.
- We received 185 comments about the strengths of the program, being available, prompt and accessible were identified.
- 99 comments about what we could improve upon. There was a wide variety of comments, (14 related to communication, 8 education)
- In the area of weaknesses, 145 highly variable comments were reviewed. (e.g.: 8 comments hard to access, 6 working with RN and MD, 5 high level of intervention, 2 non cancer referrals)
- Overall the survey suggests a high level of satisfaction among FP with the consultants. Areas to work on such as access and timeliness of letters are already being discussed.
 - A separate page connected to the survey asked FP to identify if they are willing to put their names on a list to accept new patients in the community: 49 physicians did. (List will be circulated by the Community Liaison Nurse at the Cross Cancer Institute shortly. Other physicians identified their willingness to follow patients in hospice sites.

EDUCATION PRESENTATIONS BY REGIONAL PALLIATIVE CARE TEAM*

April 1, 1999 - March 31, 2000

	In Region	Out of Region	Out of Province
Inservices/Lectures/ Orientations **	234	2	3
Workshops	21	5	8
Conference presentations or posters	16	3	8

^{*} Does not include Clinical Director

^{**} Inservices/Lectures/Orientations includes Bus Rounds, Case Rounds, Training Sessions, etc.

1999 – 2000

VISITORS & FELLOWS

Mazuryk, Mare*	Calgary, AB	Oct 5/98-Sep 30/99
Cheng, Christine	Caracas, Venezuela	Apr 01/99-Mar 31/00
Tarumi, Yoko	Sapporo, Japan	Apr 01/99-May 30/01
Martinez, Marina	Vitoria, Spain	Feb. 01-Apr 30/99
Amigo, Pablo	Buenos Aires, Argentina	Mar. 02-Apr 16/99
Reddy, Suresh	Houston, TX	Mar. 8-12/99
Cairns, W	Townsville, Australia	Mar 22-26/99
Driver, Larry	Houston, TX	Apr. 5-10/99
Socci, Maria, RN	Houston, TX	Apr. 5-10/99
Wright, John	Houston, TX	Apr. 5-10/99
Kaasa, Stein	Trondheim, Norway	Apr. 26-28/99
Engstrand, Per	Trondheim, Norway	Apr. 26-28/99
Hafting, Marit	Trondheim, Norway	Apr. 26-28/99
Lehne, Randi, RN	Trondheim, Norway	Apr. 26-28/99
Jensen, Unni, RN	Trondheim, Norway	Apr. 26-28/99
Solberg, Bodil	Trondheim, Norway	Apr. 26-28/99
Guttuik, Finn*	Trondheim, Norway	Apr. 26-28/99
Sæther θyvind [†]	Trondheim, Norway	Apr. 26-28/99
Gundersen, Terje Talseth [†]	Trondheim, Norway	Apr. 26-28/99
Leak, Jessie	Houston, TX	Aug. 9-12/99
Roemer-Becuwe, Celia 9	Nancy, France	Nov. 1/99-Sep 30/00

- * Cantel/Overton Fellows Psychologist
- † Chaplain
- * Social Worker
- P Clinical Research Fellow
- Clinical Fellow

PALLIATIVE CARE TRAINEES

Betty, Laura	Edmonton, AB	Jan 4-18/99
Doyle, Julie	London, England	May 01-Jun 13/99
Rajoo, Nischal	Winnipeg, MB	Aug 26/Sep 20/99
Modi, Shanu	Edmonton, AB	Aug 30 - Sep 24/99
Ferton, David	Edmonton, AB	Sep 27 - Oct 24/99

Publications – 1999

Bruera E, Belzile M, Neumann CM, Ford I, Harsanyi Z, Darke A. Twice-daily versus once-daily morphine sulphate controlled-release suppositories for the treatment of cancer pain. A randomized controlled trial. Support Care Cancer 1999; 7:280-83.

Bruera E, Gagnon B, Brenneis C, Kneisler P, Selmser P, Hanson J. Edmonton Regional Palliative Care Program: impacts on patterns of terminal cancer care. Can Med Assoc J 1999; 161(3):290-93.

Bruera E, Neumann CM. Respective limits of palliative care and oncology in the supportive care of cancer patients. Supportive Care Cancer 1999; 7(5):321-27.

Bruera E, Neumann CM. Bone pain. Am Soc Clin Oncol 1999; 393-401.

Bruera E, Neumann CM. The role of methadone in the management of pain in cancer patients. Oncology 1999; 1275-82.

Bruera E, Neumann CM, Pituskin E, Calder K, Ball G, Hanson J. Thalidomide in patients with cachexia due to terminal cancer: a preliminary report. Ann Oncol 1999; 10(7):857-59.

Bruera E, Pituskin E, Calder K, Neumann CM, Hanson J. The addition of an audiocassette recording of a consultation to written recommendations for patients with advanced cancer. Cancer 1999; 86(11):2420-2425.

Bruera E, Neumann CM, Pituskin E, Calder K, Hanson J. A randomized controlled trial of local injections of hyaluronidase versus placebo in cancer patients receiving subcutaneous hydration. Ann Oncol 1999; 10:1255-1258.

Bruera E, Walker P and Lawlor P. Opioids in Cancer Pain. Pain Control: Basic and Clinical Aspects. Cambridge University Press 1999

Cantwell, P, Turco S, Brenneis C, Hanson J, Neumann C, Bruera E. Predictors of Home Death in Palliative Care Cancer Patients.

Centeno C, Bruera E. Letter: Subcutaneous hydration with no hyaluronidase in patients with advanced cancer. J Pain Symptom Manage 1999; 17(5):305-06.

Daeninck PJ, Bruera E. Opioid use in cancer pain. Is a more liberal approach enhancing toxicity? Acta Anaesthesiol Scand 1999; 43:924-938.

Daeninck P, Bruera E. Reduction in constipation and laxative requirements following opioid rotation to methadone. A report of 4 cases. J Pain Symptom Manage 1999; 18(4):303-309.

