

INTRODUCTION

Good morning, what a turnout! Clearly people who didn't skip history in high school. What a powerful Society we have. One only 24 years old which has grown 10 fold in membership and has done so much to fulfill the original mission of the founders to serve witness that patients and families with advanced chronic illness were suffering, when suffering could be alleviated, to advocate for change and to create a national environment favourable for palliative care education and research.

Thanks to our Society for the honour of asking me to take a walk down memory lane with you. I do so with temerity as our history is an account of events and people responsible for those events. One risks omitting exceptional work that deserves recognition. All cannot be mentioned in a concise discourse and I must select models to illustrate our progress. I beg your understanding when I omit mention of work well worthy of an accolade. My history trip will only take you to about 2004 with a few tendrils extending a bit further. The more recent history, I think, will be familiar to most of you.

Our history resembles one of our northern rivers, fed at origin by springs that coalesce into a mighty broad waterway which in turn generates powerful tributaries carving their own creative path. Our rivers take rise from two seminal programs, one at St Boniface Hospital and the other at McGill's Royal Victoria Hospital – the two programs starting within weeks of each other in 1974.

Dr Balfour Mount started the Montreal Program. I asked him recently how he came to do so. He was a urologic surgeon – and a good one – in 1972 he was inspired by a lecture given by Dr Elizabeth Kubler Ross – she of the 5 stages of dying fame. He then read her book ‘On Death and Dying’ and noted many references to Dr Cicely Saunders who in 1967 had opened St Christopher’s Hospice in South London.

Dame Cicely was an extraordinary woman – she first trained as a social worker, became a nurse and then a physician – what a background for palliative care – a one woman team. Evident of the spiritual-religious theme that enriches palliative care in virtually all countries, her sensitivities to the suffering of dying patients was raised by her experience working at St Joseph’s Hospital – a Hospice operated by an order of nuns with a long history of care for the dying. Bal gave her a cold call one morning and ended up with an invitation to work at St Christopher’s for one week. Within that short time he was gobsmacked – absolutely moved by their work and their ability to control symptoms in an atmosphere of patient/staff partnership – the spiritual – existential element of palliative care. (insert Bal and Cicely) He returned to the Vic where, with the support of Lloyd MacLean, his Department Chair, and Ken MacKinnon his boss as head of Urology, he conducted studies on advanced cancer patients in the Hospital. The results were stunning. In this great McGill teaching hospital people were suffering in spite of the well meaning but uninformed care they were receiving.

I am not certain whether St Boniface had the same St Christopher’s tie. This program was conceived by Dr David Skelton, a thoughtful geriatrician,

and Dr Paul Henteleff. St Boniface is a Grey Nuns Hospital. As a native westerner – a Calgarian – I am very familiar with the work of this order in setting up compassionate hospitals throughout the pioneer West. I suspect that St Boniface arose as an amalgam of their traditions with David and Paul’s knowledge of Dame Cicely’s work.

From the get-go Bal’s Vic Program covered all the bases – an inpatient unit, consult services, home care service, a bereavement program, research and education components – all carried out by a team with members beyond the traditional nurse-doctor dyad. I think he takes particular pride in his visionary inclusion of volunteers who went far beyond the traditional volunteer role, serving as patient family comforters and bereavement aides. I believe this team approach also characterized St Boniface. Of note St Boniface and the Vic were teaching hospitals – thus Canadian palliative care started in academic centres.

Dr Mount introduced the phrase ‘Palliative Care’ as the name for our field. St Christopher’s was a hospice and initially ‘Hospice’ was to be the name of the new program. Bal had been cautioned by francophone colleagues that hospice had a negative connotation in the French language, conveying a disengagement from life. He tells me he was pondering this conundrum in the shower one day and ‘palliative care’ popped into his fertile mind – and thus ‘palliative care’ entered our lexicon, initially opposed by Dame Cecily and British colleagues, but ultimately accepted. It is used internationally and to this day is the flag behind which we march.

