Advancing End of Life Care Provision
A Provincial Framework

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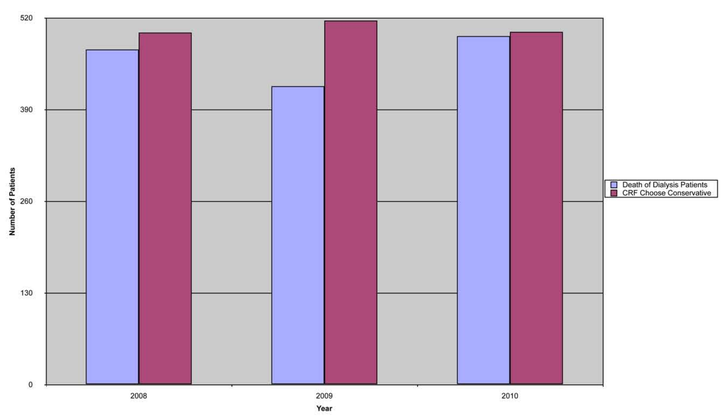
BC Renal Agency
An agency of the Provincial Health Services Authority

BACKGROUND INFORMATION

British Columbia (BC) has a population of 4.5 million people and as of Dec 31, 2010 there were 2,791 dialysis pts (all modalities), 11,219 registered CKD pts, and 2,500 kidney transplant patients, receiving care across 5 health authorities (HAs) Renal care delivery in BC is spread across the five geographic HAs at 13 hospital programs and 26 community dialysis units. Province-wide delivery of care is planned, monitored and funded through the BC Provincial Renal Agency (BCPRA). The network structure of the BCPRA enables clinical input from members of the nephrology teams that provide direct patient care.

INTRODUCTION

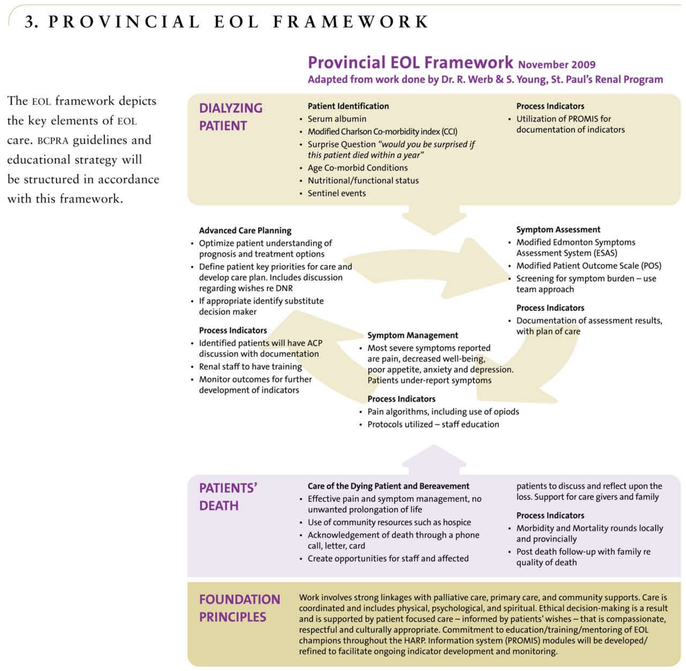
Despite medical advances and improvements in technology, dialysis program mortality rates hover in the range of 20 - 25 %. Growing numbers of CKD patients opt to forgo dialysis treatment and pursue conservative treatment.



The need for improved end-of-life (EOL) care strategies for dialysis and CKD patients is also triggered by advances in dialysis that make it increasingly difficult to identify the point at which a patient is recognized as "dying". If patients have incomplete information about their prognosis or a limited understanding of the progression of their illness, health care providers are left treating patients and dealing with families unprepared for difficult end-of-life decisions. As a result, palliative care is often delayed or not initiated for patients with end-stage renal disease (ESRD).

METHODS

Utilizing the BC renal network structure, a formal working group was established to systematically develop and implement an evidence-based EOL framework to provide a standard approach to EOL care accessible to all BC renal patients. Through an iterative process involving multi-disciplinary representation and a linkage to the Provincial Palliative Program, the Renal EOL Working Group defined the following evidence-based elements as essential to providing quality end -of-life care to renal patients. These included:
1. Patient Identification
2. Symptom Assessment and Management
3. Advanced Care Planning
4. Care of the Dying Patient/Bereavement



This four-year learning process culminated in the publication of the framework report, "END-OF-LIFE FRAMEWORK - Recommendations for a Provincial End of Life Care Strategy" in Dec 2009. (Available on the BCPRA website: www.bcrenalagency.ca). This document includes identification of consistent guidelines and tools to assist in caring for patients requiring EOL care, development of a sustainable education strategies, integration of renal EOL strategies with those of the Ministry of Health, provincial and regional palliative care strategies.