Fainsinger RL. Letters to the Editor: Re: Biochemical dehydration in terminally ill cancer patients. J of Palliative Care 1999; 15(2):59-61.

Fainsinger RL, Luis T. Ethics Rounds: Case Presentation: When is Palliative Care Alone Appropriate? J of Pain & Sympt Manage 1999; 17(6):446-447.

Fainsinger RL, Voth, AJ. Commentary: Is this a palliative care patient? J of Pain & Sympt Manage 1999; 17(6):448-449.

Gagnon B, Bielech M, Watanabe S, Walker P, Hanson J, Bruera E. The use of intermittent subcutaneous injections of oxycodone for opioid rotation in patients with cancer pain. Support Care Cancer 1999; 7:265-70.

Gagnon B, Bruera E. Differences in ratios of morphine to methadone in patients with neuropathic pain versus non-neuropathic pain. J Pain Symptom Manage 1999; 18(2):120-25.

Gagnon B, Lawlor PG, Mancini I, Perieira J and Bruera E. Delirium impacts on the circadian patterns of breakthrough analgesia in advanced cancer patients. American Society of Clinical Oncology 9ASCO) Proceedings 1999, Atlanta, Abstract 2249

Gagnon B, Lawlor PG, Mancini I, Perieira J and Bruera E. The impact of delirium on pain and other symptoms in advanced cancer patients. Proceedings of the World Congress of the International Association for the Study of Pain (IASP), Vienna 1999

Iscoe NA, Bruera E, Choo RC. Prostate cancer: 10. Palliative Care. Can Med Assoc J 1999; 160(3):365-71.

Jenkins CA, Bruera E. Nonsteroidal anti-inflammatory drugs as adjuvant analgesics in cancer patients. Palliat Med 1999; 13:183-96.

Lawlor PG, Daeninck P, Doyle J, Quan H, Hanson J and Bruera E. Dose ratio of oral to subcutaneous morphine in the treatment of cancer pain. Proceedings of American Pain Society (APS) Annual Meeting in Fort Lauderdale, Florida October 31-24th 1999

Michaud M, Dutch J, Watanabe S, Bruera E. Audio Cassettes for Patients Attending a Tertiary Symptom Control & Palliative Care, Book of Abstracts, 1999: 54

Nekolaichuk CL, Bruera E, Spachynski K, MacEachern T, Hanson J, Maguire TO. A comparison of patient and proxy symptom assessments in advanced cancer patients. Palliat Med 1999; 13:311-23.

Nekolaichuk CL, Maguire TO, Suarez-Almazor M, Rogers WT, Bruera E. Assessing the reliability of patient, nurse, and family caregiver symptom ratings in hospitalized advanced cancer patients. J Clin Oncol 1999; 17(11):3621-3630.

Neumann CM, Hanson J, Kuehn N, Bruera E. Temporal distribution of deaths in cancer patients admitted to a palliative care unit. J Palliat Care 1999; 15(3):10-13.

Oneschuk D, Bruera E. The potential dangers of complementary therapy use in a patient with cancer. J Palliat Care 1999; 15(3):49-52.

Oneschuk, D. The Use of Baclofen for Treatment of Chronic Hiccups. Journal of Pain and Symptom Management 1999; 18(1): 4. (Letter)

Taube A, Bruera E. Is this patient palliative? J Palliat Care 1999; 15(1):53-55.

Taube AW, Bruera E. Palliative Care Round: Collegial disagreements over appropriate palliative care: a case study. J Pain Symptom Manage 1999; 18(1):67-71.

Taube AW, Bruera E. Are these Neurological Changes Caused by Opioids or a Brain Tumour? Primary Care and Cancer 19(3): 9-11

Taube AW, Bruera E. Letter to the Editor. J Pall Care 15(2)

Vigano A, Dorgan M, Bruera E, Suarez-Almazor ME. The relative accuracy of the clinical estimation of the duration of life for patients with end of life cancer. Cancer 1999; 86(1):170-76.

Vigano A, Bruera E, Suarez-Alamzor ME. Terminal cancer syndrome: myth or reality? J Palliat Care 1999; 15(4):32-39.

Watanabe S. The Edmonton Regional Palliative Care Program: An Integrated Model of Home and Institutional Palliative Care. Japanese Journal of Palliative Medicine 1:2 108-110

Watanabe S, Pituskin E, Calder K, Neumann C, Bruera E. Thalidomide (T) in the Symptomatic Treatment of Cachexia in Patients ({TSD) with Terminal Cancer. Presented at ASCO Annual Meeting. Proc Am Soc Clin Oncl 18: 180.Atlanta, Georgia May 15-18

Watanabe S, McKinnon S, Macmillan K, Pituskin E, Hanson J. Survey of Palliative Care Nurses Attitudes Towards the Edmonton Symptom Assessment System (ESAS). Journal of Palliative Care 15: 3 70.

Regional Palliative Care Program Volunteer Program Statistics April 1999 – March 2000

Site	Newly Trained Volunteers	Active Volunteers	Hours	
Norwood Hospice	5	9	1262	
Mel Miller Hospice, EGH	11	12	1651	
St. Joseph's Hospice	5	6	855	
Grey Nuns Community Hospital	11	22	1922	
Royal Alexandra Hospital	0	1	200	
University of Alberta Hospital	0	0	0	
Home Care	1	10	551	
Sturgeon	1	8	285	
Youville Nursing Home	0	1	104	
Bereavement Support Team	0	5	136	
Regional Palliative Care Program	1	2	52	
Cross Cancer	10	46	6551	
Sub Total	45	122	13569	
Other				
Leduc	1			
Lakeland	1			
Pilgrim's Hospice	2			
Good Samaritan Society	1			
Total	50	122	13569	

Note: Cross Cancer staff are trained in Palliative Care; however, their work is not strictly Palliative Care.

