

Report of
Symptoms and Outcomes Measurement for
End of Life Care in Nova Scotia, Canada

For Workshop on February 29, 2012

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Network for End of Life Studies
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Executive Summary

Background

The Network for End of Life Studies (NELS) is a team of researchers in Nova Scotia, Canada who are working to enhance interdisciplinary research capacity through collaborations aimed at improving end of life care. NELS received funding from the Canadian Institutes of Health Research (CIHR) through a multi-year (2006-2013) Interdisciplinary Capacity Enhancement (ICE) grant to help build research capacity through a systematic focus on vulnerable populations. The goal of this ICE grant was to improve care for persons at end of life by enhancing interdisciplinary research capacity.

This report is part of a series of reports produced by NELS ICE. It is focused on the need for province-wide symptom and outcome measurement to facilitate improvement in care provision, greater access to care and the assessment of palliative support for persons at end of life. The report synthesizes the findings from a workshop that was held on February 29, 2012 to gain a better understanding and discussion of some of the symptoms and outcome measures that are being used in Nova Scotia.

Workshop Objectives:

- **Demonstrate the need for symptom and outcome measurements**
- **Review the emerging diversity of measures**
- **Identify strengths, weaknesses and implementation challenges associated with symptom and outcome measurement**
- **Enable collaboration and leadership in end of life care symptom and outcome measures**

To plan and assess care at end of life, symptom assessment can be more critical than disease classification or location of care. The current symptom and outcome measures being used in Nova Scotia have largely been developed by disease-based programs or individual health services. Person focused measurements that track across health conditions and places of care are lacking.

Symptom and Outcome Measurement

Instruments used in Nova Scotia to measure symptoms and outcomes at end of life include:

- Edmonton Symptoms Assessment Scale (ESAS);
- Patient Outcome Scale (POS);
- Abbey Pain Scale; and
- InterRAI (Home Care Resident Assessment Instrument).

A brief description of each instrument follows. Their advantages and disadvantages for end of life care across chronic diseases and locations of care were discussed at the workshop.

<p>ESAS</p> <p>The Edmonton Symptom and Assessment Scale (ESAS) was developed in 1991 to quantitatively measure symptom intensity with minimal patient burden for persons with advanced stages of cancer. It has been validated and adapted for use for persons with other chronic conditions.</p>	
<p>Advantages</p> <ul style="list-style-type: none"> - Designed for repeated comparative measurement; comparative data available - Minimal patient burden - Quantitative - Tested in a variety of patient populations; large body of literature using the tool - Multiple purposes (clinical, administrative and research); used in multiple venues; flexible administration 	<p>Disadvantages</p> <ul style="list-style-type: none"> - Reliability of self-assessment measures - Could be confusion re: self- assessment; may require assistance from trained staff; literacy may be an issue; cannot be used with those with cognitive impairment - Multiple versions in use - Historic focus on cancer only - Lack of standardization in use

<p>POS</p> <p>The Patient Outcome Scale (POS) was developed by a Palliative Care Core Audit Project Committee in the UK to measure patients’ physical symptoms as well as their psychological, emotional and spiritual needs, and provide information and support at the end of life.</p>	
<p>Advantages</p> <ul style="list-style-type: none"> - Outcome measure, benchmarking - Validated - Multiple purposes (clinical care, audit, research, training) - Available in 12 languages - Staff and patient versions (and care giver) - Helps to address practical patient issues and foster interdisciplinary team discussion - Has more domains than ESAS - Flexible and can be customized for symptoms and diseases 	<p>Disadvantages</p> <ul style="list-style-type: none"> - Reliability of self-assessment - Format may not fit with model of care - Literacy issues for some - Lack of functional measures - Not all questions appropriate at all points in time and for all sectors - Four point scale inconsistent with traditional 10 point pain assessment

<p><i>Abbey Pain Scale</i></p> <p>The Abbey Pain Scale was developed in Australia and uses non-verbal observable care (e.g., facial expressions, vocalization, physiological, behaviours, body language and physical conditions) to assess and score pain in residents with end-stage dementia.</p>	
<p><i>Advantages</i></p> <ul style="list-style-type: none"> - Can be used with persons who have dementia or who cannot verbalize - Quick - Developed using a variety of care providers 	<p><i>Disadvantages</i></p> <ul style="list-style-type: none"> - Based on care provider observation and so there may be variability in assessment

<p><i>InterRAI Home Care (HC)</i></p> <p>InterRAI HC was developed to create a common language for assessing the health status and care needs of frail elderly and disabled individuals living in the community. RAI-HC is one of many assessment tools developed by InterRAI which is a network of researchers in over 30 countries committed to improving health care for persons who are elderly, frail, or disabled.</p>	
<p><i>Advantages</i></p> <ul style="list-style-type: none"> - Standardized - Comparable with other provinces - Validated in many countries and settings - Linked to outcomes - Pain and Palliative CAPs (Client Assessment Protocols) 	<p><i>Disadvantages</i></p> <ul style="list-style-type: none"> - Requires technology - Training of staff required - Relies on assessment by trained personal to ensure accuracy of information gathered

Symptom and outcome measures need to be considered for a wide range of community based services, two of which are emergency health services and primary care.

Care in the Emergency Health Services and Primary Care Settings: In addition to the presentation and discussion of the four measures (ESAS, POS, Abbey Pain Scale and InterRAI HC), workshop participants also learned about end of life care and symptom measurement within Emergency Health Services (EHS) and Primary Care settings.

The EHS Extended Care Paramedic (ECP) Program is an initiative funded by the provincial government to help bring the emergency services to nursing home residents to reduce the need for transfers to Emergency Departments. ECPs receive additional training to broaden their scope and enable them to assess clients in long term care (LTC) facilities. Sixteen ECPs respond

to calls from 15 LTC facilities in Capital Health using EHS-based patient codes. ECPs work collaboratively with family physicians assigned to LTC residents and Emergency Department physicians. Evaluation results show a 48% reduction in transport of patients and illustrate the role that ECPs can play in supporting end of life care. Potential future roles for ECPs include: enabling 24/7 pain and symptom control for persons in their own homes at end of life; supporting a care plan and limiting family and care provider distress; and building community and professional collaborative understanding while supporting community-based end of life care.

A literature review highlighted measures that are useful in the primary care setting including ESAS, POS, Palliative Performance Scale, and satisfaction tools. Measures of access are also important. An end of life algorithm that provides links to tools to help primary care providers support end of life care has been developed through the Practice Support Program of the British Columbia General Practice Service Initiative and was of interest to the Workshop participants. The potential to develop a version of the tool for the Nova Scotia context was noted.

Workshop participants discussed whether ESAS, POS, the Abbey Pain Scale or other symptom assessment would be useful. It was felt that all of the tools would be useful in primary care, although there are advantages and disadvantages of the various measures and potential challenges to implementation. The challenges include potential to interfere with the face to face interactions, timing of administration, determining eligibility to administer, policy to support training in using tools, the need for communication across provider groups, the importance of electronic application, and building public awareness about end of life care and assessment processes.

Next Steps

End of life care encompasses multiple settings and providers and therefore collaboration is essential. Because of the range of providers and sectors involved in end of life care, it will be challenging to develop standardized assessment. Broader system issues need to be addressed to including the development and use of electronic medical records and change management at the practice level. Interest in end of life care is building and leadership is required to move forward with practice and system enhancements that will support effective symptom and outcome measurement for persons at end of life, their families and care providers.

Introduction

The Network for End of Life Studies (NELS) is a team of researchers in Nova Scotia, Canada who are working to enhance interdisciplinary research capacity through collaborations aimed at improving end of life care. NELS received funding from the Canadian Institutes of Health Research (CIHR) through a multi-year (2006-2013) Interdisciplinary Capacity Enhancement (ICE) grant to help build research capacity through a systematic focus on vulnerable populations. The goal of this ICE grant was to improve care for persons at end of life by enhancing interdisciplinary research capacity. The specific objectives of the NELS ICE were to:

1. Develop a system that will enhance identification and surveillance of populations that are vulnerable at end of life.
2. Design and conduct pilot studies to facilitate the development of research proposals to examine and address vulnerability and inequity in the provision of quality end of life care.
3. Engage in knowledge translation to inform decision-makers, health professionals and researchers on the provision of end of life care in vulnerable populations.
4. Further build an interdisciplinary team of researchers, trainees, health professionals and community partners.

Two NELS ICE surveillance reports were released in 2008¹. This was followed by the production of a series of NELS newsletters². This is a further report funded by the ICE grant. NELS work is expected to continue through support from new research grants and in-kind contributions.

The focus of this report is on the need for a province-wide symptom and outcome measurement to facilitate improvements to care provision, greater access to care, and the assessment of palliative support for persons at end of life. This report includes information presented and feedback gathered at the NELS ICE Symptoms and Outcome Measurement for End of Life Care in Nova Scotia Workshop, held Wednesday, February 29, 2012 in Halifax. Appendix A is the workshop agenda. Appendix B is the list of workshop participants.

¹ See: <http://nels.schoolofhealthservicesadministration.dal.ca/pdfs/Listening%20to%20Stakeholders%20Report.pdf>
<http://nels.schoolofhealthservicesadministration.dal.ca/pdfs/End%20of%20Life%20Care%20in%20Nova%20Scotia%20Surveillance%20Report.pdf>

² See NELS News at: <http://nels.schoolofhealthservicesadministration.dal.ca/nelsnews.html>

Definition and Description of End of Life Care

The term “end of life care” has been used to mean 1) all health care that a person receives during the last weeks and months with a life-limiting chronic disease, 2) terminal care in the last hours and days of life, and 3) synonymously with palliative and hospice care. The first definition is the most inclusive, distinct from other terms, reflective of emerging trends, and therefore is the definition used in this report.

End of life care is a term that has emerged internationally in academic research and government reports (Lien Foundation, 2010; National Gold Standard Framework Centre, 2011; Carstairs, S. 2000; Field, M.J., et al, 1997; Palliative Care Australia, 2008). These reports feature multi-sectoral approaches to improving care for persons with life-limiting chronic disease in contrast to specialty palliative or hospice care and a traditional focus on cancer (Lorenz, et al, 2005). End of life care reports often focus on the appropriateness of curative, hospital, (Bloomer, et al, 2011) emergency department and intensive care services (Nelson, et al, 2006) during the time when a person’s health is steadily or intermittently failing and death approaches. Improving the delivery of primary care is featured (National Association for End of Life Care, 2009) to enable access to care for the increasing numbers of people at end of life given an aging population. To achieve patient focused care, greater coordination and integration of services is advocated (Wilson, et al, 2008). As major economic challenges confront national health systems, improving cost effectiveness is paramount, as is assessing quality of care (Department of Health, 2008; Grunfeld, et al, 2008) and outcomes (Lorenz, et al, 2005).

