ACHIEVING EXCELLENCE IN PALLIATIVE CARE

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GREETINGS FROM CANADA
PLAN FOR THE SESSION

• REVIEW SELECTED DEFINITIONS AND BASIC IDEAS ABOUT EXCELLENCE AND QUALITY
• HIGHLIGHT BASIC TENANTS ABOUT PALLIATIVE CARE
• DISCUSS SYSTEM/PROGRAM PLANNING
• FOCUS ON PERFORMANCE MEASUREMENT IN HEALTH CARE/PALLIATIVE CARE
• HIGHLIGHT NURSING STANDARDS, ROLES AND NURSE SENSITIVE INDICATORS IN PALLIATIVE CARE
WHAT IS EXCELLENCE?

• WEBSTER DICTIONARY
  • QUALITY OF BEING OUTSTANDING OR EXTREMELY GOOD

• SYNONYMS:
  • QUALITY, SUPERIORITY, BRILLIANCE, GREATNESS, VALUE, WORTH

• CENTRE OF EXCELLENCE:
  • A PLACE OF HIGH ACHIEVEMENT IN SOME AREA
WHAT IS EXCELLENCE IN HEALTH CARE?

• QUALITY
• VALUE/BENEFIT
• HIGH STANDARD
• PERFORMANCE
QUALITY IN HEALTH CARE

• CLINICAL
  • APPROPRIATE
  • EFFECTIVE
  • SAFETY

• SOCIAL
  • PERSON-CENTERED
  • ACCESSIBILITY
  • CONTINUITY

• ECONOMIC
  • EFFICIENCY
WORLD HEALTH ORGANIZATION (WHO): PALLIATIVE CARE DEFINITION

• An approach that **improves the quality of life of patients** and their families facing the problems associated with life threatening illness, through the **prevention and relief of suffering** by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.

• Is **applicable early in the course of illness**, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to understand and manage distressing clinical complications.
CAN YOU DELIVER ON YOUR PURPOSE?

• PURPOSE/OBJECTIVE(S)

• PROGRAM (VARIATIONS)
  • STRUCTURE: RESOURCES, SET-UP
  • PROCESS: HOW YOU WORK
  • OUTCOME: WHAT YOU ACHIEVE/END RESULTS

• EVALUATION
  • ACHIEVE OUTCOMES YOU EXPECT
  • DELIVER CARE AS YOU DESIRE
BASIC TENANTS OF PALLIATIVE CARE

• PALLIATIVE CARE, AS A PHILOSOPHY OF CARE, IS THE COMBINATION OF ACTIVE AND COMPASSIONATE THERAPIES INTENDED TO COMFORT AND SUPPORT INDIVIDUALS AND FAMILIES WHO ARE LIVING WITH LIFE-THREATENING ILLNESS.

• DURING PERIODS OF ILLNESS AND BEREAVEMENT, PALLIATIVE CARE STRIVES TO MEET PHYSICAL, PSYCHOLOGICAL, SOCIAL AND SPIRITUAL EXPECTATIONS AND NEEDS, WHILE REMAINING SENSITIVE TO PERSONAL, CULTURAL AND RELIGIOUS VALUES, BELIEFS AND PRACTICES.
BASIC TENANTS OF PALLIATIVE CARE

• IT SHOULD BE AVAILABLE TO THE INDIVIDUAL AND HIS/HER FAMILY AT ANY TIME DURING THE ILLNESS TRAJECTORY AND BEREAVEMENT.