Source: Regional Palliative Care Volunteer Program

Date: April 6, 2001

Regional Palliative Care Program Hours Contributed by Year

Site	1999/2000	1998/1999	1997/1998	1996/1997
Norwood Hospice	1262	1449	996	1926
Mel Miller Hospice, EGH	1651	1295	1445	1590
St. Joseph's Hospice	855	890	378	934
Grey Nuns Community Hospital	1922	1063	1683	1006
Royal Alexandra Hospital	200	271	249	406
University of Alberta Hospital	0	0	0	0
Home Care	551	940	124	552
Sturgeon Community Hospital	285	25	163	294
Youville Nursing Home	104	200	156	150
Bereavement Support Team	136	218	63	0
Regional Palliative Care Program	?	110	127	42
Sub Total	6966	6461	5384	6900
Training Hours	-	1521	1431	1646
Cross Cancer Institute	6281	5104	2752	1563
Total	13247	13086	9567	10109

Note: Cross Cancer staff are trained in Palliative Care; however, their work is not strictly Palliative Care.

Source: Regional Palliative Care Volunteer Program

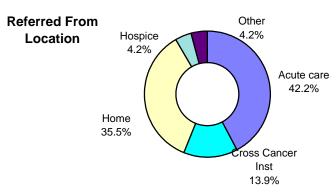
Date: April 6, 2001

Tertiary Palliative Care Unit (TPCU) Patient Profile

22.3%

For Patients Discharged between Apr 01,1999 and Mar 31, 2000

n = 166



AGE at Time of Admission

Mean	61.2
Minimum	24
Maximum	84

Gender

GENDER	PERCENT
Male	51.8
Female	48.2

Diagnosis

Diagnosis	Percent
BREAST	16.3%
GASTRO-INT	18.1%
GENITO-URI	12.7%
HEAD&NECK	3.6%
HEMATOLOGI	1.8%
LUNG	20.5%
OTHER	5.4%
OTHER CANCER	17.5%
SARCOMA	1.2%
UNKNOWN	3.0%
TOTALS	100.0%

Length of Stay (days)

Mean	26.8
Median	20
Mode	11
Minimum	1
Maximum	133

CAGE Scores(n=140)

SCORE	PERCENT
0 to 1	87.1
2 to 4	12.9
TOTALS	100.0

Pain Stage(n=134)

STAGE	PERCENT
1	11.9
2	14.9
3	73.1
TOTALS	99.9

Occupancy Stats *

Number of Beds	14
Total LOS**	4714
%Occupancy(adjusted)	91.80%

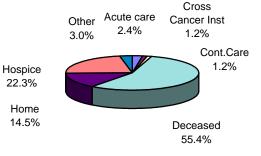
^{*}Grey Nuns Health Records

**LOS- Length of Stay

Source: Palliative Care Information System

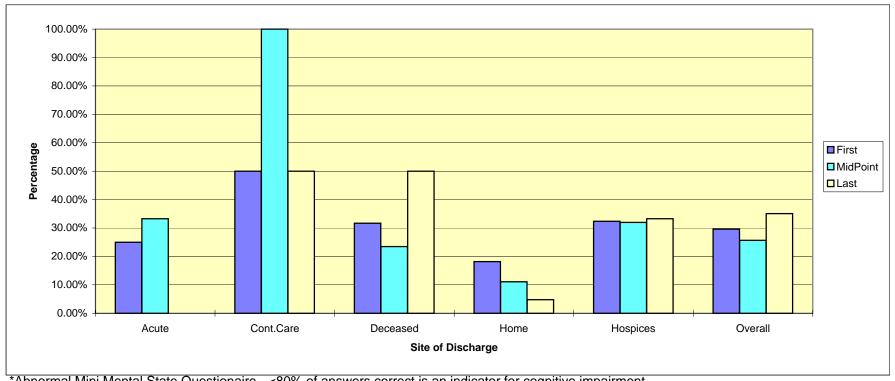
Date: June 08, 2000

Discharge To Location



Tertiary Palliative Care Unit (TPCU) Abnormal MMSQ* -First, MidPoint and Last Measures by Discharge Location For Patients Discharged between Apr 01,1999 and Mar 31, 2000

	Acute	Cont.Care	Deceased	Home	Hospices	Overall	Overall (count)	ToTal
First	25.00%	50.00%	31.70%	18.20%	32.40%	29.60%	45	152
MidPoint	33.30%	100.00%	23.50%	11.10%	32.00%	25.70%	19	74
Last	0.00%	50.00%	50.00%	4.80%	33.30%	35.10%	46	131

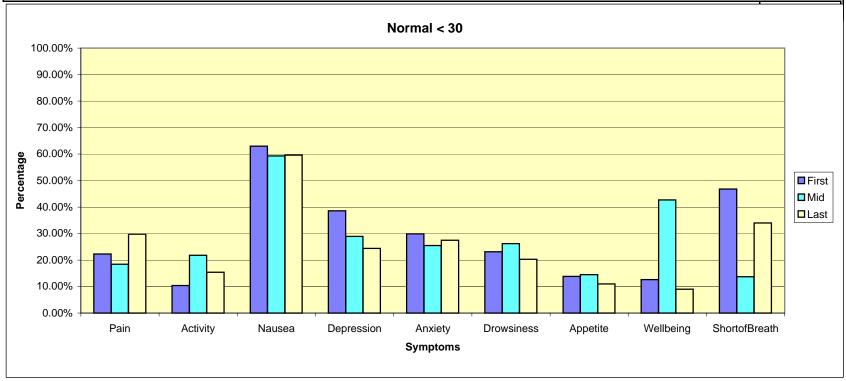


*Abnormal Mini Mental State Questionaire - <80% of answers correct is an indicator for cognitive impairment

Source: Palliative Care Information System

Tertiary Palliative Care Unit (TPCU) ESAS Scores -First, Mid and Last Measures For Patients Discharged between Apr 01,1999 and Mar 31, 2000