A palliative hospice ‘approach’ or ‘philosophy’ is increasingly being used as the language to advocate for a transfer of the goals and specialized skills of hospice and palliative care in symptom control to a wide range of health services that traditionally focused on curative, life extending, and rehabilitative care (Thompson, et al, 2006). Palliative and hospice care are terms that have been used for a number of decades for services that highlight quality of life and supportive care over attempts at cure which are likely to be futile at prolonging good quality of life.

Good end of life care implies a planned and coordinated palliative approach for symptom control and reassessing disease treatment goals (Lunney, et al, 2003; Lorenz, et al, 2005). End of life care is a balance of palliative and curative care which shifts over time reflecting the disease trajectory of one’s life-limiting illness (Lunney, et al, 2003). A theme in end of life care reports is the need to begin earlier to plan for the possibility of death through the development of advance care plans.

Purposes of the Symptom and Outcomes Workshop

The focus of the workshop was on gaining a better understanding of some of the symptoms and outcome measures that are being used in Nova Scotia. In his opening remarks, Dr. Fred Burge commented that we need to record the symptoms and care for persons at end of life and better understand the outcomes we are trying to achieve. He indicated that the workshop would allow for reflection on the current measurement infrastructure, and discussion on what else is needed to better support symptom and outcome measurement at end of life.

The Gold Standards Framework (GSF) of the United Kingdom (UK) is accepted internationally as providing guidance for best practices for palliative and end of life care. An implicit assumption during the development of the workshop was that Nova Scotia should consider a modified GSF approach, including adapting the GSF prognostic approach³. Concurrent with the development of the workshop, Elaine Loney was contracted to prepare a literature review of best practices for tools to support primary palliative care. The summary of this review is in Appendix C. The review noted that the Palliative Support Program (PSP) introduced in British Columbia (see Appendix D) might have particular relevance for adaption in Nova Scotia. Both documents were provided to workshop attendees.

The objectives of the workshop on Symptoms and Outcomes Measurement for End of Life Care were:

1. To demonstrate the need for symptom and outcome measurements and review some of the emerging diversity of measures that track persons needing a palliative approach and receiving care at end of life;
2. To identify the strengths, weaknesses, and implementation challenges associated with symptom and outcome measures being used or considered for Nova Scotia;
3. To enable input on recommendations for collaboration and leadership to develop comprehensive symptom and outcome assessment; and
4. To aid in the emergence of cross-sector collaborative leadership in end of life care symptom and outcome measures for research and operational planning in Nova Scotia.

³ Gold Standards Framework (2008) **Prognostic Indicator Guidance Paper**. National Gold Standards Framework Centre. England. Retrieved December 27, 2011 from: <http://www.goldstandardsframework.org.uk/Resources/Gold%20Standards%20Framework/PDF%20Documents/PrognosticIndicatorGuidancePaper.pdf>

Limitations and Assumptions

Some limitations of this workshop and report are:

1. Focus was on some of the measurements currently in use and under consideration in Nova Scotia. *A comprehensive review and discussion of all measurement tools has not been carried out.*
2. Focus was on knowledge exchange of researchers with practitioners and policy makers. The workshop organizers are researchers, not operational leaders. *Further emergence of policy and operational leadership is a next step that is needed.*
3. Focus was on end of life care symptom and outcome measures for all persons in Nova Scotia with advanced life limiting chronic disease. *Assessment of needs and support for their family caregivers is critically important, but was not the focus of this workshop and report.*
4. This symptom and outcome measurement focus is grounded in the current state of knowledge of biomedical, evidence-based, categorical/quantitative care assessment⁴. *A holistic, qualitative understanding of the life experience and context of persons at end of life is very and possibly more important but not the focus of this report.*

An assumption in the development of this workshop was that ESAS and POS were the gold standards for symptoms and outcome measurement, respectively, and that they should be used, recorded electronically, and tracked over time to enable 24/7 collaborative care for individuals who are at end of life. However, it was recognized that other measures being used in Nova Scotia should also be considered or adapted for a comprehensive, system-wide end of life care information system.

Before summarising the workshop proceedings, the next section provides an overview of the current state of selected components of symptom and outcome assessment of persons at end of life in Nova Scotia.

⁴ An excellent critique of the biomedical model of symptom assessment for persons with advanced disease can be found in the recent (April 2012) Dalhousie University MAHSR thesis by Margaret Donahue entitled: "Being-Breathless-In-The-World: A Heideggerian Hermeneutic Phenomenological Interpretation of the Lived Experience of Advanced Chronic Obstructive Pulmonary Disease (COPD)", pages 1-3, 11, 15, 20, 80-87.

Workshop Context

Symptom Measurement: To plan and assess care at end of life, symptom assessment can often be more critical than disease classification. To date, the delivery of health care has usually been developed on the basis of clinical standards for specific diseases and health care facilities, but these are not optimal approaches for person-centred end-of-life care which typically crosses disease silos and care settings, e.g., hospital, home, long term care (LTC) facility, clinics, and emergency services. Not surprisingly, as will be seen below, the current symptom and outcome measures that are being used in Nova Scotia have largely been developed by disease-based programs or individual health services. Person-focused measurements that are accessible and track across health conditions and places of care are lacking.

In Nova Scotia, the *Edmonton Symptoms Assessment Scale (ESAS)* is beginning to be used by cancer patient navigators and others for distress screening for persons with cancer. The Veteran's Memorial has introduced the *Abbey Pain Scale* for use by care workers providing personal care for non-verbal (dementia, etc.) persons. The *InterRAI Home Care (HC)* is advocated by the Canadian Institute for Health Information (CIHI) and is used across Nova Scotia for the assessment of need for home care and LTC facility placement. The 2011 Nova Scotia Department of Health and Wellness "Better Care Sooner" report is a response to the Emergency Department report by John Ross (2010), which recommends changes to primary care provision.⁵ The Comprehensive Geriatric Assessment tool is advised for consideration for frail elderly 75 years and older. In February 2011, an innovative Extended Care Paramedic program was introduced in Capital Health as a component of 'care by design' for persons in LTC facilities to reduce avoidable transfers to emergency departments and hospital admissions. Primary care is expected to have an increasing role in palliative and end of life care and so useful cross sector end of life care assessment tools will be needed.

Outcomes Measurement: For the evaluation of health services provision, outcomes measurement often includes mortality rates, recovery rates, survival or disease free survival, and cure rates. For the assessment of care at end of life, these are not appropriate outcome measures. Alternate, measures of good care are needed. Internationally, the *Patient Outcome Scale (POS)* is advocated through the leadership of Dr Irene Higginson and others in the UK, and by the European Association of Palliative Care.

⁵ Information on Nova Scotia's "Better Care Sooner" is at: <http://gov.ns.ca/health/bettercaresooner/>

Workshop Process

During the workshop, participants heard presentations and worked in small groups to review key questions. Clare Levin from Research Power Incorporated recorded the workshop proceedings. After Dr Fred Burge set the stage by presenting the purpose of the Workshop, Dr Grace Johnston provided further context for the day (Appendix E). This was followed by presentations by Dr Janice Howes on ESAS (Appendix F) and by Dr Paul McIntyre and Glenna Thornhill on POS (Appendix G). After the ESAS and POS presentations, there was a small group discussion on whether the tools should be used province-wide and potential challenges to implementation. Volunteers from the small groups recorded and submitted their discussion. A summary of submitted workshop attendee comments are included in this report.

In the afternoon, other measures being used were reviewed. Elsie Rolls presented on using the Abbey Pain Scale at the Veteran's Memorial for non-verbal Veteran residents (Appendix H). Joanne Boudreau described the InterRAI Home Care (RAI-HC) screening and assessment tool that is being used across the province to assess the need for home care or admission to a long term care (LTC) facility (Appendix I). New roles for emergency and primary care practice for persons at end of life are emerging. Therefore, Jan Jenson and Dr Andrew Travers were asked to present on the Extended Care Paramedic (ECP) Program (Appendix J) and Dr Fred Burge on the delivery of primary care (Appendix K). After these four presentations, a small group carousel process was used to invite attendee feedback on integrating measures across disease silos (e.g. should ESAS be used across other care settings, and if so what are factors that would need to be considered?) and care settings (e.g. RAI-HC in relation to other measures and care settings; what might be useful to the ECP Program and primary care?). The small group discussions were facilitated and recorded by the presenters and their colleagues. The written notes submitted from the small group sessions are summarized in this report.

The final session of the workshop was a large group discussion on implementation challenges, leadership, and next steps which was facilitated by Stephanie Heath from Research Power Inc. The remainder of this report provides background information prepared prior to the workshop for reflection⁶, insights from the workshop presentations, and summary points from the discussion sessions⁷.

⁶ Alyson Lamb assisted Grace Johnston and Stephanie Heath in the preparation of an early version of this document that was reviewed by the presenters and circulated prior to the workshop.

⁷ This Report was circulated to all presenters for review and further editing prior to its release.
Network for End of Life Studies (NELS) Interdisciplinary Capacity Enhancement (ICE)

Symptom and Outcome Measurement

EDMONTON SYMPTOMS ASSESSMENT SCALE (ESAS)

The Edmonton Symptom and Assessment Scale (ESAS) was developed in 1991 in Edmonton, Alberta to quantitatively measure symptom intensity with minimal patient burden (Bruera, Kuehn, Miller, Selmsler, Macmillan, 1991) for persons with advanced stages of cancer. It has been validated (Nekolaichuk, Watanabe, Beaumont, 2008) and adapted for use by persons with other chronic conditions. It is useful for symptom assessment at any stage of the disease trajectory, not just at end of life.

ESAS is advocated by the Canadian Partnership Against Cancer (CPAC) to assess symptoms experienced by cancer survivors. ESAS has been implemented by Cancer Care Ontario for self-completion by all patients at registration for every cancer clinic visit. In Nova Scotia, ESAS is used along with a distress thermometer and symptom checklist (Canadian Problem Checklist) for distress screening by patient navigators, Palliative Care Services and in selected cancer clinics.