So here are two streams soon giving rise to other Canadian Palliative Care programs. This is clearly seen in David Skelton moving to the Grey Nuns Hospital in Edmonton where he recruited an Edmonton family physician, Dr Helen Hayes, who had established a reputation amongst her peers for compassionate care. She was the first Director of the Edmonton Grey Nuns Palliative Care inpatient unit.

New leaders emerged – (PICTURES) In 1974 Ina Cumming joined Bal and a year later a gifted family physician, John Scott, became part of the team. In subsequent years they both became leaders, Ina in Halifax and John in Ottawa. Of interest, Ken McKinnon, Dr Mount's mentor in urology, whom he highly admired, on retirement from the Vic became a palliative care physician in the Maritimes. Michael Downing's creative Victoria Hospice starting in 1980 – it pioneered a number of community initiatives now widely reproduced in Canada: others – a unique travelling home chart, an acute 24/7 response team and a series of excellent career guides for professionals, patients and families. Others, Larry Librach in Toronto, Liz Latimer at McMaster and that wonderful duo of Allard and Seely in Ottawa. In Quebec Maurice Falardeau at Hopital Notre Dame and Louis Dionne who started the Michel Sarrazin Centre; in Calgary Neil Hagen and in Winnipeg Deb Dudgeon.

And so we grew, with palliative care programs springing up across the country. We were nurtured to a variable extent by the hospital establishment but always by lay community groups who immediately comprehended palliative care, influenced decision makers and raised

funds. Their support was evident in the numerous Community Support Councils locally, and nationally by the Canadian Hospice and Palliative Care Association.

EDUCATION

Our field started because people like Elizabeth Kubler Ross, Dame Cicely and Bal Mount had demonstrated that the suffering of the dying was manifest yet not recognized and alleviated. This state existed despite the care offered by good, but ill-trained people. Clearly, education had to be a primary palliative care concern. Indeed it was palliative care educational endeavours that led to the formation of the CSPCP.

A few early training programs emerged, witness the careers of people mentioned earlier, all of whom started a chain of teaching others.

In 1976 the McGill group organized the first global palliative care gathering – The International Congress on the Care of the Terminally Ill. That Congress thrived; the 22nd Congress will be held in Montreal this fall. Of note, the organizers set out a program that attracted all members of the palliative care team, including volunteers and those concerned with spiritual care. This multi-disciplinary pattern still informs the current Congress.

Nationally a small coterie of physicians started to meet informally. I credit Dorothy Ley, a hematologist at Toronto Western Hospital, who formed the Canadian Palliative Care Foundation, for calling us together from

time to time. She also started the *Journal of Palliative Care*, subsequently edited by David Roy.

We had to find a way to reach our student physicians in medical schools mainly bereft of any palliative care content.

To this end, in 1988 Dr. Mount enlisted the aid of his supportive dean, Dick Cruess, who asked the deans of all Canadian schools to nominate faculty members to a palliative care curriculum committee. Ultimately, responders from 12 of the 16 schools came together. We recommended that each school have a designated block for palliative care and developed a curriculum covering what must be taught, laying out specific goals of teaching which covered 13 symptoms and 9 psychosocial issues. These were set out using the hierarchies used at that time of attitudes, skills, and knowledge.

The Canadian Palliative Care Curriculum was published in 1991 (*insert*) and circulated to the deans of each medical faculty. It was also used by the WHO to assist its efforts to advance a worldwide palliative care initiative under the leadership of a charismatic Swedish radiotherapist, Jan Sjernsward. Our Canadian group stayed together. We now used our curriculum as the outline to write a textbook illustrating each curricular point. This textbook – (*insert*) *Palliative Care: a case based manual* was published by Oxford Press; copies were given to every medical student in Canada at some point in their medical training. We have maintained a clearly directed in undergrad/graduate education.

The book sold well internationally. Indeed, it is now going into its fourth edition and, as with the first edition, the content remains Made in

Canada, with all chapters written by Canadians and endorsed by our Society.