	Pain	Activity	Nausea	Depression	Anxiety	Drowsiness	Appetite	Wellbeing	ShortofBreath	Pain(count)
First	22.3%	10.4%	63.0%	38.6%	29.9%	23.1%	13.8%	12.6%	46.8%	38
Mid	18.40%	21.80%	59.30%	28.90%	25.50%	26.20%	14.50%	42.70%	13.70%	28
Last	29.80%	15.40%	59.60%	24.40%	27.50%	20.30%	11.00%	9.00%	34.00%	48

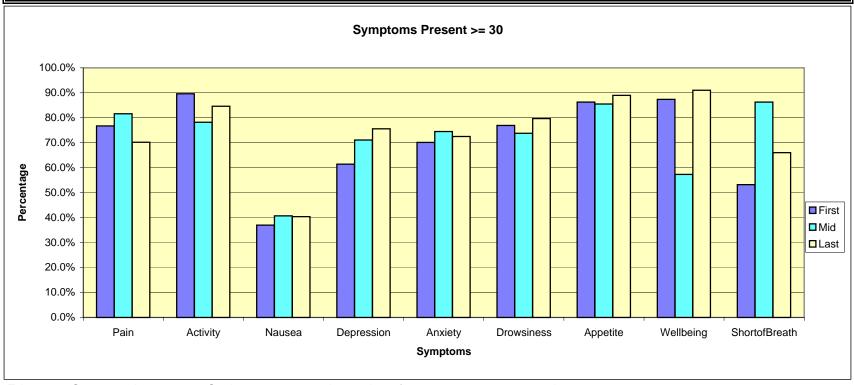


Edmonton Symptom Assessment Scale-scores are patient rating of symptoms on 0 to 10 scale

Source: Palliative Care Information System

Tertiary Palliative Care Unit (TPCU) ESAS Scores -First, Mid and Last Measures For Patients Discharged between Apr 01,1999 and Mar 31, 2000

	Pain	Activity	Nausea	Depression	Anxiety	Drowsiness	Appetite	Wellbeing	ShortofBreath	Pain(count)
First	76.7%	89.6%	37.0%	61.4%	70.1%	76.9%	86.3%	87.4%	53.2%	127
Mid	81.6%	78.2%	40.7%	71.1%	74.5%	73.8%	85.5%	57.3%	86.3%	125
Last	70.2%	84.6%	40.4%	75.6%	72.5%	79.7%	89.0%	91.0%	66.0%	113

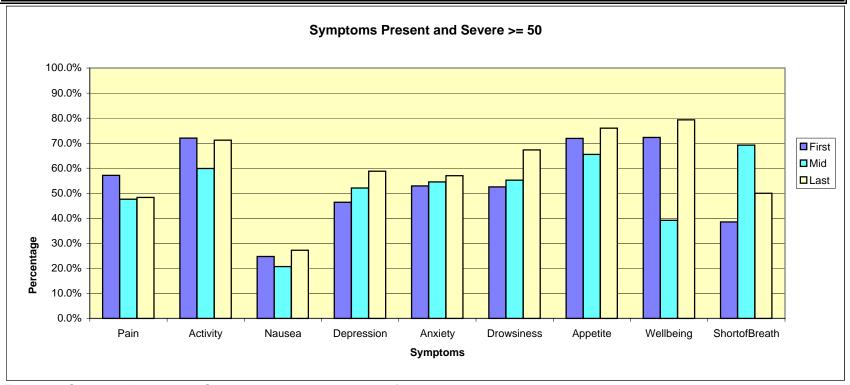


Edmonton Symptom Assessment Scale-scores are patient rating of symptoms on 0 to 10 scale

Source: Palliative Care Information System

Tertiary Palliative Care Unit (TPCU) ESAS Scores -First, Mid and Last Measures For Patients Discharged between Apr 01,1999 and Mar 31, 2000

	Pain	Activity	Nausea	Depression	Anxiety	Drowsiness	Appetite	Wellbeing	ShortofBreath	Pain(count)
First	57.1%	72.0%	24.7%	46.4%	52.9%	52.5%	71.9%	72.3%	38.5%	94
Mid	47.6%	59.9%	20.7%	52.1%	54.5%	55.2%	65.5%	39.2%	69.2%	73
Last	48.3%	71.2%	27.2%	58.8%	57.0%	67.3%	76.0%	79.3%	50.0%	78



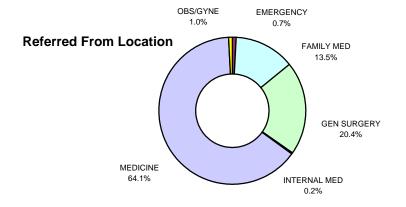
Edmonton Symptom Assessment Scale-scores are patient rating of symptoms on 0 to 10 scale

Source: Palliative Care Information System

Referral Hospital RAH* Pallliative Consult Team Patient Profile

For Patients Discharged Between Apr 01,1999 and Mar 31, 2000

n = 421



AGE at Time of Admission

Mean	69.6
Minimum	18
Maximum	96

Gender

GENDER	PERCENT
Male	54.90%
Female	45.10%
TOTALS	100.00%

Diagnosis

Diagnosis	Percent
BREAST	4.80%
GASTRO-INT	31.60%
GENITO-URI	13.50%
HEAD&NECK	2.90%
HEMATOLOGY	3.30%
LUNG	21.60%
OTHER CANCER	9.30%
SARCOMA	1.00%
OTHER	12.10%
TOTALS	100.00%

Length of Stay (days)

Mean	16.9
Median	12
Mode	9
Minimum	0
Maximum	81

CAGE Scores(n=311)

SCORE	PERCENT
0 to 1	84.90%
2 to 4	15.10%
TOTALS	100.00%

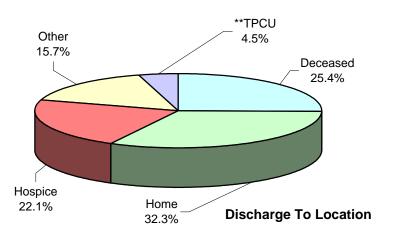
Pain Stage(n=314)