ESAS started as an eight-item patient-related symptom visual analogue scale developed for self-reporting symptom intensity by advanced cancer patients (Bruera et al., 1991). A ninth symptom (shortness of breath) was later added, as well as an optional tenth item, a specific symptom identified by the patient (Bruera et al., 1991). The most recent version of the scale uses an 11-point numerical rating scale for each symptom (higher scores indicate worse symptom intensity).

ESAS is one of the Accreditation Canada recommended quality indicators for hospice palliative care services. The format of use may vary across clinics (e.g. sometimes a tenth item is added, sometimes it is not). Alberta Health Services has developed a modified version of the ESAS, the ESAS-r which is more user-friendly and overcomes some of the problems using ESAS. ESAS is intended to be completed by patients with minimal assistance from health professionals or family members. However, it should be reviewed by a health care provider with the patient after it is completed.

Advantages of Measure	Disadvantages of Measure
<ul style="list-style-type: none"> • Designed for repeated comparative measurement • Minimal patient burden • Quantitative measurement • Tested in a variety of patient populations • Used for clinical, administrative and research purposes 	<ul style="list-style-type: none"> • Reliability of self-assessment measures are not always trusted by clinicians and researchers • Could be confusion regarding self-assessment and therefore may require assistance from trained staff • Multiple versions in use

Workshop Feedback:

At the workshop, participants worked in small groups to discuss ESAS. While most groups felt that it could be used across Nova Scotia, each group identified advantages and disadvantages to using the tool, as well as implementation considerations if the use of the tool was further expanded across the province.

Advantages of Measure	Disadvantages of Measure
<ul style="list-style-type: none"> • Can be used in multiple venues (i.e. hospital, LTC facility, at home) • Already used in Nova Scotia • Comparable data is available (data is collected systematically for all cancer patients in Ontario) • Large body of literature using the tool • Flexible administration of the tool, but there is a need to indicate who reports the scores (patient, caregiver, health professional, etc.) 	<ul style="list-style-type: none"> • Literacy may be an issue in using the tool • The tool cannot be used by individuals who have cognitive impairments • The symptoms list in the tool are cancer-focused and may not adequately represent other chronic diseases (e.g. dementia, renal or liver disease) • With current use in Nova Scotia, there is a lack of standardization in how it is used (e.g. different recall periods being used) • Need to determine the frequency and carry out training in terms of standardized protocols • The tool does not include a functional screen/physical assessment • A barrier in using it across sectors (hospital, primary care, LTC facilities) could be a lack of communication between these sectors – communication is needed to ensure over-screening is not occurring • The self-reported nature of the scale may make it difficult to interpret given individual variations

Considerations for Implementation:

- Important to standardize the tools being used to measure distress, and to develop a standardized protocol for using the selected tool (e.g. frequency of screening/re-screening, protocol following screening, etc.)
- ESAS may need to be used in collaboration with other tools (e.g. Functional Assessment Activities of Daily Living (ADL), Spiritual Assessment, POS – Palliative Outcome Scale, Assessment of Family Distress)
- Communication between different care providers (e.g. primary care, hospital) is critical to ensure that patients are not being over-screened
- ESAS needs to be valid for use with other conditions/diseases and in settings with older adults with frailty
- A plan for broad implementation needs to consider the time involved in conducting the screening and follow up, including time for data entry, and could identify which health care professionals may be responsible for which tasks
- Practices need to be appropriately supported to adopt the tool (practice change support), especially in non-cancer sectors, including education and training
- If the data is going to be held centrally, this location needs to be determined (may be difficult when data are collected across diseases and sectors)
- Need to consider how the broader family picture of distress can be assessed – can families be included in this or is another type of assessment required?
- Resource structure for referral and management needs to be clarified

PATIENT OUTCOME SCALE (POS)

Patient Outcome Scale (POS)⁸ was developed by a Palliative Care Core Audit Project Committee in the UK from a systematic review of palliative care tools which identified problems with current tools. The tool was developed in eight centres providing palliative care across England and Scotland; 450 patients were involved in the initial study. Initially, POS was called the Palliative Outcome Scale, but may be renamed the Patient Outcome Scale, at the discretion of the user, since its use is not restricted to end of life care. Use is open to registered users (no fee).

POS is a tool to measure patients' physical symptoms as well as their psychological, emotional and spiritual needs. It provides information and support at the end of life. POS consists of 10 questions which focus on control of pain and other symptoms, patient anxiety, family anxiety, provision of information, level of support, life worth, self-worth, wasted time and personal

⁸ See more information on POS at: <http://pos-pal.org/>
Tool download is at: <http://pos-pal.org/POS-in-English.php>

affairs. In addition to these ten questions, patients are asked to list their “main problems”. There are three different versions of the questionnaire to be used respectively by the patient, a family member/caregiver, or a health care provider. POS has been translated into 12 languages and validated (Hearn, Higginson, Palliative Care Core Audit Project Advisory Group, 1999). There are modular optional versions of the POS (i.e. specific to certain diseases, e.g. MS) as well as an add-on symptom card, the POS-S.

POS has been widely adopted in both Europe and Africa, but it is not widely used in Canada and the United States. Since mid 2009, the Capital Health Integrated Palliative Service has used and recorded both POS and ESAS in medical charts for every patient to track needs over time. The plan is to begin recording these measures electronically through the CASPER platform.

Advantages of Measure	Disadvantages of Measure
<ul style="list-style-type: none"> • Outcome measure • Validated tool (validated for use in broad population, i.e. not just cancer) • Can be used as a clinical care, audit, research, and training tool • Widely used internationally (Europe, Australia, Asia, Africa and America) with internationally comparable data available • Available in 12 languages • Staff and patient versions 	<ul style="list-style-type: none"> • Inherent issues with self assessment • Not widely used in Canada and Nova Scotia

Workshop Feedback:

At the workshop, participants worked in small groups to discuss POS. Each group identified advantages and disadvantages to using the tool, as well as implementation considerations if the tool was used across the province.

Advantages of Measure	Disadvantages of Measure
<ul style="list-style-type: none"> • The tool helps to ensure clinicians address issues that may not be on their chart (e.g. practical issues) and issues that patients may not otherwise have identified that they need assistance with • Can be used as a benchmarking tool • POS’s scope is broader and looks at more domains than the ESAS • Tool can be completed by patient, caregiver, or health care provider – this means that data could be collected for a longer time period than 	<ul style="list-style-type: none"> • Checkbox style of the tool may not fit with the model of care • Literacy may be an issue for some patients • Some questions may not be applicable at all points – i.e. frequency of appointments, wasted time • Functional measures are not included in the tool • Not all questions are appropriate for all sectors

Advantages of Measure	Disadvantages of Measure
<p>for tools requiring a self-report</p> <ul style="list-style-type: none"> • Symptom add-on checklist and different versions of the tool (for different diseases) provide added flexibility and customization • Fosters inter-disciplinary team discussion • Factor analysis shows POS captures two factors: quality of care and psychological status as well as three independent items: family anxiety, pain and symptoms. 	<ul style="list-style-type: none"> • POS uses a scale of 0-4 for rating pain – this may cause confusion and is inconsistent with the standard 0-10 scale that has been used for years • Efforts are already being made to implement ESAS in the province, so it may be challenging to implement a different scale ; however ESAS and POS have different functions and therefore using both is appropriate
<p>Considerations for Implementation:</p> <ul style="list-style-type: none"> • Important to develop a standardized protocol for using POS (e.g. frequency of screening/re-screening, follow up protocol following screening, etc.) – the frequency of screening may need to be adjusted depending on disease trajectory • Need to consider how data will be stored and the results/changes tracked over time • Training and support for its use is key, as well as support/structure for practice change; education and communication will be needed to ensure a standardized approach • Leadership and resources will be needed to support implementation • The patient scale should be used for self-reporting outcomes when possible • If the patient completed the scale prior to the visit, collecting the data would not become the focus of the visit – instead the health care provider could focus on reviewing and discussing the information with the patient • Would be good to have a way to also assess caregiver needs • May work well to use both POS and ESAS concurrently – POS does not measure what ESAS measures, it's a complement 	

ABBEEY PAIN SCALE

The Abbey Pain Scale (Abbey, Piller, De Bellis, Esterman, Parker, Giles, Lowcay, 2004) was developed in Australia, after it was recognized that a significant number of elderly people were dying of end-stage dementia and their pain was not being adequately assessed or treated. The tool was developed in two stages, in 1997 and in a 2002 sampling residents in 24 residential facilities in Australia. The first stage focused on developing the tool and the second stage modified the tool to make it more efficient and effective for a variety of people to use to assess pain in residents with end-stage dementia.

The tool is a one page assessment that uses non-verbal observable care to score the observed level of pain that the person is experiencing. Observations of facial expressions, vocalization, physiological, behaviours, body language and physical conditions are used.

At the Veterans’ Memorial facility in Halifax, this tool is used by care providers on each shift, i.e., three times a day, for each resident Veteran. More than 90% of the residents are affected by Alzheimer’s disease or dementia. A palliative philosophy has been introduced along with the Abbey Pain Scale.

Advantages of Measure	Disadvantages of Measure
<ul style="list-style-type: none"> • Can be used with persons who have dementia or who cannot verbalize • Quick (1 minute) • Developed using a variety of care providers 	<ul style="list-style-type: none"> • Based on care provider observation and so there may be variability in assessment

Workshop Feedback:

At the workshop, participants worked in small groups to discuss the Abbey Pain Scale and it was agreed that there may be value in using the scale in addition to ESAS or other symptom measurements for persons at end of life who are non-verbal including those with dementia. Each group discussed if a common symptom assessment scale should be used for non-verbal persons in all settings. A summary of the discussion is provided below.

- Important to assess pain but it is also important to go beyond pain assessment and explore other types of scales for symptom assessment in persons who are non-verbal
- Good observational skills are required to use the tool and training would be required to ensure the tool is used consistently
- Advantages to using a common symptom assessment scale for non-verbal persons across setting as this would enable comparability and could help to facilitate continuity of care
- Tool that is best for the client should be used
- If the tool is not validated, it is not good for research purposes but might be useful in clinical settings

INTERRAI HOME CARE (RAI-HC)

InterRAI (Resident Assessment Instrument) is a collaborative network of researchers in over 30 countries committed to improving health care for persons who are elderly, frail, or disabled and living in the community. Their goal is to promote evidence-based clinical practice and policy decisions through the collection and interpretation of high quality data about the characteristics and outcomes of persons served across a variety of health and social services settings.