The CSCPC grew directly as a continuum from these education initiatives. At one educational meeting – the idea arose that a National Society of physicians was needed to move in common effort, not just for education but for advocacy on a broad front. And so we drafted by-laws and formally introduced the CSPCP in 1994 with 57 members. I was amazed that when I suggested a membership fee of \$100 it was cheerfully endorsed.

Another early initiative – this one aimed at establishing a specialty in Palliative Care as already existed in Britain and Australia – was not successful. In 1995 the Royal College received a submission from a representative group led by Dr Mount which was initially greeted with enthusiasm – one Royal College leader stated that it was one of the strongest submissions in years and yet after the Royal College met with the College of Family Physicians it was not approved. Presumably The College of Family Physicians thought that palliative care with Specialty status would impede the progress of family physician palliative care colleagues while the Royal College wanted to keep peace in the family. Ultimately a Certificate of Special Competence was approved. It took 13 years before a group under the auspices of the CSPCP, led by Deb Dudgeon (picture) succeeded in getting a Canadian sub- Specialty approved – now many years after Specialty Status had been established in other countries. Clearly those of us in the 1995 group were very unhappy and of the opinion that the Royal College decision would

lessen our rights to sit at the table with academic peers within our faculties, thus limiting our opportunity to influence student/resident education and Faculty research. We old timers have scars but applaud the skill and finesse of Deb and her colleagues who were ultimately successful.

I had earlier mentioned creative tributaries budding off the mainstream. Some of these include the Canadian Virtual Hospice, the brainchild of Harvey Chochinov (picture) and Pallium – Jose Pereira’s (picture) initiative.

These two digital programs have thrived, providing direct access to experts and well structured education programs readily accessed by the whole palliative team plus practitioners in the field as well as patients and their families.

From McGill came the Centre for Whole Person Care, directed first by Dr Mount and now Tom Hutchinson. This embodies teaching and research on the core principles of palliative care.

PEDIATRIC PALLIATIVE CARE

Their history lies not inside our Society but the CHPCA. Before we were founded, a pediatric special interest group was formed in the ‘80s under CHPCA sponsorship. Gerri Frager,(picture) arguably the doyen of pediatric cancer in the country. Early leaders include Mike Harlos (picture) and Stephen Liben (picture) who wrote the first chapter on PPC in the pediatric text bible Nelson’s Textbook and Hal Siden.

These people were true trailblazers as Gerri tells me – ‘our care required a lot of thinking outside the box – we bent a lot of rules – there was no protocol for administering many of the medications, as our patient population was recognized as pharmacologic orphans. Our work was 24/7. Okay, most of us have worked 24/7 on occasion, but across provincial lines? At the dawn of pediatric palliative care there were only two dedicated programs in Eastern Canada – Gerri in Halifax and Steven in Montreal. They would sign out to each other when one was away. There are now _____ programs in Canada and our colleagues still network as the Canadian Network of Palliative Care for Children, still under CHPCA auspices, a network founded by Mike Harlos and Filomena Nalewajek.

Let me move on to Research...

RESEARCH

It is a tenet that a medical discipline must have a sound research foundation. We had a very modest foundation in our early years. A wealth of wisdom and informed opinion, but little in the way of evidence based practice. Palliative care research faced many hurdles. Most of us had little training in research methodology and we worried about ethical issues related to informed consent and causing patient/family distress. We wished to protect our patients, not recognizing that ethical research could be done and that our patients would welcome participation, seeing themselves as advancing human well being. Granting agencies followed traditional patterns of funding; using cancer research as an example

most of our then Oncology leaders wore blinkers. They were only interested in research attacking cancer tissue and regarded symptom research as a subservient issue; these views were strongly influenced by the pharmaceutical industry which controlled the Canadian oncology clinical research agenda as they were the major funders. Trials of palliative agents often involved simple inexpensive drugs which had modest potential for increasing profit. The industry only permitted trials studying one entity and did not allow admission of a patient on a concomitant palliative care trial and thus controlled patient access to research. This pattern of research was not patient/family based – they were not partners; rather they were passive recipients of therapies, often not well understood.