• PALLIATIVE CARE IS PLANNED AND DELIVERED THROUGH THE COLLABORATION EFFORTS OF AN INTER-DISCIPLINARY TEAM INCLUDING THE INDIVIDUAL, FAMILY, CAREGIVERS, AND SERVICE PROVIDERS.
BASIC TENANT OF PALLIATIVE CARE

• WHILE MANY SERVICE PROVIDERS MAY BE ABLE TO DELIVER SOME OF THE THERAPIES THAT PROVIDE COMFORT AND SUPPORT, THE SERVICES OF A SPECIALIZED PALLIATIVE CARE PROGRAM MAY BE REQUIRED AS THE DEGREE OF DISTRESS, DISCOMFORT, AND DYSFUNCTION INCREASES.
BASIC TENANT OF PALLIATIVE CARE

• EVERY INDIVIDUAL HAS THE RIGHT TO PARTICIPATE IN INFORMED DISCUSSION 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.
BASIC TENANT OF PALLIATIVE CARE

• 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, WHETHER OR NOT THE PATIENT IS RECEIVING ANTI-DISEASE THERAPY.
BASIC TENANT OF PALLIATIVE CARE

• IT IS THE PATIENT’S RIGHT TO ACCESS INFORMATION AND SERVICES FROM AN INTERDISCIPLINARY TEAM OF APPROPRIATELY TRAINED PROFESSIONALS AND VOLUNTEERS WHO RECEIVE CONTINUING PALLIATIVE CARE EDUCATION AND EVALUATION.
BASIC TENANT OF PALLIATIVE CARE

• CARE SHOULD BE DELIVERED IN A PATIENT-FOCUSED, FAMILY CENTERED ENVIRONMENT
BASIC TENANT OF PALLIATIVE CARE

• INTEGRAL TO EFFECTIVE PALLIATIVE CARE IS THE PROVISION OF OPPORTUNITY AND SUPPORT FOR THE CAREGIVERS AND SERVICE PROVIDERS TO WORK THROUGH THEIR OWN EMOTIONS AND GRIEF RELATED TO THE CARE THEY ARE PROVIDING.
MODERN PALLIATIVE CARE...

- INTEGRATED APPROACH
- TRANSCENDS DISCIPLINES, MODELS OF CARE, DISEASES
- DELIVERS EFFECTIVE AND TIMELY CARE TO ALL THOSE WHO NEED IT THROUGHOUT THE COURSE OF ILLNESS
- NOT RESERVED FOR THE WEEKS AND MONTHS BEFORE THE END OF LIFE WHEN ALL OTHER OPTIONS ARE EXHAUSTED
- END OF LIFE CARE IS PART OF A PALLIATIVE CARE APPROACH; PLANNING FOR IT NEEDS TO START EARLY
- FOCUS ON THE FAMILY AND BEREAVEMENT ARE IMPORTANT
CONCEPTUALIZING PALLIATIVE CARE: INITIAL TRAJECTORIES
HAWLEY MODEL: BOW TIE
Australian Population-based Palliative Approach Model

Groups

C

B

A

Needs

Complex

Intermediate

Primary care

Increasing intensity of needs

Patient movement between levels

Exhibit 1. Original Australian model for population-based palliative approach (See Palliative Care Australia 2005, p.13)
WHAT IS A SYSTEM?

• A SET OF THINGS WORKING TOGETHER AS PARTS OF A MECHANISM OR INTERCONNECTING NETWORK (OXFORD)

• COLLECTION OF ELEMENTS THAT ARE ORGANIZED FOR A COMMON PURPOSE

• A REGULARLY INTERACTING OR INTERDEPENDENT GROUP OF ITEMS FORMING A UNIFIED WHOLE
HOSPICE PALLIATIVE CARE
(CREATING A SYSTEM)

- SPECIALIZED UNITS
- SPECIALIZED (INTER-PROFESSIONAL) TEAMS
- GENERALISTS...WITH PALLIATIVE CARE KNOWLEDGE AND SKILL
- ACUTE CARE SETTINGS
- HOME CARE AND COMMUNITY SETTING
- LONG TERM CARE/NURSING HOME SETTINGS
PALLIATIVE CARE PROGRAM PLANNING

• STRUCTURES
  • SET-UP, RESOURCES (HUMAN, MATERIAL)