1	43.30%
2	29.60%
3	27.10%
TOTALS	100.00%

^{*}RAH-Royal Alexandria Hospital

Source: Palliative Care Information System

Date: May 31, 2000



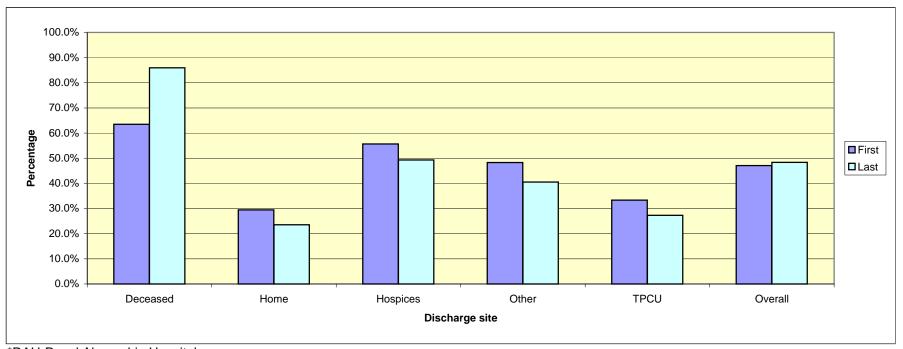
Appendix 27

^{**}TPCU-Tertiary Palliative Care Unit

Referral Hospitals RAH* Pallliative Consult Team Abnormal MMSQ First and Last Measures

For Patients Discharged by Site of Discharge Between Apr 01,1999 and Mar 31, 2000

	Deceased	Home	Hospice	Other	TPCU	Overall
First	66	38	49	28	6	187
First Total	104	129	88	58	18	397
Last	49	16	34	15	3	117
Last Total	57	68	69	37	11	242



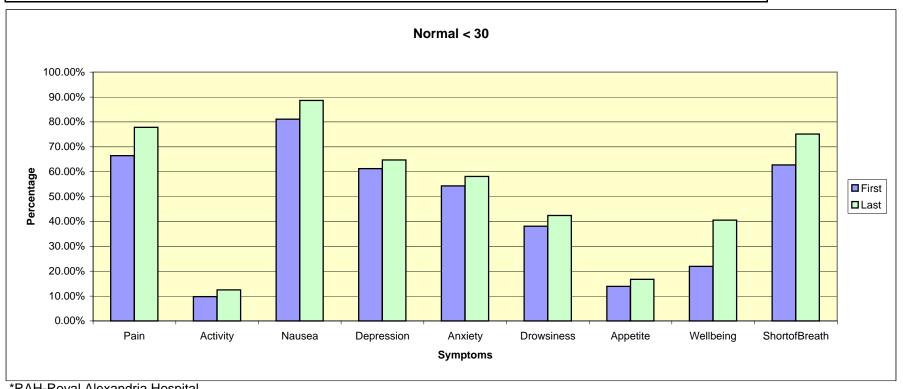
*RAH-Royal Alexandria Hospital

Abnormal Mini Mental State Questionaires-<80% of answers correct Indicator for cognitive impairment

Source: Palliative Care Information System

Referral Hospital RAH* Pallliative Consult Team **ESAS Scores** _ First and Last Measures For Patients Discharged Between Apr 01,1999 and Mar 31, 2000

	Pain	Activity	Nausea	Depression	Anxiety	Drowsiness	Appetite	Wellbeing	ShortofBreath
First	66.40%	9.8%	81.1%	61.2%	54.3%	38.1%	13.9%	21.9%	62.7%
Last	77.8%	12.5%	88.6%	64.7%	58.1%	42.4%	16.7%	40.5%	75.1%



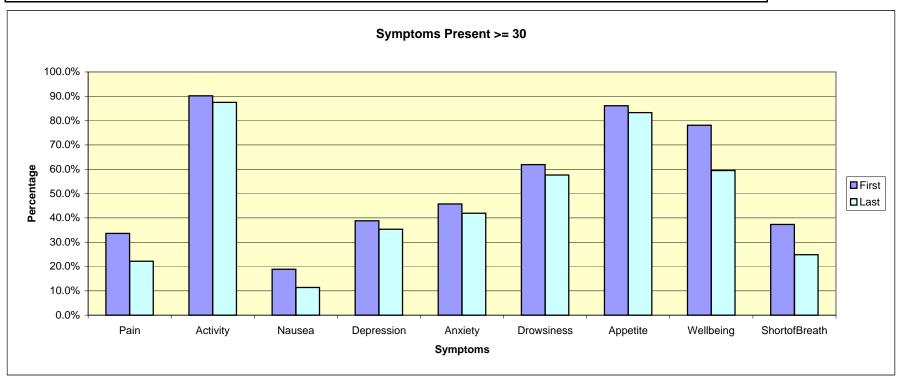
*RAH-Royal Alexandria Hospital

Edmonton Symptom Assessment Scale-scores are patients rating of symptoms on 0 to 10 scale

Source: Palliative Care Information System

Referral Hospital RAH* Pallliative Consult Team ESAS Scores _ First and Last Measures For Patients Discharged Between Apr 01,1999 and Mar 31, 2000

	Pain	Activity	Nausea	Depression	Anxiety	Drowsiness	Appetite	Wellbeing	ShortofBreath
First	33.6%	90.2%	18.9%	38.8%	45.7%	61.9%	86.1%	78.1%	37.3%
Last	22.2%	87.5%	11.4%	35.3%	41.9%	57.6%	83.3%	59.5%	24.9%