A turning point came in 1984 with the recruitment of Eduardo Bruera (*insert*) to a fellowship post at the Cross Cancer Institute and the University of Alberta. I had started a Palliative and Symptom Control Program at the Cross, and one day received Eduardo's CV from Peter Scholefield, Head of the NCI. This young Argentinian was only in his 20's he had already published seminal articles on the use of corticosteroids in symptom management and on autonomic system dysfunction. I encouraged him to join us in Edmonton as a Fellow and within a few months the 'Fellow' was establishing a flourishing palliative care research program with studies in opioids, hydration, autonomic effects on gastric emptying amongst others. Many of you have heard Eduardo speak; like Bal Mount ideas and outcomes bubble forth at warp speed. Both are true polymaths, gifted compassionate clinicians, program leaders, and

mentors. Two of the most influential palliative care physicians in the world.

There is a Chinese aphorism to the effect that you only understand things when you can give them a name. Eduardo was very interested in quantifying system severity and brought forward the ESAS – Edmonton Symptom Assessment Scale which is widely used today, not only in Canada but also in other countries. Deb Dudgeon championed its use as a screening tool to be used by all patients attending Cancer Ontario Clinics. Eduardo passed on his evaluation skills to then trainee and subsequently Eduardo's successor as Director of the University of Alberta Palliative Care Program, (*insert photos*) Robin Fainsinger who together with Cheryl Nickolaichuk developed the Edmonton Classification System for cancer pain. This instrument facilitated the formation of an international consortium to study cancer pain with members from Tel Aviv to Australia. About the same time in the eighties, psychosocial research was flourishing in Winnipeg where Leslie Degnar and Linda Kristjenson were studying the palliative needs of patients and families while serving as mentors for many nurse researchers. Latterly in Winnipeg, (*insert photo*) Harvey Chochinov launched a series of studies on anxiety and depression. He opened a unique field of study on human dignity in the face of illness and suffering. Again, a made in Canada, internationally recognized topic for research and enriching care.

In Montreal, again in the 80's, (*insert photo*) Robin Cohen and Bal Mount expounded the value of quality of life studies. They affirmed that these

studies as used in oncology were deficient as there is much more to quality of life than physical wellbeing. Spiritual, existential elements should be included, and were in their public MQual.

I will jump to 2000, another landmark year for palliative care research with the inauguration of the federally supported Canadian Institutes of Health Research – the CIHR. The Institute of Cancer Research within the CIHR was led by (*insert photo*) Phil Branton, a biochemist who had the praiseworthy quality of embracing all promising lines of research – traditional and otherwise. Under his guidance, the institute undertook the task of setting cancer research priorities in Canada with an emphasis on previously underfunded areas. They winnowed the list to six and, to the surprise of many; palliative care was selected as the top priority for special CIHR funding.

6.5 million dollars was set aside over six years to support the setting up of 10 national networks plus funds for designated grant support, as well as funds for innovative pilot project grants – something we had long sought – our own dedicated grants panel.

I sat on that Cancer Institute Board, which was made up of a mixture of clinicians, basic scientists, and health service researchers. I remember with admiration the quick appreciation by this community of the broader issues involved in cancer research. They readily left their laboratories to reckon with the need for studies aimed at alleviating suffering.

The CIHR impetus has been reviewed and judged to be a success. Certainly funding for investigator initiated grants has increased after the CIHR

Initiative was completed – and 67 million was spent over 10 years. The CIHR remains our largest supporter, with the CCS next. Of interest, the majority of our funding is on care delivery, access to care and quality of life – 42%. But we still represent, in 2014, only 1.4% of all cancer research. Much more remains to be done.