• PROCESSES
  • HOW YOU WORK/DELIVER CARE

• OUTCOMES
  • END RESULTS, ACCOMPLISHMENTS
PROGRAM PLANNING IN PALLIATIVE CARE

• STRUCTURE

• PROCESSES

• OUTCOMES

WHAT IS THE BEST WAY TO ACHIEVE YOUR PURPOSE?
Figure #6: The Principal Activities of Hospice Palliative Care

- Patient and Family Care
- Education of Primary and Expert Healthcare Providers
- Research
- Advocacy on any of a number of levels

Management / Administrative Infrastructure
PROGRAM STRUCTURE

• TYPE OF PROGRAM
• WHO IS INCLUDED (PATIENTS, CAREGIVERS, DISCIPLINES)
• WHEN DO THEY COME TO YOUR PROGRAM (REFERRALS)
• REGION/REFERRAL AREA/GEOGRAPHY
• ORGANIZATIONS/PARTNERS
• FUNDING/SOURCES
• LOCATION
WHO ARE THE PALLIATIVE CARE PATIENTS?

Table 1: The RADboud indicators of PAlliative Care needs (RADPAC)

<table>
<thead>
<tr>
<th>Condition</th>
<th>Indicators</th>
</tr>
</thead>
</table>
| Congestive Heart Failure           | 1. The patient has severe limitations, experiences symptoms even while at rest. Mostly bedbound patients. (NYHA IV)  
                                 | 2. There were frequent hospital admissions (> 3 per year)             |
|                                    | 3. The patient has frequent exacerbations of severe heart failure (> 3 per year) |
|                                    | 4. The patient is moderately disabled; dependent. Requires considerable assistance and frequent care (Karnofsky-score ≤ 50%) |
|                                    | 5. The patient increases in weight what is not responding to increased dose of diuretics |
|                                    | 6. A general deterioration of the clinical situation (oedema, orthopnoe, nycturie, dyspnoea) |
|                                    | 7. The patient mentions ‘end of life approaching’                         |
| Chronic Obstructive Pulmonary Disease | 1. The patient is moderately disabled; dependent. Requires considerable assistance and frequent care (Karnofsky-score ≤ 50%) |
|                                    | 2. The patient has substantial weight loss (± 10% loss of bodyweight in six months) |
|                                    | 3. The presence of congestive heart failure                               |
|                                    | 4. The patient has orthopnoe                                              |
|                                    | 5. The patient mentions ‘end of life approaching’                         |
|                                    | 6. There are objective signs of serious dyspnoea (decreased dyspnoea d’ effort, dyspnoea with speaking, use of respiratory assistant muscles and orthopnoe) |
| Cancer                             | 1. Patient has a primary tumour with a poor prognosis                    |
|                                    | 2. Patient is moderately disabled; dependent. Requires considerable assistance and frequent care (Karnofsky-score ≤ 50%) |
|                                    | 3. There is a progressive decline in physical functioning               |
|                                    | 4. The patient is progressively bedridden                                |
|                                    | 5. The patient has a diminished food intake                              |
|                                    | 6. The presence of progressive weight loss                               |
|                                    | 7. The presence of the anorexia-cachexia syndrome (lack of appetite, general weakness, emaciating, muscular atrophy) |
|                                    | 8. The patient has a diminished ‘drive to live’                          |
Figure 1: Domains of Issues Associated with Illness and Bereavement

**DISEASE MANAGEMENT**
- Primary diagnosis, prognosis, evidence
- Secondary diagnoses (e.g., dementia, psychiatric diagnoses, substance use, trauma)
- Co-morbidities (e.g., delirium, seizures, organ failure)
- Adverse events (e.g., side effects, toxicity)
- Allergies

**PHYSICAL**
- Pain and other symptoms* Level of consciousness, cognition
- Function, safety, aids: (e.g., mobility, swallowing, excretion)
- Sensory (e.g., hearing, sight, smell, taste, touch)
- Physiologic (e.g., breathing, circulation)
- Sexual
- Fluids, nutrition
- Wounds
- Habits (e.g., alcohol, smoking)