InterRAI HC (Home Care)⁹ was developed in 1993-94 and revised in 1999 to develop a common language for assessing the health status and care needs. RAI-HC is one of many InterRAI assessment tools. InterRAI assessment tools are designed to work together, sharing common language and common measures.

InterRAI supports a standardized process in clinical assessment, care planning, and generation of quality indicators and other outputs to support system planning. The care provider assesses functional status, health status, social support, and service use and asks both the clients and caregiver the questions. There are a suite of 15 assessments that highlight function and quality of life. There are 19 domains and the assessment usually takes place in the client's home and usually requires two to three hours or more to complete. InterRAI HC is linked to Client Assessment Protocols (CAPs) that have over 30 problem oriented plans that can be used to guide the care of the client. CAPs related to end of life care include palliative care, pain, cognition, depression and anxiety, nutrition, oral health, medication management, bowel management, urinary incontinence and indwelling catheter.

InterRAI HC outcomes related to palliative and end of life include: a pain scale, CHESS (Change in Health, end stage disease and signs and symptoms), depression rating scale, ADL (Activities of Daily Living) self-performance hierarchy scale, cognitive performance scale, and MAPLE (Method of Assigning Priority Level risk of adverse outcomes based on 14 elements).

InterRAI Palliative Care (PC) assessment has been tested internationally and has many similar domains as RAI-HC but they are more related to palliative and end of life. Additional domains include psychosocial well-being, treatments and procedures, responsibility/directive. Domains not included in the InterRAI PC tool are: vision patterns, disease diagnosis, health conditions and preventative health measures, dental status and environment assessment. Currently,

⁹ <http://www.interrai.org/section/view/?fnode=15>

InterRAI is finalizing CAPS for palliative care. CAPS include pain, mood, anxiety, dyspnea, bowel-GI, skin ulcers, sleep disturbance, fatigue, life completion, advance care, client wishes, delirium, nutrition, information supports, and caregiver distress.

The Canadian Institute for Health Information (CIHI) advocates using InterRAI assessment tools for interprovincial comparisons¹⁰. Since 2002 in Nova Scotia, the Single Entry Access (SEA) program has used the RAI-HC for assessment for both home care and eligibility for LTC facility admission. The InterRAI LTC (MDS 2.0) tool was piloted in the province and is currently used at six LTC facilities, but is not in widespread use. The palliative tool, InterRAI PC, has been purchased but is not implemented in Nova Scotia at this time.

Advantages of Measure	Disadvantages of Measure
<ul style="list-style-type: none"> • Standardized tool • Able to compare with other provinces • Tested and validated in many countries and settings • Linked to outcomes • Pain and Palliative CAP's 	<ul style="list-style-type: none"> • Requires technology • Training of staff required • Relies on assessment by trained personal to ensure accuracy of information gathered

Workshop Feedback:

At the February 29 workshop, participants worked in small groups to discuss the InterRAI HC assessment and screening tool including its strengths and whether ESAS or other symptom measurement should be used along with InterRAI HC for continuing care (HC and LTC) assessment in the province. A summary of the discussion is provided below.

- Could help to inform the allocation of resources
- Using ESAS or other symptom measurement may be redundant if the questions are already captured through the InterRAI HC assessment
- ESAS should be used for commonality and comparability – it is used in other settings
- Would be great if the InterRAI assessment findings could be provided to health care providers beyond the home care program

¹⁰ http://www.cihi.ca/CIHI-ext-portal/pdf/internet/HCRS_PIA_2006_EN

EMERGENCY HEALTH SERVICES (EHS) EXTENDED CARE PARAMEDIC (ECP)

Research by Barry Clarke et al in Halifax in 2006 has shown that 60% of patients that are taken from long term care facilities to Emergency Departments (EDs) by ambulance in response to a 911 call for emergency services are returned to the LTC facility without admission to hospital.

The typical EHS response differs dramatically from end of life care in the following ways:

- EHS calls are quick whereas end of life care requires time
- The public assumes EHS will always resuscitate and this is what paramedics are trained to provide
- Lack of protocols for end of life care by EHS
- Paramedics discomfort in providing palliative service

Through the provincial government's Better Care Sooner initiative, a commitment was made to develop a new Extended Care Paramedic (ECP) Program to bring emergency services to nursing home residents – reducing the need for transfers to hospitals in Capital Health. The ECP program was initiated in February 2011 after seven ECPs received training for this new role. After a second cohort was trained a year later, there are 16 ECPs. The program includes one week of in-class training, one day of clinical at a teaching LTC facility and one day of training in the ED. ECPs work in non-transport capable vehicles with a broadened scope of practice. ECPs respond to 15 LTC facilities in the Halifax region and consult with the family physician assigned to the LTC resident and an ED physician on every call. ECPs offer more disposition options than are available to traditional EHS paramedics including:

- Urgent ambulance transport to the ED
- Transfer to the ED or other location (e.g., diagnostic imaging) at times when the wait time can be minimized
- Assessment of the patient on site by the ECP in collaboration with LTC nursing staff and consultations with the ED physician and LTC physician for the patient and providing care as directed

Both qualitative and quantitative research methods were used to assess the new ECP program. The findings include:

- The ECP approach to LTC emergency calls differs from a standard paramedic approach in terms of time on calls, consultation and discussion and complexity of decision making
- Advance care directives influence the approach and subsequent care plans of the ECP
- ECPs can bring important information and a fresh perspective when communicating with the LTC resident, the resident's family members, and LTC staff

- End of life care handover is critical in terms of recognizing when it was time for the ECP to leave and the importance of the hand-over of health care back to the LTC care team
- ECP preparation for end of life care was discussed somewhat in their initial training but the ECPs are seeing more terminal care cases than was initially expected; ECPs feel they are learning as they go and that their experience is important for learning

The quantitative data revealed a 48% risk reduction in transport of LTC residents.

The program received a gold medal for Healthcare Innovation from the Institute of Public Administration of Canada.

The presentation concluded with a review of the potential expanded role of the EHS ECP in end of life care including supporting improvement of:

- Pain and symptom control for all persons at end of life
- Community and professional understanding and support
- Coordination of 24/7 care for all persons at end of life
- Satisfaction with care and better control of family and care provider distress

ECPs have the potential to facilitate quality, timely and cost-effective care; decrease the delay in commencement of a palliative approach; decrease multiple assessments, referrals and transfers; and decrease ineffective use of hospital beds, emergency departments and diagnostic testing.

Workshop Feedback

The small groups discussed if ESAS, POS and/or the Abbey Pain Scale (or other symptom assessment for non-verbal patients) would be useful for paramedics assessing the needs of a person that could be at end of life. It was felt that the results of all three measures would be useful for paramedics to know (would provide a baseline) but assessment in isolation would not be effective. ESAS and POS would not be useful for crisis intervention. However it was felt that the Abbey Pain Scale (or other symptom assessment for non-verbal patients) could be helpful for paramedics and emergency departments.

Another tool that was identified for EHS use is POLST (Physician Orders for Life Sustaining Treatment) which states a person's wishes for end of life care. The importance of the EHS Special Patient Program (SPP) and registry was noted. The SPP provides EHS paramedics with the pre-defined care plans of a patient and includes contact information for the physician that the paramedics to call in relation to caring for the patient. This EHS program is underutilized but could readily be expanded to improve care for persons at end of life.

PRIMARY CARE

In the primary care presentation, it was noted that many sectors or parts of the health system are increasingly working together to support more effective end of life care. Some questions were raised for consideration:

- Have we identified those who should be identified as potentially palliative?
- Have we assessed their needs well?
- Has care been coordinated with others well?
- Have we provided good care?
 - Access
 - Patient-centered: Patient goals, information sharing, joint decision-making
 - Physical comfort
 - Practical support

The literature review completed by Elaine Loney (Appendix C) highlights measures that may be useful to apply in Primary Care settings including: POS, ESAS, Palliative Performance Scale (PPS) and satisfaction tools (information, shared decision making). Measures of access are also important e.g., family reported, patient reported, reports by other health care providers, and by others services such as palliative care. It is also important to consider markers of good care such as low use of EDs, minimal hospitalization, use of community resources, etc.

The Practice Support Program (PSP) of the British Columbia (BC) General Practice Service Initiative provides training for practitioners to improve care of patients and families living with, suffering and dying from life-limiting and chronic illnesses. Physicians learn how to identify patients who could benefit from a palliative approach to care; increase confidence and communication skills to enable Advance Care Planning (ACP) conversations; and improve collaboration with palliative care and non-palliative specialist services, patients, families and caregivers. An end of life algorithm has been developed and is available through the electronic medical record (EMR). The algorithm provides links to tools to help providers support end of life care for their patients e.g., there is a link to the ESAS. There is the opportunity to develop a Nova Scotia version of the BC tool. However, Nova Scotia does not have the same degree of support as BC to facilitate primary health care practice change e.g., a structure such as the BC Practice Support Program that provides learning modules, tools, etc.

Workshop Feedback

The small groups discussed whether ESAS, POS, the Abbey Pain Scale or other symptom assessments would be useful in primary care to assess the needs of a person that could be at end

of life. Participants were also asked to reflect on potential challenges to using the tools in primary care.

Participants of the small groups appeared to feel that ESAS or other symptom scales or checklists would be useful. Participants noted that ESAS was similar to a targeted system review. It has utility to monitor response to drug therapy to reduce symptoms. They liked the simplicity and low responder burden compared to POS. Participants preferred the original layout of ESAS compared to the CCNS layout with the distress tool. Some had concerns that it may not cover symptoms for other causes of death as it was designed for cancer.

In terms of POS, the small groups noted that it may not be as easily integrated as ESAS. Some items in the tool serve clinical care and some serve performance monitoring of the system, and the wording was not “Canadianized”. It was noted that one tool could lead to another e.g., POS triggers ESAS.

Participants felt that self-assessment should be used for ESAS and POS when the person at end of life is able to complete as it enables the person to contribute directly to care planning. A large number of persons receiving primary care are still physically able to complete the tools. One group asked if POS would be more easily completed by patients than ESAS. It was also noted that assessment tools could be placed on-line, e.g., in a personal health record, or requested by a health care provider, and if the score is at or above a certain level, this could trigger the need for action to be taken.