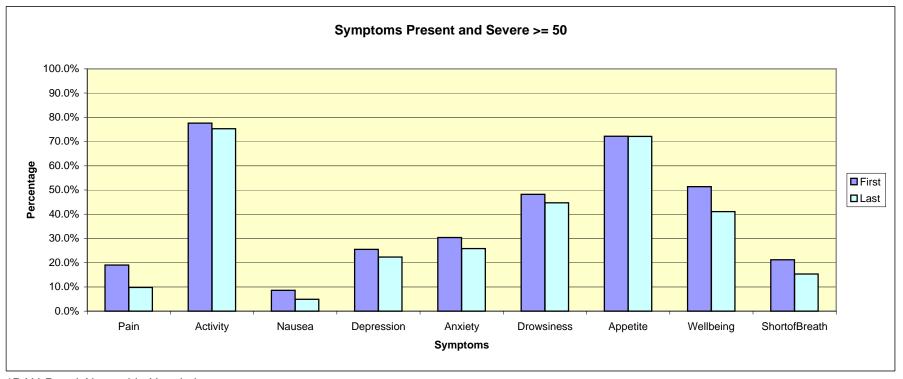
*RAH-Royal Alexandria Hospital

Edmonton Symptom Assessment Scale-scores are patients rating of symptoms on 0 to 10 scale

Source: Palliative Care Information System

Referral Hospital RAH* Pallliative Consult Team ESAS Scores _ First and Last Measures For Patients Discharged Between Apr 01,1999 and Mar 31, 2000

	Pain	Activity	Nausea	Depression	Anxiety	Drowsiness	Appetite	Wellbeing	ShortofBreath
First	19.0%	77.6%	8.6%	25.5%	30.4%	48.2%	72.2%	51.4%	21.2%
Last	9.8%	75.3%	4.9%	22.3%	25.8%	44.7%	72.1%	41.1%	15.3%



*RAH-Royal Alexandria Hospital

Edmonton Symptom Assessment Scale-scores are patients rating of symptoms on 0 to 10 scale

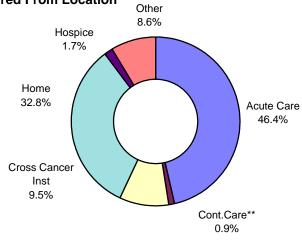
Source: Palliative Care Information System

Palliative Hospices Patient Profile: All Sites

For Patients Discharged between Apr 01,1999and Mar 31, 2000

n = 545

Referred From Location



Age at Time of Admission

Mean	71.8
Minimum	30
Maximum	105

Gender

GENDER	PERCENT
Male	48.90%
Female	51.10%
TOTALS	100.00%

Diagnosis

DIAGNOSIS	PERCENT
BREAST	7.3%
GASTRO-INT	24.4%
GENITO-URI	16.0%
HEAD&NECK	10.8%
HEMATOLOGI	2.2%
LUNG	25.5%
OTHER CANCER	4.4%
SARCOMA	0.4%
UNKNOWN	2.0%
OTHER	7.0%
TOTALS	100.0%

Length of Stay (days)

Mean	36
Median	17
Mode	1
Minimum	0
Maximum	1139

Occupancy Stats *

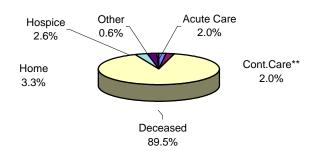
Number of Beds	57
Days Occupied	19237
Days Available	20805
Occupancy Rate	92.50%

* Source: Regional Continuing Care **Cont Care - Continuing Care

Source: Palliative Care Information System

Date: May 31, 2000

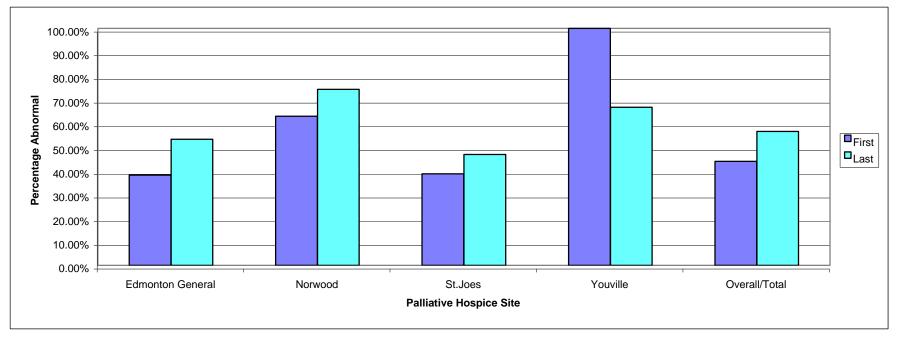
Discharge To Location



Appendix 32

Palliative Hospices
Abnormal MMSQ Scores* - First and Last Measures
For Patients Discharged between Apr 01,1999and Mar 31, 2000

Hospices	First	Last	First(count)	Last(count)
Edmonton General	38.10%	53.20%	64	50
Norwood	62.90%	74.30%	39	26
St.Joes	38.60%	46.80%	27	22
Youville	100.00%	66.70%	3	2
Overall/Total	43.90%	56.50%	133/303	100/177



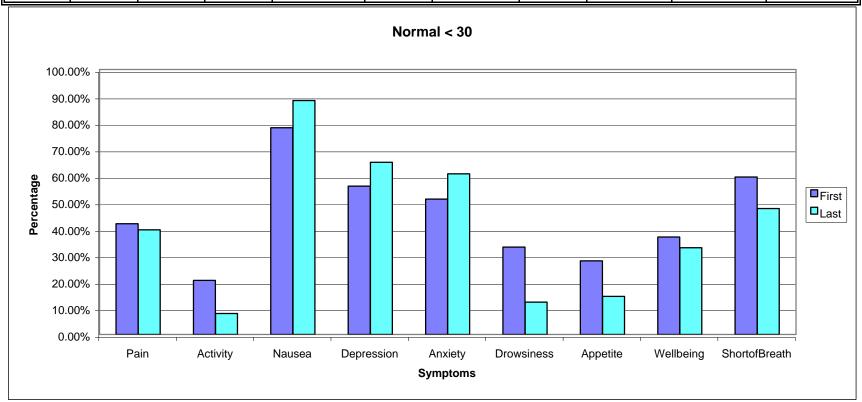
*Abnormal Mini Mental State Questionaires-<80% of answers correct Indicator for cognitive impairment