**PSYCHOLOGICAL**
- Personality, strengths, behavior, motivation
- Depression, anxiety
- Emotions (e.g., anger, distress, hopelessness, loneliness)
- Fears (e.g., abandonment, burden, death)
- Control, dignity, independence
- Conflict, guilt, stress, coping responses
- Self-image, self-esteem

**LOSS/GRIEF**
- Loss
- Grief (e.g., acute, chronic, anticipatory)
- Bereavement planning
- Mourning

**SOCIAL**
- Cultural values, beliefs, practices
- Relationships, roles with family, friends, community
- Isolation, abandonment, reconciliation
- Safe, comforting environment
- Privacy, intimacy
- Rutines, rituals, recreation, vacation
- Financial resources, expenses
- Legal (e.g., powers of attorney for business, healthcare, advance directives, last will and testament, beneficiaries)
- Family caregiver protection
- Guardianship, custody issues

**END OF LIFE CARE/DEATH MANAGEMENT**
- Life closure (e.g., completing business, closing relationships, saying goodbye)
- Gift giving (e.g., things, money, organs, thoughts)
- Legacy creation
- Preparation for expected death
- Anticipation and management of physiological changes in the last hours of life
- Rites, rituals
- Pronouncement, certification
- End of life care of family, handling of the body
- Funerals, memorial services, celebrations

**PATIENT AND FAMILY**
- Characteristics
  - Demographics (e.g., age, gender, race, contact information)
  - Culture (e.g., ethnicity, language, cuisine)
  - Personal values, beliefs, practices, strengths
  - Developmental state, education, literacy
  - Disabilities

**PRACTICAL**
- Activities of daily living (e.g., personal care, household activities)
- Dependents, pets
- Telephone access, transportation

**SPIRITUAL**
- Meaning, value
- Existential, transcendental
- Values, beliefs, practices, affiliations
- Spiritual advisors, rites, rituals
- Symbols, icons

* Other common symptoms include, but are not limited to:
  - Cardio-respiratory: breathlessness, cough, edema, hiccups, apnea, agonal breathing patterns
  - Gastrointestinal: vomiting, constipation, obstruction, bowel obstruction, diarrhea, bloating, edema, diarrhea, edema.
<table>
<thead>
<tr>
<th>Common Issues</th>
<th>Assessment</th>
<th>Information Sharing</th>
<th>Decision-Making</th>
<th>Care Planning</th>
<th>Care Delivery</th>
<th>Confirmation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disease Management</td>
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<tr>
<td>Psychological</td>
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<td>Social</td>
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<tr>
<td>Spiritual</td>
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<td>Patient and</td>
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<td></td>
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<tr>
<td>Practical</td>
<td></td>
<td></td>
<td>Family Care</td>
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<tr>
<td>End of life/Death Management</td>
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<tr>
<td>Loss, Grief</td>
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</tbody>
</table>
SUPPORTING THE PROCESSES OF CARE

- ASSESSMENT TOOLS
- EDUCATION MATERIALS
- DECISION-MAKING AIDS
- EQUIPMENT
- DATA COLLECTION
- DOCUMENTATION RECORDS/SYSTEM
- TEAM INTERACTION/COMMUNICATION/COORDINATION (ROUNDS, HUDDLES, CONFERENCES, ETC)
- EDUCATION AND SUPERVISION/STAFF SUPPORT
# Figure 8: The Square of Organization

<table>
<thead>
<tr>
<th>Principal Activities</th>
<th>Governance &amp; Administration</th>
<th>Planning</th>
<th>Operations</th>
<th>Quality Management</th>
<th>Communications, Marketing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Financial</td>
<td></td>
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<tr>
<td>Human</td>
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<tr>
<td>Informational</td>
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<tr>
<td>Physical</td>
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<tr>
<td>Community</td>
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</tbody>
</table>

| Resources |
|-----------|----------|----------|-----------|-------------------|
| Financial | Human    | Informational | Physical | Community |