RESULTS

Under the direction of the BCPRA EOL Working group, each of the five HA renal programs (HARPs) has now adopted the framework. In addition to forming a Renal Program EOL group, each of the five programs have embarked on a series of projects and initiatives aimed at implementing the four elements at the local level.
It is recognized that the role of "EOL Champions" within each of the HARPs is critical. Equally critical is ensuring each of these champions feels well supported from a knowledge and educational perspective.

Embedding skills in day-to-day practice across the professional disciplines and sustaining knowledge and skills among staff are key considerations in the ongoing work of the EOL group. A final area of attention was incorporating PROMIS as the information system to help track patient needs and outcomes and to establish metrics for future program evaluation.

PROGRESS SINCE DECEMBER 2009 PUBLICATION OF FRAMEWORK DOCUMENT

Strategic Advances

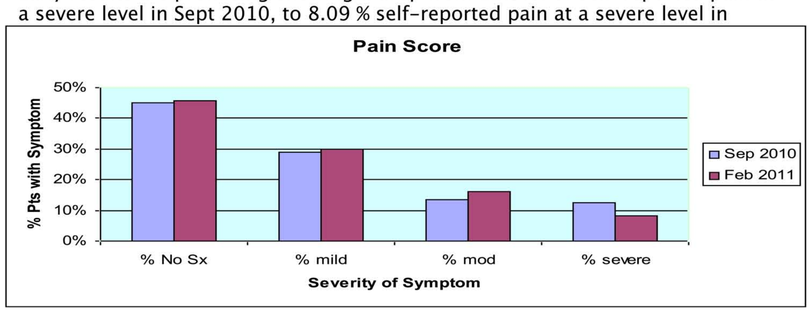
- EOL work recognized within strategic plans of each HARP.
- Three HARPs have term-specified project managers to help design their EOL strategies
- Collapsing the broad EOL working group into a steering committee
- May 2010: Two-day intensive training session for self-identified EOL renal champions from across the BC renal network. Featured presentations from experts in pain management, palliative care and law

Patient Identification

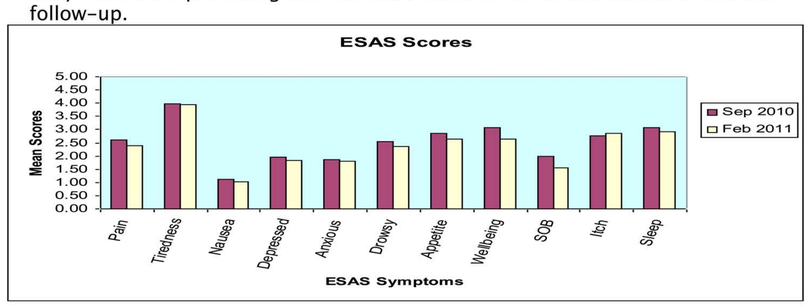
•Various renal programs are evaluating the processes needed to systematically review patients (analysis of low albumin, age, sentinel events, CCI, IPM) who may have a higher need for ACP and/or palliative services.

Symptom Assessment and Management

•Development of a provincial pain algorithm for hemodialysis patients, based on work previously done at both Providence Health Care and Fraser Health. Provincial roll-out in 2011.
•Pain algorithm implementation at Providence Health Care – St Paul's Hospital. Early results are promising showing a drop from 12.57% of self-reported pain at a severe level in Sept 2010, to 8.09 % self-reported pain at a severe level in



- Integration of the provincial renal pain algorithm into toolkit being developed for primary care physicians through the work of the General Practice Service Committee (GPSC)
- Provincial agreement re use of the modified Edmonton Symptom Assessment Scale (ESAS)
- Integration of ESAS into PROMIS
- ESAS implementation at Providence Health Care – St Paul's Hospital. 275 chronic hemodialysis patients visit the St Paul's hemodialysis unit each week. As part of their integrated approach to EOL care the St Paul's EOL champions worked with the frontline nursing staff to administer the ESAS twice over a six-month period. Early results are promising and indicate a value in self assessment and focused follow-up.



Advanced Care Planning (ACP)

•BC Ministry of Health Services announcement that "My Voice" will be the provincial advanced care directive and planning tool (across all areas of the health sector)
• A number of renal programs in all five HARPs , including hospital units, community dialysis units, and pre-dialysis clinics, have aggressively worked to have ACP embedded in practice and become part of the medical record. The process often takes a CQI perspective with changes made based on iterative feedback.

Grief and Bereavement

- Referral process and linkages to palliative care and hospice support being pursued

CONCLUSIONS

The provincial framework and documents have permitted significant changes in care strategies. To our knowledge, this is the first province-wide, comprehensive initiative for EOL care in a CKD population. Evaluations of the impact on patient outcomes are ongoing.

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