Source: Palliative Care Information System

Palliative Hospices

ESAS Scores _ First and Last Measures For Patients Discharged between Apr 01,1999and Mar 31, 2000

	Pain	Activity	Nausea	Depression	Anxiety	Drowsiness	Appetite	Wellbeing	ShortofBreath	Pain(count)
First	41.80%	20.40%	78.00%	56.00%	51.10%	33.00%	27.80%	36.80%	59.40%	203
Last	39.50%	7.90%	88.30%	65.00%	60.60%	12.20%	14.40%	32.70%	47.50%	177

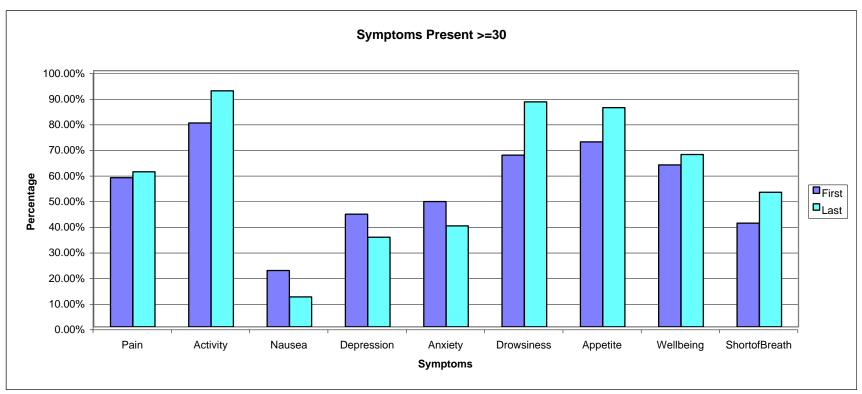


Edmonton Symptom Assessment Scale-scores are patients rating of symptoms on 0 to 10 scale

Source: Palliative Care Information System

Palliative Hospices ESAS Scores _ First and Last Measures For Patients Discharged between Apr 01,1999and Mar 31, 2000

	Pain	Activity	Nausea	Depression	Anxiety	Drowsiness	Appetite	Wellbeing	ShortofBreath	Pain(count)
First	58.20%	79.60%	22.00%	44.00%	48.90%	67.00%	72.20%	63.20%	40.50%	282
Last	60.50%	92.10%	11.70%	35.00%	39.40%	87.80%	85.60%	67.30%	52.50%	272

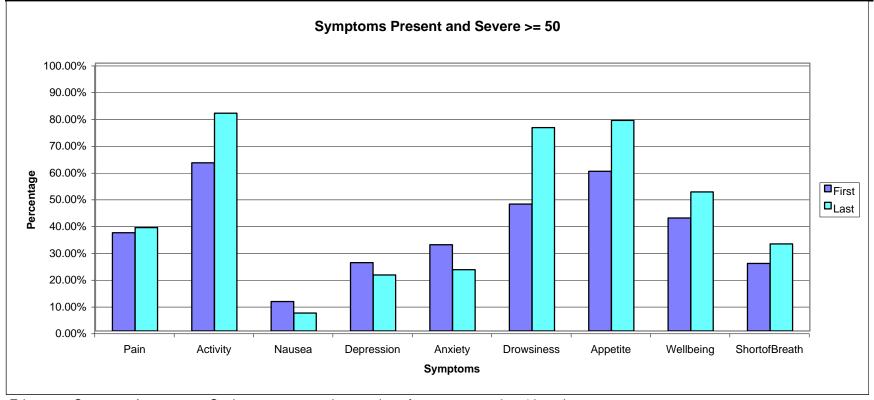


Edmonton Symptom Assessment Scale-scores are patients rating of symptoms on 0 to 10 scale

Source: Palliative Care Information System

Palliative Hospices ESAS Scores _ First and Last Measures For Patients Discharged between Apr 01,1999and Mar 31, 2000

	Pain	Activity	Nausea	Depression	Anxiety	Drowsiness	Appetite	Wellbeing	ShortofBreath	Pain(count)
First	36.70%	62.80%	11.00%	25.50%	32.20%	47.40%	59.60%	42.20%	25.20%	178
Last	38.60%	81.30%	6.70%	20.90%	22.90%	75.90%	78.60%	51.90%	32.50%	173



Edmonton Symptom Assessment Scale-scores are patients rating of symptoms on 0 to 10 scale

Source: Palliative Care Information System

Capital Health Home Care Palliative Patient Profile For Patients Discharged Between Apr 01,1999 and Mar 31, 2000 n = 862

Diagnosis

AIDS	0.6%
AMYOTROPHIC LATERAL SCLEROSIS	0.2%
CANCER	84.2%
CARDIOVASCULAR DISEASE	2.0%
OTHER	7.3%
UNKNOWN	11.8%
TOTAL	100.0%

Age at Discharge

Mean	69.1
Minimum	3
Maximum	100

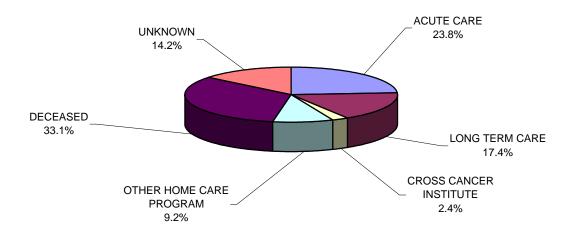
Length of Stay (days)