Participants felt that the Abbey Pain Scale or other symptom assessments for non-verbal patients could be used in primary care (in the office or home) for cognitively impaired patients and would also be useful to monitor symptom response to drug therapy. Participants felt that family assessment should be used for the Abbey Pain Scale as it would engage them in the process and families may be attuned to behaviour change.

Potential challenges identified to using the tools in primary care included:

- Concern about how to implement tools without interfering with the face-to-face meeting
- Timing in terms of administering the tools
- Determining if the PPS should be used for all those identified as potentially palliative and determining who is eligible to administer the tool
- The need to exercise judgment in tool use
- Ensuring tools are completed as intended, e.g., by patients, not providers when applicable

- Need for policy to support training in use of the tools
- Communicating across care provider groups, e.g., family physicians, palliative care programs, homecare
- Need to ensure providers have results of previous administration of tool to guide care
- Importance of administering the tool electronically. Tools are not useful if they exist in paper format only
- Need to enhance the public's ability to deal with this area of the life experience

Next Steps

At the conclusion of the workshop, meeting participants were asked to reflect on next steps in moving forward with symptoms and outcomes measurement for end of life care in Nova Scotia.

The following points were noted:

- No one owns end of life care as it cuts across all sectors and all sectors have responsibility to support end of life care
- Collaboration is critical
- Further discussions are required and leadership is needed to continue to move forward
- It is daunting to think of developing a standardized assessment for end of life care across sectors and the entire system
- Broader issues need to be addressed including how the electronic medical record (EMR) can support the implementation of end of life assessments across sectors
- There is a need to identify and explore opportunities to use the EMR and other communication and information technology techniques
- End of life care algorithm from BC could provide a framework that Nova Scotia could start to populate. Currently providers cannot readily access tools for end of life care
- Support for implementation and practice change are critical for all types and locations of care including primary care, hospitals, long term care, etc
- It is important to learn from our own experiences. When implementing the Abbey Pain Scale, a change model was used that included education of staff, involvement of leadership in delivering the training and education, and reaching out to staff to ensure education sessions were convenient, etc
- Interest in end of life care is increasing and there is the beginning of a public health or community health lens on end of life care. This could become an opportunity to further improve access and use of measures and tools for symptom and outcome assessment

The workshop organizers are hopeful that other groups will sponsor sessions to continue to invite stakeholder input. Cancer Care Nova Scotia is sponsoring a half day concurrent session on April 20, 2012 at their provincial meeting. The Nova Scotia Renal Program is sponsoring a day long workshop in May 4, 2012 for renal and palliative care providers from districts across the province. Researchers, operational programs, and policy makers are encouraged to further build on this progress.

Conclusion

The workshop presented several tools for symptom and outcome measurement at end of life that are being used in Nova Scotia. Workshop participants had the opportunity to review the measures and discuss their advantages and disadvantages. Participants discussed potential challenges and opportunities for implementation in a variety of settings across the continuum, e.g., primary care, emergency health services, continuing care etc. The workshop helped to illustrate the diversity of measures that track persons needing a palliative approach for their care. Meeting participants recognized the potential for duplication and inconsistency in symptom and outcomes measurement given the many tools available. Standardized assessment for end of life care across settings would be challenging.

The need to address broader system issues such as implementation of electronic medical records and change management support was highlighted. Systems supports will be required to effectively support symptom and outcome measurement at end of life. The meeting concluded with the acknowledgement of the growing interest in end of life care, and the need for further discussion related to supporting effective end of life care including symptom and outcomes measurement.

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Appendix A ~ Agenda

Symptoms and Outcomes Measurement for End of Life Care in Nova Scotia Workshop

Wednesday, February 29, 2012
8:00 a.m. to 4:30 p.m.
Lord Nelson Hotel, Halifax, Nova Scotia

AGENDA

8:00 am – 8:30 am	Registration and Continental Breakfast
8:30 am – 9:00 am	Welcome <ul style="list-style-type: none"> • Introductions (<i>Grace Johnston</i>) • Purpose of workshop and report¹¹ (<i>Fred Burge</i>) • Workshop and Report Process (<i>Stephanie Heath</i>)
9:00 am – 9:40 am	Presentation: Planning for Symptom and Outcome Measurement (<i>Grace Johnston</i>)
9:40 am – 10:10 am	Presentation: Symptoms Measurement - Edmonton Symptom Assessment Scale (ESAS), Distress Thermometer and Symptom Checklist (<i>Janet Howes</i>)
10:10 am – 10:45 am	Small Group Work: Strengths and Weaknesses of the ESAS in Nova Scotia
10:45 am – 11:00 am	MORNING BREAK
11:00 am – 11:30 am	Presentation: Patient Outcomes Scale (POS) (<i>Paul McIntyre and Glenna Thornhill</i>)
11:30 am – 12:00 pm	Small Group Work: Strengths and Weaknesses of POS in Nova Scotia
12:00 pm – 1:00 pm	LUNCH BREAK
1:00 pm – 2:00 pm	Panel: Alternate Measures and their relationship to ESAS and POS (Chair - <i>Stephanie Heath</i>) <ul style="list-style-type: none"> • Abbey Pain Scale for non-verbal persons including those with Dementia (<i>Elsie Rolls</i>) • InterRAI assessment in SEAScape (NS single entry access) for Continuing Care (<i>Joanne Boudreau</i>) • Emergency Health Services Extended Care Paramedic Assessment (<i>Jan Jenson</i>) • Primary Care (Family Physician, Advanced Practice Nurse) Measures (<i>Fred Burge</i>)
2:00 pm – 3:00 pm	Small Group Work: Feedback on the Above Measures
3:00 pm – 3:15 pm	COFFEE BREAK
3:15 pm – 4:15 pm	Large Group Work: The Way Forward - What Should Be the Process for Integration and Leadership?
4:15 pm – 4:30 pm	Wrap Up and Next Steps
4:30 pm	Adjourn

¹¹ This workshop is a one step in planning for symptom and outcomes measurement for persons at end of life in Nova Scotia. The NELS ICE research objective is to enable improved population based analyses of care for persons with advanced (life limiting) disease in the future in Nova Scotia using linked electronic health records.

Appendix B – List of Participants

Yukiko Asada	Lynn Lethbridge
Darrell Bardua	Elaine Loney
Joanne Boudreau	Todd MacDonald
Michelle Boudreau	Peter MacDonald
Fred Burge	Maureen MacIntyre
Loriann Cormier	Carolyn Marshall
Sandee Crooks	Emily Marshall
Jillian Demons	Ruth Martin Misener
Judith Fisher	Paul McIntyre
Gordon Flowerdew	Melanie Parsons-Brown
Rick Gibson	Gredi Patrick
David Henderson	Nikki Richards
Tom Henneberry	Elsie Rolls
David Hey	Mark Scales
Katherine Houde	Glenna Thornhill
Janice Howes	Andrew Travers
Jan Jensen	Theresa Marie Underhill
Grace Johnston	Robin Urquhart
Farhana Kanth	Grace Warner
Susan Kirkland	Arlene Wiggins
Bev Lawson	Tallal Younis
	Kathryn Yuill

***List may be incomplete;
some persons arriving
without pre-registering
may have been missed.
List was in part based on
persons registered to
attend rather than
actually attending.***

Appendix C – Outcomes Instruments from Primary Care from Literature Review by Elaine Loney

	GPSC-PSP End of Life Module, British Columbia	Gold Standards Framework (GSF), United Kingdom	Other Instruments and Examples-- Program/Research Use	Palliative Care Outcomes Collaboration (PCOC), Australia
Program Overview	<p>Practice support module for general practitioners on end of life care.</p> <p>http://www.gpsc.bc.ca/psp/learning</p> <p>Training & resources to:</p> <ol style="list-style-type: none"> 1) Help general practice physician learn identify patients who could benefit from a palliative approach to care 2) Increase confidence and communication skills to enable Advance Care Planning (ACP) conversations; 3) Improve collaboration with palliative care and non-palliative specialist services, patients, families and caregivers. <p>Paid learning sessions followed by a 6-8 week action period to try practice change with visits from Practice Support Team members, including GP and MOA "champions."</p>	<p>Optimize end of life patient care delivered by generalist providers. Supported nationally. Primary care, care homes, hospitals. Emphasizes coordinated anticipatory planning and care. Current focus on increasing consistency, effectiveness, equity for non cancer patients, and integrated quality improvement. Access to all tools listed below except After Death Audit Tool:</p> <p>http://www.goldstandardsframework.org.uk/ http://www.goldstandardsframework.org.uk/TheGSFToolkit/ToolsandTemplates</p> <p>Primary Care (1): 5 Goals: 1. Consistent high quality care, 2. Alignment with patients' preferences, 3. Pre-planning and anticipation of needs, 4. Improved staff confidence and teamwork, 5. More home based, less hospital based care 3 Steps: 1. Identify, 2. Assess, 3. Plan 7 Key tasks: 1. Communication, 2. Coordination, 3. Control of symptoms, 4. Continuity out of hours, 5. Continual learning, 6. Carer Support, 7. Care in dying phase.</p> <p>GSF Foundation Level</p> <ul style="list-style-type: none"> • Identification – Prognostic Guidance and Needs-based coding and use of Needs Support Matrices <p>GSF Higher Level</p> <ul style="list-style-type: none"> • Advance Care Planning discussions • Cross boundary care & communication - GSF care homes and hospitals - Home Packs, 'passport information' key worker for patient. 		<p>Voluntary national data collection (2, 3) using standardized validated clinical assessment tools to benchmark and measure outcomes in palliative care.</p> <p>Participation open to all palliative care services providers from public and private health sectors; rural and metropolitan areas and inpatient and ambulatory settings.</p> <p>All tools listed below available on website .</p> <p>http://www.pcoc.org.au/</p>

Report of Symptoms and Outcomes Measurement for End of Life Care in Nova Scotia, 2012