This diagram visualizes the relationship between principal activities and different functions within an organization, illustrating how resources are allocated across various departments.
### Figure #9: The Square of Care and Organization

#### Process of Providing Care

<table>
<thead>
<tr>
<th>Assessment</th>
<th>Information Sharing</th>
<th>Decision-Making</th>
<th>Care Planning</th>
<th>Care Delivery</th>
<th>Confirmation</th>
</tr>
</thead>
</table>

#### Common Issues

- Disease Management
- Physical
- Psychological
- Social
- Spiritual
- Practical
- End of Life/Death Management
- Loss, Grief

#### Principal Functions

- Governance & Administration
- Planning
- Operations
- Quality Management
- Communications, Marketing

#### Resources

- Financial
- Human
- Informational
- Physical
- Community

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**Patient and Family**
OUTCOMES: FOCUSING ON PERFORMANCE

- **CLINICAL**
  - APPROPRIATE
  - EFFECTIVE
  - SAFETY

- **SOCIAL**
  - PERSON-CENTERED
  - ACCESSIBILITY
  - CONTINUITY

- **ECONOMIC**
  - EFFICIENCY
WHY WE NEED MEASUREMENT

• MEASUREMENT ALLOWS IDENTIFICATION OF THOSE WITH DIFFICULTIES AND MONITORING OF THEIR STATUS OVER TIME

• IMPORTANT TO BE ABLE TO MEASURE THE IMPACT OF INTERVENTIONS IN A STANDARDIZED WAY

• MEASUREMENT FACILITATES COMPARISONS AND QUALITY IMPROVEMENT

• “IF YOU CAN NOT MEASURE IT, YOU CAN NOT IMPROVE IT” ~SIR WILLIAM THOMSON
PERFORMANCE INDICATOR

DEFINITION

NUMERICAL MEASURES THAT CAN BE USED AS A GUIDE TO MONITOR PROCESS PERFORMANCE

DATA OFTEN REQUIRES FURTHER INVESTIGATION TO ISOLATE ACTUAL PROBLEM/PINPOINT SOLUTION
WHAT DO WE NEED TO MEASURE?
## EXAMPLES OF DATA THAT COULD BE REPORTED

<table>
<thead>
<tr>
<th>Evaluation question</th>
<th>Domains</th>
<th>Structure</th>
<th>Process</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did the program achieve its objectives</td>
<td>Patient/family</td>
<td>Number of individuals</td>
<td>How completely assessments were completed</td>
<td>Reduction in pain</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Diagnosis of patients</td>
<td></td>
<td>Reduction in anxiety</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Number of family conferences held</td>
<td></td>
</tr>
<tr>
<td>Did the program accomplish its work as desired (i.e., principles and values)</td>
<td>Administrative</td>
<td>Number of referrals</td>
<td>Number of advanced care planning conversations</td>
<td>Reduced days in hospital</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Source of referrals</td>
<td></td>
<td>Number of patient who died in preferred location</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Number of staff</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Amount of budget</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
INDICATORS NEEDED AT ALL LEVELS

- National
- System Performance
- Regional, Provincial
- Program Level
- Point of Care
MEASUREMENT AND RESPONSE AT MULTIPLE LEVELS

REPORTING PATHWAYS...

National
System Performance
Regional, Provincial
Program Level
Point of Care

Response at each level
- National – bench-marking and comparison across jurisdictions
- Regional/provincial – standardize best practices; resource allocation
- Program - evaluating/adjusting programs
- Clinical – guide practice, communication with patient
### EXAMPLES: DATA COLLECTION AND VARIABLES