INTERNATIONAL

Our educational and research activities have benefitted from forging international links, both formal and informal. Notable ones include Kathy Foley at Memorial Sloan Kettering Cancer Center in New York – the doyenne of Pain Research, the aforementioned Jan Stjernsward at the WHO, Derek Doyle and Geoff hanks in Britain, Ken Fearon in Scotland and, of course, Eduardo Bruera from his Houston post, always ready to give a lift to Canadian palliative care. In Europe Stein Kaasa in Norway stands out. Stein is the leader of the European Palliative Care Initiative which includes Canadian members.

These are names from earlier days – younger members among you have no doubt forged other partnerships – these are essential. We learn from them, but they learn from us. – Networks – Peter Lawlor – Shirley Bush -

GOVERNMENT

I would like to say a few words about government support. While having a hard time cracking the medical hierarchy we have enjoyed political support. Even in 1974, lean economic years with health budgets shrinking Dr Mount received a grant from the Quebec Government to

start his program. I know that most provinces, like Quebec, have had oft fruitful support for palliative care.

Here I will reflect only on federal support. The Canadian Senate became interested in Palliative Care in large part due to the advocacy of Senator Sharon Carstairs from Winnipeg and a prior Liberal Party leader in Manitoba.

The Senate had a clear interest in end-of-life issues, manifest by their 1995 report “On Life and Death” centred primarily on euthanasia – the Report did not support euthanasia, but offered a series of recommendations for improving Canadian Palliative Care

In 2000 another Senate report entitled “Quality End of Life Care – a right for Every Canadian” was published which contained a specific call for family/ caregiver support together with better access to palliative care services and improvements in research and education. Shortly after the Report was published, a unique political decision was made – Prime Minister Chretien appointed Senator Carstairs to a Cabinet post with special responsibility for palliative care. Tangible positive results included:

Streamlining disability support and a Government pledge to ensure that Canadians can provide compassionate care to a gravely ill child, a spouse or parent without putting at risk their income or job.

A Canada Research Chair emerged, awarded to Harvey Chochinov, and support for Harvey’s initiative, the Canadian Virtual Hospice.

Federal involvement is renewed with the passage of Bill 277 (title...)The advocacy of our Society was instrumental in setting the scene for

Parliamentary comprehension of palliative care and the need for a national plan for it. Bill 277 is a private members Bill put forward by an opposition member – an almost unheard of event.

THE FUTURE

Anna has asked me to say a few words about how our history informs our future:

Well, where we have been successful those paths are clear – we have pioneered a person centred care system, now the stated mission of nearly all other branches of medicine.

We have earned a nation-wide cascade of community and government support

Stemming from small national groups in the '80s and early 90's we have developed multiple societies and other networks which bring us together in common cause – leading to a powerful shared advocacy.

We are now embracing not just cancer, but other life limiting disorders and we are moving palliative care forward, recognizing that palliative care is really the 4th phase of disease prevention – the prevention of suffering – while maintaining our end-of-life skills. Well...What's left? Certainly we have a mile to go in research –I will advance a few ideas on how we address one key area of research - Early Palliative Care Research.

Our research thrust must prioritize early palliative care of cancer, but also a broader scope encompassing heart failure, COPD, renal disease and also

perhaps the frail elderly. As we move into this sphere we will note two key observations:

1. All chronic illnesses share, in large part, a common pathophysiology. Notably, all of them are characterized by the common presence of a chronic inflammatory state and abnormal autonomic balance with the sympathetic arm in the ascendancy. As well demonstrated in cancer, (Slide) the tumor immune response engendered turns traitorous and the dominant immune activity stimulates cancer growth and metastases as does increased sympathetic production of catecholamines. They also, increase symptom frequency and activity, notably the anorexia cachexia syndrome.
2. There are cardiologists, geriatricians COPD experts and numerous basic science colleagues out there already practicing palliative care, although they may call it by another name – commonly rehabilitation. Have you ever encountered a COPD program supporting end stage lung disease patients? It looks like a palliative care team although they add nutritionists and physio/occupational therapists to their team. They are more akin than we are to the importance of nutrition and exercise in both preventing symptom progress and disease progress

Cancer studies show that early palliative care certainly relieves suffering and enhances family quality of life – whether it prolongs life is less certain. As I review the studies, it seems that Early Palliative Care Research Teams are rich in nurse/physician dyads and psychosocial enterprise. They rarely include nutritionists, physios and OT's. As these colleagues

are commonly key members of geriatric, COPD and advanced heart disease teams - when we interface with them they will wonder why we ignore nutrition and exercise as part of our early palliative care research model.