	Most tools available on website.	<ul style="list-style-type: none"> • Anticipatory prescribing & Just in Case Boxes • Audit using ADA audit tool. Significant Event Analysis with action plan. • Carer enablement, information & support • Admission avoidance in final stage. <p>GSF Advanced level</p> <ul style="list-style-type: none"> • Measures of consistency, effectiveness, non cancer equity, use of some Next Stage GSF Additional tools & developments. Accreditation. 		
Identifica- tion of patients near end of life	<p>GSF Prognostic Indicator Guidance (4)(Sept. 2011). See GSF.</p> <p>Patient Registry</p>	<p>GSF Prognostic Indicator Guidance (4)(Sept. 2011). Components: 1) surprise question, 2) general indicators of decline and increased needs, 3) specific clinical indicators for cancer, organ failure and frailty / dementia.</p> <p>Patient Registry (incl. summary of problems, anticipated needs, preferred place of care, out of hours hand over form sent, bereavement care, etc.)</p>	<p>SPARRA data (Scotland) identifies patients at risk of admission/ readmission based on 3 years previous hospital data. Data routinely provided to general practices in Scotland. In a pilot program data triggered proactive coordinated care planning that included advance care planning.(5, 6)</p>	
Symptom assess- ment	<p>Edmonton Symptom Assessment Scale-revised (ESAS-r) (7-11) Patient reported.</p> <p>BC Guidelines: Frailty in Older Adults – Early Identification and Management. Includes:</p> <p>* CSHA Frailty Severity Index (12)(validated);</p> <p>*Seniors Assessment Tool (Patient reported, on GPSC-PSP website,</p>	<ol style="list-style-type: none"> 1. PACA Score (4 patient symptoms plus patient’s & carer’s open problems/concerns. Referral criteria.) 2. Pepsi-Cola Aide Memoire monthly checklist (multidomain) 3. Initial Pain Assessment. Uses 0-3 pain scale (3= most severe). 4. Abbey Pain Scale(13-15) for people with dementia. http://www.dementiacareaustralia.com/index.php/library/abbey-pain-scale.html 	<ol style="list-style-type: none"> 1. Palliative Care Outcome Scale-Symptoms.(16-18) Patient reported. Versions: Generic (POS-S), Parkinson’s Disease (POS-PD), Renal (POS-R) & Multiple Sclerosis (POS-MS) . http://pos-pal.org/index.php 2. Edmonton Comfort Assessment Form (Caregiver & health professional reported; for patients incapable of completing ESAS). An older tool, not currently available on the 	<p>Symptom Assessment Scale (SAS) (19, 20) Similar to ESAS-r; patient reported. Unlike ESAS /ESAS-r, it does not contain an emotional assessment item unless specified by patient as “other problem.”</p>

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	unknown validation)		Edmonton program website.	
Functional Assessment	<p>1. Palliative Performance Scale PPSv.2 (21-26). Included in algorithm and data collection. V.2 --Minor changes in punctuation and instructions did not require revalidation. Developed by Victoria Hospice: http://www.victoriahospice.org/health-professionals/clinical-tools</p> <p>2. Clinical criteria for Patient Identification includes assessment with Barthel Index,(27) Karnofsky Performance Scale (KPS) (28-30) or Eastern Cooperative Oncology Group Performance Status (ECOG) (31) tools.</p>	<p>Clinical criteria for patient identification includes functional assessment using Barthel Index (27), KPS , (28-30), ECOG (31) or PULSE screening)</p>	<p>1. PPSv.2 (32) will be used in ICCP impact assessment.</p> <p>PPS used for all ambulatory cancer patients.</p> <p>2. Karnofsky Performance Scale (28, 29) used in Edmonton Regional Palliative Care Program. Original version available: at http://www.palliative.org/PC/ClinicalInfo/AssessmentTools/AssessmentToolsIDX.html</p>	<p>1. Karnofsky (Australian) Performance Scale. (29, 33) KPS modified for community use.</p> <p>2. Resource Utilization Group – ADL (RUGS-ADL) (case mix/staffing application,(34) referral trigger for care placement, OT assessment). Embedded in InterRAI instruments. Additional info: http://www.interrai.org/section/view/?fnode=28</p>
Multiple Domain		<p>1. PACA score. (Problems and Concerns Assessment). Patient and caregiver sections; to cover physical, social, psychological and spiritual issues. Used to trigger referral.</p> <p>2. PEPSI-COLA aide Memoire Monthly checklist. (Physical, Emotional, Personal (spiritual, caregiver agenda, etc.), Social support, Information / communication, Control (choice, advance directive, etc.), Out of hours/emergency, Late (terminal care), Afterwards (bereavement)</p>	<p>1. Palliative Outcome Scale (POS).(16-18) Patient, caregiver, staff questionnaires & scoring sheets. Complementary POS Symptom Scales. V.2 designed for nonspecialist setting use. [Nomenclature note: V.2 questionnaires re-titled “Patient outcome scale”; scoring sheets retain “palliative outcome scale” title. V.1 for specialist settings retains “Palliative outcome scale” title. Complementary symptom scales (POS-S, POS-R, POS-MD, POS-PD) use original ‘Palliative Outcome Scale’ title.]</p>	<p>Palliative Care Problem Severity Score (43, 44)</p> <p>Domains: Pain, symptom, psychological, spiritual, caregiver. Problem lists in each domain. Referral trigger for SW, Psychological, Spiritual care.</p>

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			<p>2. InterRAI-Palliative Care (InterRAI-PC). (35, 36) Will be used in ICCP impact assessment. Used by CCAC case managers. Additional info:http://www.interrai.org/action/view/?fnode=18</p> <p>3. Functional Assessment of Chronic Illness Therapy-Palliative Care (FACIT –Pal) (37-39) Patient reported measure. Physical, social/family, emotional, & functional well-being subscales (27 items) plus 19 items of additional palliative related concerns. (3 pages long). Used in ENABLEII RCT.(40, 41)</p> <p>Functional Assessment Cancer Treatment –Lung (FACT-L) FACT-C (cancer) used by Temel et al. (42). There are 50+ FACT/FACIT scales for cancer and non cancer. Access at: http://www.facit.org/FACITOrg</p>	
<p>Psychological/ Distress</p>	<p>Item in ESAS-r.</p>	<p>Prompt in PEPSI-COLA.</p>	<p>1. Distress Thermometer (45) used in shared care model, Niagara.(46)</p> <p>2. Canadian Problem Checklist.(47) Recommended Canadian Partnership Against Cancer (2009) to be used with ESAS as part of minimum data set for screening for distress.</p>	<p>In SAS only if specified by patient.</p> <p>Psychological/Spiritual Problem list in Problem Severity Score.</p>

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Spiritual	?	Prompt in PEPSI-COLA.	Recommended tools listed in reviews by Hanson et al. (48) and Selman et al.(49)	Psychological/Spiritual Problem list in Problem Severity Score .
Advance Care Planning (ACP)	<p>Support tools: “Discussing Goals of Care” to aid physician in discussion. Use of My Voice(50) patient resource.</p> <p>Measures: Documentation of provision of “My Voice” workbook, advance directive completion/greensleeve and No CPR form completion on care plan template and in monthly reporting.</p>	<p>‘Thinking Ahead: Advance Care Planning Tool’. Guides and documents discussion of what patient wishes to happen (separate from advance care directive, do not resuscitate order).</p>	<p>SPARRA data patient identification trigger for proactive planning & coordination that includes ACP and communication of directives among providers/care sites. (5, 6) Mayo Clinic primary care recording completion of advance medical directives (AMD) in EPR. Used EPR data to identify patients 60+ without AMD provide info before health maintenance visit, and EPR prompt for discussion at time of encounter.(51) Patient/Caregiver satisfaction instruments include questions on discussions about wishes for future care and consistency of care with patient wishes. (52-54) CANHELP(52) does not specifically inquire about <i>signed</i> directives. Speak Up (55) a new national resource similar to My Voice used in BC.</p>	

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<p>Planning & Coordination</p>	<p>Clinical Tools:</p> <ol style="list-style-type: none"> 1. Care plan template incl. care planning documentation 2. MOA checklist incl. care planning documentation 3. Care Team communication record 		<p>Needs Assessment Tool: Progressive Disease – Cancer (NAT: PD-C). (56, 57) and Needs Assessment Tool: Progressive Disease (NAT: PD) Australia. Multiple purposes: needs assessment (multiple domains), matching needs & services, referral; records level of concern & action taken, discharge planning, communication between generalists & specialists. NAT-PD can be used for cancer patients.(58)</p>	
<p>Caregivers</p>	<p>Survey question. See “Retrospective” below.</p>	<p>Caregiver problems/concern are considered in PACA Score and PEPSI-COLA monthly report (under “Personal”)</p>	<p>Search for tools beyond scope of assigned task. Hanson et al. (48) and Hudson et al. (59) provide reviews.</p>	<p>Included in Problem Severity Score.</p>
<p>Satisfaction with Care</p>	<p>Survey question on Patient/Family comfort with end of life care plan</p> <p>Survey question on Caregiver support</p>		<p>1. CanHELP (patient & caregiver versions). (52, 60). Recently used by Stajduhar (unpublished). Access: http://www.thecarenet.ca/</p> <p>2. Family Satisfaction with Advanced Cancer Care (FAMCARE)(61-67) Identified as a higher scoring tool. (48) Used in Palliative Care Integration Project evaluation S.E. Ontario.(68) Access original version: http://www.promotingexcellence.org/tools/pe1154.html</p> <p>After Death Bereaved Family Member Interview.(54) Modified by Burge et al. for NS use.</p>	