Mean	101.1
Median	64
Mode	7
Minimum	1
Maximum	683

Gender

Male	53.0%
Female	46.0%
TOTAL	99.0%

Discharge To Location



Capital Health Home Care Palliative Data-April 23, 2001

Appendix 37



PALLIATIVE COST TRACKING SHEET

Date Submitted:/ Network:				
Case Manager: Re			esource Coordinator:	
Attach Completed: CSR ESAS Graph				
Diagnosis:		Estimated	d Prognosis:	
Expected Outcome:				
			Review D	ate:/
Initial Assessment Update		Complete th	e following sections only if cha	anged since last assessment)
Home Death Assessment Tool	/4		Comments:	
Client Desires Home Death	☐ Yes	□ No	If No, Explain:	
Family Supportive of Home Death	☐ Yes	□ No	If No, Explain:	
Family Dr. Available 24hrs/7 days week	☐ Yes	☐ No	If No, Explain:	
More Than One Informal Support Person	☐ Yes	□ No	If No, Explain:	
OPTIONS EXPLORED:			Comments:	
Family/Friends Help	☐ Yes	□ No	Comments.	
				
Ability to Cost-Share	☐ Yes	□ No		
Third Party Insurance Access	☐ Yes	□ No		
Pilgrim's Hospice Day Program/Other Day Programs	☐ Yes	□ No		
RPCT Consultation for:				
□ symptom control	☐ Yes ☐ Yes	□ No		
☐ placement Other (Explain)	☐ Yes	□ No		
Cuter (Explain)	13 .00	3 .10		
Cost per week				
Professional Service Hours		@ \$35.0	0 hrs	\$
Support Service Hours		PN @ \$	hrs	\$
	F	PCA @ \$	hrs	\$
Service:		PM Care	Total Cost	\$
(check ALL that apply)		Night Care	(If > \$500.00/wk, MUST Rev	
Date Services Initiated:/ Date Services Changed/Terminated://				
Date Client Deceased:/				
Signature - Network Manager			D	Pate:/

REGIONAL PALLIATIVE CARE PROGRAM EXPECTED AND ACTUAL OUTCOMES

TERTIARY PALLIATIVE CARE UNIT

Outcome	1992	Plan ^a	1999 ^b
#deaths/year c	120 (9%)	96 (8%)	91 ^d (6%)
ALOS	25	15	27 (median 20) ^d
# pts./year	168	273	166 ^d
Criteria	exist	monitor	monitor

ACUTE CARE HOSPITALS

Outcome	1992	Plan	1999
#deaths/year c	1050 (78%)	265 (22%)	678 °(45%)
ALOS	25	15	16.6 ^f
Consult Teams	varied	develop	421 ^g
Criteria for Admission	inconsistent/absent	develop & monitor	monitor

PALLIATIVE HOSPICES

Outcome	1992	Plan	1999
#deaths/year c	62 (< 5%)	360 (30%)	489 ^d (32%)
ALOS		66	31.3 (median 17) ^d
Consult Teams		develop	exist
Criteria	varied	develop	exist and reviewed
Continuing Care ^c			28 ^{d,h} (2%)

PALLIATIVE HOME CARE

Outcome	1992	Plan	1999
#deaths/year c	109 (9%)	480 (40%)	196 ^h (13%)
ALOS	4 months	3 months	not available
medical care	minimum	↑ education of f.p.	409 distinct MD referrals to
			RPCP/year; > 698 since July/95
Consult Teams	absent	develop	exist: in home
24 hr. service	absent	develop	present
Criteria	varied	develop	exist
Drugs 24	minimum	24 hour	5 - 24 hour delivery
hour		available	
Lab service	varied	develop	exists
Died out of region c			25 h (2%)
Other c			6 ^h (0.3%)

^a Plan based on 1200 patients/year. Actual deaths 1513^e(1999), including Leduc county etc.

^b Numbers will differ from other appendices due to use of calendar year to align with Alberta Cancer Board data (in region, see e) .

^C Percentage based on number of deaths divided by actual 1992 (1341) and 1999 (1513) cancer deaths for region. #deaths/year from Alberta Cancer Board, Division of Epidemiology, Prevention & Screening.

^d Regional Palliative Care DataBase, Jan 01, 1999 to Dec 31, 1999. Only Cancer deaths are included in #deaths. ALOS and #pts/year include all diagnosis.

^e Number of deaths at all acute care sites including Cross Cancer Institute CCI. Number used in table includes out of region patients who died in region including CCI (146). This is first year in/out region reporting on deaths has been available. The numbers provided in the table are provisional as some cases (deaths) may be registered in subsequent years. Methods of coding of cancer on the Alberta cancer Registry have varied through the years; therefore caution should be exercised when comparing data to that of previous years.

^f Evaluation, Information, and Research, Capital Health, Jan 01, 1999 to Dec 31, 1999.

^g Consultations to RAH palliative care team (UAH data are not available).

^h Alberta Cancer Board, Division of Epidemiology, Prevention & Screening, Jan. 1, 1999 - Dec. 31, 1999.

REGIONAL PALLIATIVE CARE PROGRAM

Savings to Capital Health Authority Acute Care

14,979 patient days $x $508^a = $7,609,332$

Added Actual Costs of Palliative Care Program (1997/98)

Acute Care Referral Consultation (UAH) ^b	\$ 130,000
Palliative Hospices ^c	\$1,810,840
Regional Program ^c	\$ 993,132
Home Care ^d	\$2,546,40 <u>5</u>
	\$5,480,377

CAPITAL HEALTH AUTHORITY PALLIATIVE CARE SAVINGS

\$2,128,995

Overall Palliative Care Savings

Cross Cancer Institute 761 patient days x \$495^e \$ 376,695

\$2,505,390

- a Average medical inpatient cost per day, Finance, Capital Health Authority
- b Increased annual cost of Palliative Care consultant program in Acute Care at one site (UAH).
- c Actual 1997/98 costs.
- Dollars (top up) agreed upon to as transferred from Palliative care to home care when program began. Actual costs are not able to be confirmed.
- ^e Inpatient cost per day, Finance, Alberta Cancer Board.