As Ian Tannock has convincingly stated in several articles, clinical cancer research must have two primary endpoints: survival and maintenance of an ability to enable an active life.

Anorexia-cachexia fatigue with functional loss is the most common, poorly alleviated symptom complex encountered across all the illnesses where we will be researching early palliative care. A symptom complex which causes dependency with its associated dire influence on dignity and monetary cost and ultimately death. It is not just another symptom although it is commonly linked with that other rubric we use – pain and symptom control. Surely early palliative care research should include a major objective of preventing or alleviating anorexia-cachexia. We now more clearly understand the pathophysiology of cachexia. There is now a rich background of evidence, mostly basic but also clinical, including recent work by Gagnon and Chasen which offer exciting ideas for early palliative research. We are fortunate to have access to an internationally renowned doyenne of cachexia research, Vickie Baracos, the Alberta Foundation Professor of Palliative Care at the University of Alberta in our midst

We work well with physicians for end-of-life care, but I think not for Early Palliative Care. I think many, particularly oncologists, have a mindset that we're not physiologic enough – soft science. Odd, because there is good evidence that new research ideas on cachexia and other aspects of symptom control do indeed have characteristics that could prolong life. If oncologists can be convinced of the rationale for a joint attack on both symptoms, notably cachexia, and cancer progress – they are locked together – then perhaps we can enlist them in joint research – something I call platform research – one in which multiple therapies are linked within a research proposal. This type of research is clearly patient/family centred.

I had the good fortune to sit down with Bal for a three hour chat a few weeks ago. We talked of many things – my God, what a remarkable experience to spend time with this remarkable man – a wonderful project for our society would be to commission an oral history of Dr Mount.

I went over our Canadian experience with our co-founder, and asked him what he thought of our future. Bal brought me back to the beginning of his work at St Christopher's and stated that as it was then so it must continue – it is key that we do not lose the spiritual-existential dimension of palliative care – {a concept difficult for me to impart; I lack Bal's eloquence}.

Some years ago he penned a thoughtful 'personal narrative', "The Existential Moment". In it he states "in accompanying those who are dying over the past quarter century I have come to view life as a spiritual

experience, that is to say, a search for meaning, purpose and personal connection, to something greater and more enduring than the self”.

In our recent conversation he expanded on this theme, stating:

“Our success in assisting our patients and their families (not to mention ourselves) hasn’t changed in the decades since St Christopher’s opened in 1967, the key determinant in influencing quality of life (our outcome objective) remains our full understanding of the interdependence of the four domains that interact to define human experience – Physical, Psychological, Social *and* Existential/Spiritual. Each of these four domains fundamentally impacts on our moment to moment experience. To ignore one of these aspects of our consciousness is to unintentionally hamstring our outcome. The domain we most frequently ignore is the existential/spiritual domain. This aspect reflects our most effective path toward ‘healing connections’ (Greg Fricchione, Harvard), ‘meaning’ (Viktor Frankl) and ‘Self’ (Carl Jung) thus optimizing quality of life, a sense of equilibrium and calm.”

His words lead me to quote Alexander Pope – what oft was thought but ne’er so well expressed.

So concludes one person’s account of some extraordinary women and men who have painted our, all things considered, intricate but bright and positive landscape. One hopes that the examples cited in this review of our palliative care life suitably honour the thousands of Canadians, only a few of whom are named, who have selflessly built and advanced our field.

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