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<p>Retrospective, Practice level</p>	<p>Self-audit Palliative Approach (compare care of randomly selected patients with chronic illness with recommended approaches) Self-audit Patient Death (2 patients, non cancer diagnoses) Practice Support End of Life Team Monthly Reporting Tool (Excel) Process measures: *# patients identified & in registry *# pts. on registry with ESAS/PPS recorded *# pts. on registry with ACP discussion and provided with ACP tool *# pts. on registry with collaborative care plan Optional: # physicians very confident initiating EoL care discussion; 2 survey questions: patient/caregiver comfort with end of life plan and caregiver perception they are/were supported caring for pt./family member</p>	<p>After Death Audit Tool. Online voluntary tool based on GSF levels and NHS quality markers. Individual practice reports with comparison to benchmarks; comparisons over time (e.g. after intervention /practice change). Data collected: Demographics: diagnosis, gender, preferred place of care, actual place of death -Information on communication and coordination of care, including services used - -Care planning, symptom control assessment, continuity of care, out of hours -Carer support and care in the dying phase -Number of crisis admissions, hospital bed days, reasons for not achieving preferred place of care -Reflective practice section. Data source for UK 2009 “National Snapshot”. (69) After Death Audit Tool not freely available on GSF website.</p>		<p>PCOC reports.</p>
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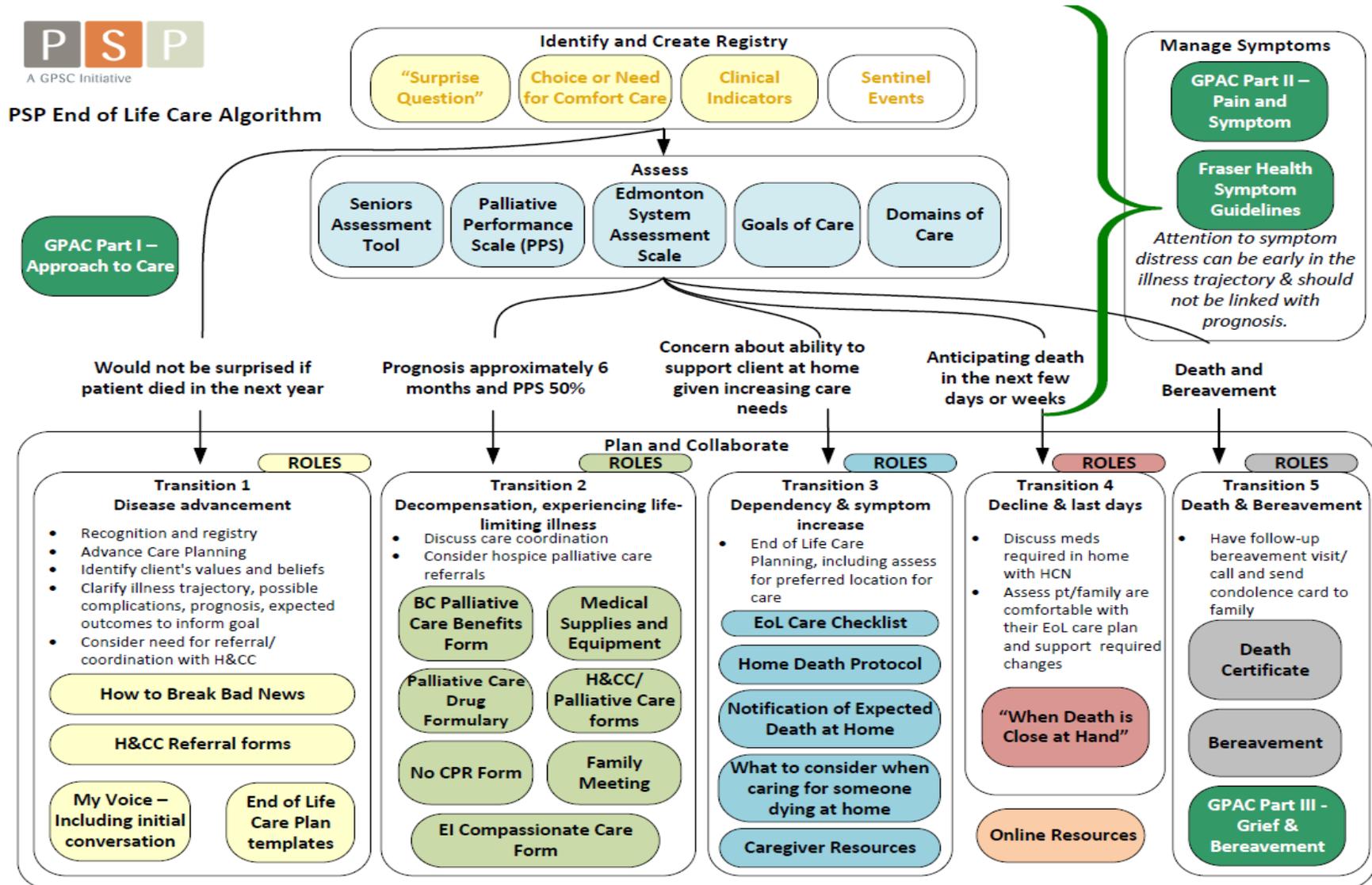
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Appendix D – Practice Support Program Algorithm



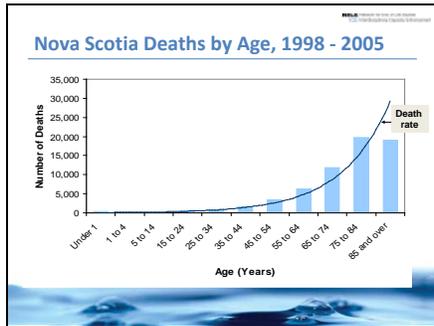
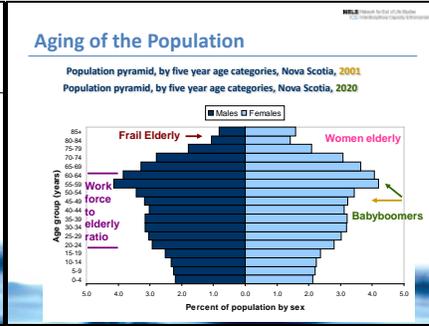
Appendix E – Planning for Symptom and Outcome Measurement in the Provision of Palliative and End of Life Care in Nova Scotia (abridged)

Planning for Symptom and Outcome measurement in the provision of Palliative and End of Life Care in Nova Scotia

Grace Johnston, MHSA, PhD
 Professor, School of Health Administration,
 Dalhousie University,
 Epidemiologist, Surveillance and
 Epidemiology, Cancer Care Nova Scotia
 Principal Investigator, NELS ICE

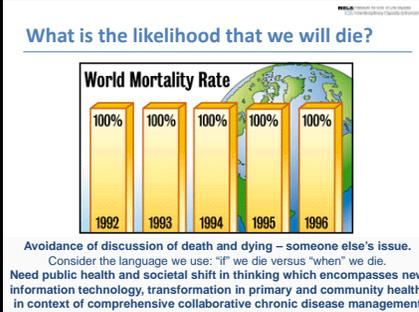
NELS Network for End of Life Studies
 I.C.E. Interdisciplinary Capacity Enhancement

February 29, 2012

What is the likelihood that we will die?

World Mortality Rate



Avoidance of discussion of death and dying – someone else's issue.
 Consider the language we use: "if" we die versus "when" we die.
 Need public health and societal shift in thinking which encompasses new information technology, transformation in primary and community health, in context of comprehensive collaborative chronic disease management

Brief Historical Context - Canada

Health is a provincial not a federal responsibility: BNA Act
 Post WW II – in 1950's built hospitals
 1960's – Canada-wide hospital insurance
 1970's – Canada-wide physician insurance added
 Led to Canada Health Act

Concurrently, palliative medicine began. Dr Balfour Mont in Montreal after studying hospice care with Dame Cicely Sanders in UK. In Canada became physician and hospital based where costs of services were publicly funded. For decades, palliative care had cancer focus and urban-based champions.

Out-of-hospital, community-based health care is underdeveloped in Canada.

Ranking countries by quality of end of life care. (2010, July 14). The Economist. Retrieved from http://www.economist.com/node/16686127?story_id=16585127&fsrc=usa Lien Foundation.



Palliative care problems are known

Since mid 1990's, Sharon Carstairs and other Canadian reports show:

- societal and professional avoidance of death and dying
- inadequate access to care
- underdeveloped palliative care
- lack and challenges in communication
- poor continuity and coordination of care across providers and in transitions in care location
- lack of central leadership and vision; improved by local champions
- care and planning of care is often in disease 'silos' but people at end of life usually have more than one condition
- quality of care and need for care and accreditation standards
- limited research and surveillance data



Population priorities in context of U.S. Institute of Medicine's quality goals

Divides population into eight groups: 1) in good health, 2) maternal/child, 3) with an acute illness, 4) stable chronic conditions 5) serious but stable disability, 6) **failing health near death**, 7) **advanced organ system failure**, 8) **long-term frailty with failing health**.
 Definitions of optimal health and priorities for services. Framework to plan resources, care arrangements, and service delivery.

Joanne Lynn, BM Straube, KM Bell, SF Jencks, RT Kambic (2007) Using population segmentation to provide better health care for all: The "Bridges to Health" model. *The Millbank Quarterly*, 85(2), 185-208

NELS ICE research

Analyses of linked administrative databases to determine service use in last months of life for persons who die of cancer and other diseases
 Mortality follow-back interviews of next of kin
 Other, e.g. vulnerable populations

Emerging valuable potential

Capitalize on diversity of "natural experiments" to inform best practices

Provider-driven studies and data analyses for rapid grass roots discovery and knowledge transfer, e.g. Elsie Rolls; Jan Jensen and Andrew Travers; others
 References: see papers by Amy Abernathy

Definitions and conceptualizations of palliative and end of life care

Palliative "Care" versus "Approach"

End of life care is all health care in the last weeks, months (or years) of life

Palliative Care

Reference: Murray, S. A et al. *BMJ* 2005;330:1007-1011

End of Life Trajectories

Lunney JR, Lynn J, Foley DJ, Lipson S, Gurinik JM. Patterns of functional decline at end of life. *JAMA*. 2003; 289:2387-2392.

Trajectories Distribution

95% of people die of a life threatening disease with end of life stage
 They access many services: nursing home, home care, specialty chronic disease care, diagnostic testing, primary care, inpatient hospital, emergency department, palliative care, ...