<table>
<thead>
<tr>
<th>Where data are collected</th>
<th>Examples of variables</th>
</tr>
</thead>
<tbody>
<tr>
<td>At point of patient care</td>
<td>Patient reported pain, constipation, delirium, nausea</td>
</tr>
<tr>
<td></td>
<td>Quality of life</td>
</tr>
<tr>
<td>At program or service level</td>
<td>Experiences (patients/families)</td>
</tr>
<tr>
<td></td>
<td>Perspectives on care</td>
</tr>
<tr>
<td></td>
<td>Satisfaction</td>
</tr>
<tr>
<td></td>
<td>What worked well</td>
</tr>
<tr>
<td>At system level (regional, national)</td>
<td>Emergency visits</td>
</tr>
<tr>
<td></td>
<td>ICU admissions</td>
</tr>
<tr>
<td></td>
<td>Home care visits</td>
</tr>
</tbody>
</table>
CONCEPTUAL MAP OF PALLIATIVE CARE MEASUREMENT

Patient reported outcomes (PROs):
- Quality of life
- Experience of care
- Symptom burden
  - Physical
  - Psychological

Family/Care Giver
- Caregiver Burden
- Caregiver well-being
- Experience

Quality of Care
- Access
- Advance Care Planning
- Availability
- Continuity of Care
- Earlier identification of palliative care

Point of Care System
DOMAINS OF OUTCOME MEASUREMENT IN PALLIATIVE/END-OF-LIFE CARE

- QUALITY OF LIFE
- PHYSICAL SYMPTOMS
- EMOTIONAL AND COGNITIVE SYMPTOMS
- ADVANCE CARE PLANNING
- FUNCTIONAL STATUS
- SPIRITUALITY
- GRIEF AND BEREAVEMENT
- SATISFACTION AND QUALITY OF CARE
- CAREGIVER WELLBEING
PATIENT-FOCUSED CANCER CARE OUTCOMES STUDY FINDINGS: PATIENT-REPORTED OUTCOMES MEASUREMENT SYSTEM IN CANCER – CORE FOR CANADA (PROMS-CANCER CORE) (HOWELL ET AL, 2012)

**Patient Self-Reported Health**

**Physical Health**
- **Physical Function**
  - Objective Mobility (walking, balance, climbing stairs)
  - Perceived Mobility (perceived difficulty in physical action)
  - Activities: Instrumental Activities of Living (role, work, care-giving, housework)

**Symptoms**
- **Pain**
- Cancer-Related Fatigue (CRF)
- Objective and Anticipatory Nausea/Vomiting/Retching
- Dyspnea
- Sleep/Wake Function Disturbance
- Nutritional Status (new outcome identified)

**Sexual Function (sexuality)**
- Physical Emotional/Cognitive Social

**Cognitive Function**
- Perceived Cognitive Function
- Objective Cognitive Function

**Emotional Distress/ Negative Affect**
- Anxiety
- Depression

**Psychosocial Adjustment**
- Coping
  - Self-Concept/Body Image/Self-Esteem
  - Meaning and Spirituality
  - Subjective Well-being

**Social Health**
- Social Function
- Social Support/Relationships

**Social Costs**
- Decision-making (i.e. drug costs)
- Out-of-Pocket Costs

**Health-Related Quality of Life**
- Physical Well-being
- Psychological Well-being
- Social Well-being
- Functional Well-being
- Spiritual Well-being

**Experience/ Satisfaction**

**Global Quality of Life**

**Emotional Health**

**Social Health**

**Experience/ Satisfaction**

**Burden**
- Distress
- Intensity
- Quality

**Trait**
- State

**Social Adjustment**
- Social Roles
- Emotional Support
- Instrumental/ Informational Support
- Affirmational Support
- Communication

**Coping**
- Self-Concept/Body Image/Self-Esteem
- Meaning and Spirituality
- Subjective Well-being
Screening for Distress
Edmonton Symptom Assessment System:

<table>
<thead>
<tr>
<th>Please circle the number that best describes:</th>
</tr>
</thead>
<tbody>
<tr>
<td>No pain</td>
</tr>
<tr>
<td>Not tired</td>
</tr>
<tr>
<td>Not nauseated</td>
</tr>
<tr>
<td>Not depressed</td>
</tr>
<tr>
<td>Not anxious</td>
</tr>
<tr>
<td>Not drowsy</td>
</tr>
<tr>
<td>Best appetite</td>
</tr>
<tr>
<td>Best feeling of wellbeing</td>
</tr>
<tr>
<td>No shortness of breath</td>
</tr>
<tr>
<td>Other problem</td>
</tr>
</tbody>
</table>

Worst possible pain: 10
Worst possible tiredness: 10
Worst possible nausea: 10
Worst possible depression: 10
Worst possible anxiety: 10
Worst possible drowsiness: 10
Worst possible appetite: 10
Worst possible feeling of wellbeing: 10
Worst possible shortness of breath: 10

Canadian Problem Checklist:
Please check all of the following items that have been a concern or problem for you in the past week including today:

**Emotional:**
- Fears/Worries
- Sadness
- Frustration/Anger
- Changes in appearance
- Intimacy/Sexuality

**Spiritual:**
- Spiritual and/or religious concerns
- Faith

**Practical:**
- Work/School
- Finances
- Getting to and from appointments
- Accommodation

**Social/Family:**
- Feeling a burden to others
- Worry about family/friends
- Feeling alone

**Informational:**
- Understanding my illness and/or treatment
- Talking with the health care team
- Making treatment decisions
- Knowing about available resources

**Physical:**
- Concentration/memory
- Sleep
- Weight
MEASURING SYMPTOMS

<table>
<thead>
<tr>
<th>Symptom</th>
<th>No symptom</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
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<tr>
<td>Pain</td>
<td>56</td>
<td>25.4</td>
<td>12</td>
<td>6.5</td>
</tr>
<tr>
<td>Tiredness</td>
<td>28.4</td>
<td>34</td>
<td>24.4</td>
<td>13.2</td>
</tr>
<tr>
<td>Nausea</td>
<td>79.8</td>
<td>14.3</td>
<td>4.2</td>
<td>1.8</td>
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<td>Depression</td>
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<td>24.5</td>
<td>11.5</td>
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<tr>
<td>Anxiety</td>
<td>43.9</td>
<td>32.6</td>
<td>13.7</td>
<td>9.8</td>
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<tr>
<td>Drowsiness</td>
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<td>28.3</td>
<td>11.9</td>
<td>6.5</td>
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<tr>
<td>Appetite</td>
<td>47.5</td>
<td>26.3</td>
<td>18.2</td>
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<tr>
<td>Well-being</td>
<td>28.6</td>
<td>37.9</td>
<td>23.6</td>
<td>9.9</td>
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<tr>
<td>Shortness of breath</td>
<td>61.6</td>
<td>22.4</td>
<td>10.7</td>
<td>5.3</td>
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</table>
Percent positive scores for self-reported patient-centred care categories and overall quality of care

Cancer patient place of death, by location, Canada – 2005 to 2009

Percent (%)

<table>
<thead>
<tr>
<th>Location</th>
<th>2005</th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
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<tbody>
<tr>
<td>Hospital</td>
<td>65.4</td>
<td>65.9</td>
<td>71.5</td>
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<td>Private Home</td>
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<td>10.7</td>
<td>13.0</td>
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<tr>
<td>Other</td>
<td>24.6</td>
<td>23.4</td>
<td>15.5</td>
<td>16.6</td>
<td>15.9</td>
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</tbody>
</table>

“Other” includes: Other health care facility, other specified locality, unknown locality.

Data source: Statistics Canada, Vital Statistics Death Database.
EMERGENCY DEPARTMENT VISITS LAST 28 DAYS OF LIFE
TWO OR MORE ADMISSIONS TO HOSPITAL WITHIN LAST 28 DAYS PRIOR TO DEATH
ADMISSIONS TO ICU
LAST 7 AND 14 DAYS OF LIFE

Percent (%)

Last days of life

<=7 days

<=14 days
# VISITS TO PATIENT HOMES LAST 6 MONTHS

<table>
<thead>
<tr>
<th>Province</th>
<th>Health Region</th>
<th>Study Population Size, by Province (n)</th>
<th>Palliative Home Care Visit by a Nurse or Personal Support Worker in Last 6 Months (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>British Columbia</td>
<td>Fraser</td>
<td>12,131</td>
<td>57.27</td>
</tr>
<tr>
<td>British Columbia</td>
<td>Vancouver Island</td>
<td>8,672</td>
<td>66.56</td>
</tr>
<tr>
<td>British Columbia</td>
<td>Vancouver Coastal</td>
<td>8,561</td>
<td>58.22</td>
</tr>
<tr>
<td>British Columbia</td>
<td>Interior</td>
<td>8,404</td>
<td>57.74</td>
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<tr>
<td>British Columbia</td>
<td>Northern</td>
<td>2,296</td>
<td>52.42</td>
</tr>
<tr>
<td>Ontario</td>
<td>Hamilton Niagara Halton</td>
<td>15,951</td>
<td>46.18</td>
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<tr>
<td>Ontario</td>
<td>Central East</td>
<td>13,746</td>
<td>43.87</td>
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<tr>
<td>Ontario</td>
<td>Central</td>
<td>11,683</td>
<td>42.6</td>
</tr>
<tr>
<td>Ontario</td>
<td>Champlain</td>
<td>11,527</td>
<td>50.19</td>
</tr>
<tr>
<td>Ontario</td>
<td>South West</td>
<td>10,165</td>
<td>33.35</td>
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<tr>
<td>Ontario</td>
<td>Toronto Central</td>
<td>10,065</td>
<td>42.59</td>
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<tr>
<td>Ontario</td>
<td>Mississauga Halton</td>
<td>7,536</td>
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<td>Ontario</td>
<td>North East</td>
<td>7,474</td>
<td>36.69</td>
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<tr>
<td>Ontario</td>
<td>Erie St Clair</td>
<td>7,124</td>
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<td>Ontario</td>
<td>Waterloo Wellington</td>
<td>6,142</td>
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<td>6,084</td>
<td>38.96</td>
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<td>North West</td>
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<td>Capital</td>
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<td>51.83</td>
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<td>740</td>
<td>56.36</td>
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<tr>
<td>Nova Scotia</td>
<td>Guysborough-Antigonish Strait</td>
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<td>35.63</td>
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<tr>
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<td>Cumberland</td>
<td>629</td>
<td>37.42</td>
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<tr>
<td>Domains</td>
<td>Structure indicators</td>
<td>Process indicators</td>
<td>Outcome indicators</td>
</tr>
<tr>
<td>--------------------------------------------------</td>
<td>----------------------</td>
<td>--------------------</td>
<td>--------------------</td>
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<tr>
<td>Structure and process of care</td>
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<td>55</td>
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<tr>
<td>Physical aspects of care</td>
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<tr>
<td>Psychological and psychiatric aspects of care</td>
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<tr>
<td>Social aspects of care</td>
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<td>11</td>
<td>4</td>
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<tr>
<td>Spiritual religious and existential aspects of care</td>
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<tr>
<td>Cultural aspects of care</td>
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<td>0</td>
<td>1</td>
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<tr>
<td>Care of the imminently dying patient</td>
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<td>9</td>
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<tr>
<td>Ethical and legal aspects of care</td>
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<td>16</td>
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<tr>
<td>Totals</td>
<td>22</td>
<td>199</td>
<td>117</td>
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</tbody>
</table>
WHERE TO START...KEEP IT SIMPLE

• INTEGRATED DATA COLLECTION
• PATIENT REPORTED OUTCOMES
• PATENT EXPERIENCE/CAREGIVER EXPERIENCES
• PATIENT/CAREGIVER ENGAGEMENT
DIALOGUE AND QUESTIONS