Nova Scotia deaths, 1998-2005, all ages

Gold Standards Framework in UK

International best practice standard
 Covers all places of care
 Continuing to evolve

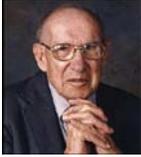
Primary care is a focus for training and audit
Registry of persons at end of life is a key component

<http://www.goldstandardsframework.org.uk/>
<http://www.goldstandardsframework.org.uk/Resources/Gold%20Standards%20Framework/PDF%20Documents/QIP%20Flyer%20Oct10%20v%202023.pdf>

Creation of an end of life care registry

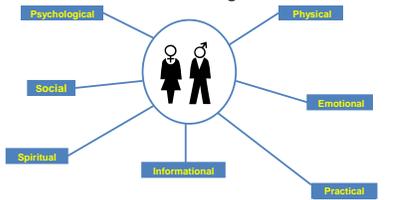
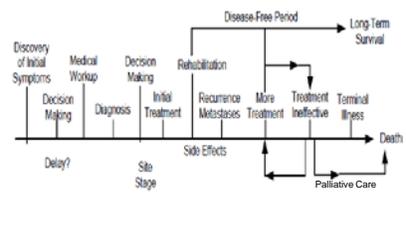
Early identification of life threatening disease for registry enrollment and earlier discussion of goals of care, care plan and coordination

Beginning of end of life markers – to be defined for Nova Scotia

<h3>Workshop Premise</h3> <p>“You can’t manage what you can’t measure.”</p> <p>Peter F Drucker</p> 	<h3>Outcomes</h3> <p>Improve</p> <ul style="list-style-type: none">pain and symptom control for all persons at end of lifecommunity and professional understanding and supportcoordinated 24/7 care for all persons at end of lifesatisfaction with care and control of family and provider distressassurance of quality, timely and cost-effective care <p>Decrease</p> <ul style="list-style-type: none">delay in commencement of a palliative approachmultiple assessments, referrals and transfersineffective use of hospital beds, emergency department and diagnostic testing <p>What else?</p>
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<h3>Address limitations of current measures</h3> <ol style="list-style-type: none">Need symptoms, not just diagnoses, recorded in a standardized form for all persons in their last months of lifeNeed useful outcomes recorded in a standardized form so that current and new approaches to the delivery of care at end of life can be more efficiently and fully evaluatedNeed coordination/bridging across care settings and diseases in electronic data entry and administrative database sharing while maintaining strengths and value of each care setting and disease program; coordination does not mean centralizationDevelop plans for a future using person based real-time web-portal health information that maximizes self management and community-based coordinated care	<h3>Purposes of this workshop</h3> <ol style="list-style-type: none">Demonstrate need for and measures of symptoms and outcomes for persons at end of lifeIdentify strengths, weaknesses, and implementation challenges in Nova ScotiaBrainstorm on collaboration and leadership to enable coordinated, evidence-based community practice in Nova Scotia to improve care for persons at end of life
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Appendix F- Edmonton Symptom Assessment System (ESAS), Canadian Problem Checklist, and Distress Thermometer for Cancer Patients

<p style="text-align: center;">Screening Cancer Patients for Distress in Nova Scotia with the ESAS, CPC, and DT</p> <p style="text-align: center;">Janice L. Howes, Ph.D., R. Psych. QEII HSC, Capital Health Clinical Leader Psychosocial Dalhousie Unive </p> <p style="text-align: center;">February, 2012</p> 	<p style="text-align: center;">Screening for Distress and Distress Management</p> <ul style="list-style-type: none"> • Provincial Initiative of Cancer Care Nova Scotia, through the Supportive Care Cancer Site Team, in partnership with Canadian Partnership Against Cancer, and all Nova Scotia District Health Authorities • Focused on Improving Person-Centered Care 
<p style="text-align: center;">Nova Scotia Goals</p> <ul style="list-style-type: none"> • To make this new standard of care, Screening for Distress and Distress Management, available to cancer patients across the illness continuum in Nova Scotia. • To Integrate Screening for Distress and Distress Management into Clinical Practice. • To sustain this clinical service to provide better person-centred care to our patients and reduce the negative effects of unaddressed distress. • To identify psychosocial resource strengths and gaps.  	<p style="text-align: center;">Needs and Concerns of Patients with Life-Threatening Illness</p> 
<p style="text-align: center;">Defining Distress</p> <ul style="list-style-type: none"> • Distress is a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioural, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. • Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis. <p style="text-align: center;">- NCCN Practice Guidelines in Oncology, 2008</p>	<p style="text-align: center;">Distress</p> <ul style="list-style-type: none"> • Significant levels of distress are experienced by at least 35-45% of cancer patients • Distress: The 6th Vital Sign in Cancer Care • Evaluation of and monitoring of client's emotional distress is now an accreditation standard (2009).
<p style="text-align: center;">Clinical Course of Cancer</p> 	<p style="text-align: center;">Higher Risk for Distress</p> <ul style="list-style-type: none"> Higher levels of physical disability Advanced illness; Poorer prognosis Later stage disease Greater disease burden Younger age (some studies) Pre-existing Psychological Problems Lower Levels of Social Support Limited/Ineffective Coping Strategies Other Concurrent Life Stressors

When cancer strikes it has the potential to create needs in various areas. No two individuals will have exactly the same needs. Needs arise in relation to a number of factors such as the type of cancer, extent of the disease, resources available to the person, his or her age, etc.

<p>Screening for Distress versus Assessment</p> <p>Screening: Rapid identification of patient's key concerns, and allows health care professionals to identify the need to conduct further assessment and/or refer to specialist.</p> <p>Assessment: A more thorough, in-depth examination of the patient's concerns that is conducted after screening.</p> <p style="text-align: right;">CIAG, Canadian Partnership Against Cancer</p>	<p>Why Screen and Manage Distress?</p> <ul style="list-style-type: none"> • Heightened Distress often goes unrecognized. • Heightened Distress is associated with a number of negative outcomes. • Heightened Distress is treatable. • Improve the patient's experience and quality of life. <p style="text-align: right;">(Jacobsen et al, 2007)</p>
<p>Heightened distress is associated with a number of negative outcomes.</p> <ul style="list-style-type: none"> • Lower Quality of Life • Increased Difficulty Coping • Poorer Adherence to Medical Treatment • Lower Satisfaction with Health Care • Relationship Between Greater Depression and Poorer Survival • Increased Health Care Costs <p style="text-align: right;">(Jacobsen et al., 2007)</p>	<p>Screening Domains</p> <ul style="list-style-type: none"> • Physical • Practical • Psychosocial
<p>Screening for Distress Tool: Nova Scotia</p> <ul style="list-style-type: none"> • Canadian Problem Checklist: 24 items <ul style="list-style-type: none"> – Three Items added <ul style="list-style-type: none"> • Relationship Difficulties (Social/Family) • Medication Coverage (Practical) • Swallowing (Physical) • Edmonton Symptom Assessment System • Distress Thermometer (NCCN, 2003) 	
<p>Standard Approach to Screening for Distress and Management:</p> <ul style="list-style-type: none"> • Patient Completes Screening Tool • HCP has Therapeutic Conversation with patient "What concern is bothering you the most today?" • Use Two Referral Pathways from the Best Practice Guidelines for the Management of Cancer-Related Distress in Adults (CCNS, in final Preparation) to help manage distress. • HCP completes Distress Management Summary Sheet 	<p>Levels of Distress</p> <div style="border: 1px solid black; padding: 5px; margin-bottom: 10px;">Mild Distress</div> <div style="border: 1px solid black; padding: 5px; margin-bottom: 10px; background-color: yellow;">Moderate Distress</div> <div style="border: 1px solid black; padding: 5px; margin-bottom: 10px; background-color: red; color: white;">High Distress</div> <p>Distress Thermometer or ESAS score ≥ 4 to 7</p> <p>Distress Thermometer or ESAS score ≥ 8</p>
	<p>Palliative Cancer Patients Experience a range of symptoms as disease progresses:</p> <ul style="list-style-type: none"> • Pain • Anorexia • Nausea • Asthenia • Dyspnea • Delirium • Psychological Distress (Depression, Anxiety, Worry, Grief) • Practical Concerns/Worries

Advanced Cancer

- **Emotional Distress** is common among patients with advanced cancer
- **50%** (or more) of patients with advanced cancer meet diagnostic criteria for:
 - Adjustment Disorders: 11% - 35%
 - Major Depression: 5% - 26%
 - Anxiety Disorders: 2% - 14%

(Miovic & Block, 2007)

- **Subsyndromal Symptoms** are displayed by many patients:
 - Anxiety symptoms in 25% - 48% of cancer patients.
 - Post-Traumatic Stress Features occur in 20% - 80% of cancer patients.

(Miovic & Block, 2007)

- **Depression** is a major risk factor for desire to hasten death.
- Many terminally ill patients (up to 59%), who request assisted suicide are depressed.

(Miovic & Block, 2007; Emanuel et al., 2000)

Edmonton Symptom Assessment System

- Developed as a brief, clinically useful tool for self-reporting symptom intensity by advanced cancer patients.
- Designed for repeated measurement of symptom intensity with low patient burden.
- Used by Palliative Care Programs across Canada, and also internationally.

(Nekolaichuk et al., 2008)

Edmonton Symptom Assessment System (ESAS)

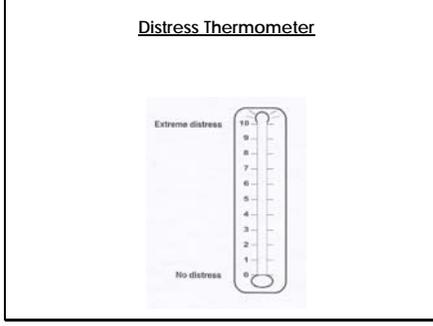
- Original version: eight symptoms using visual analogue scales (Bruera et al., 1991)
- 9th symptom (shortness of breath) added and option of rating a 10th symptom. (Bruera et al., 1991)
- More recent version: 11-point numerical rating scale for each symptom (higher scores indicate worse symptom intensity).
- ESAS format varies across clinics and studies.

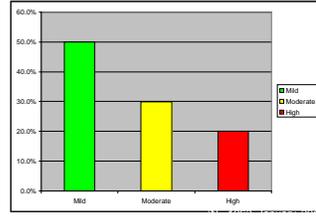
(Nekolaichuk et al., 2008)

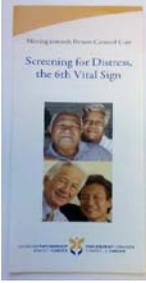
- Patients may experience difficulties in scoring and interpretation of the ESAS items which could potentially lead to suboptimal treatment.
- Bergh et al. (2011) recommend that the ESAS should always be reviewed with the patient after completion to improve symptom management.

ESAS and ESAS-r

- Watanabe et al. (2011) compared 2 numerical versions of the ESAS.
 - Most patients rated both versions very easy or easy to understand and complete.
 - The ESAS-r was significantly easier to understand, and more patients preferred it (due to its clarity, definitions, and format).

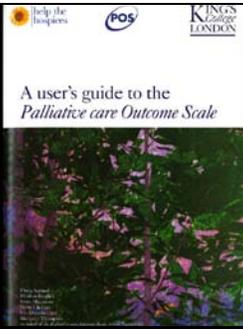


<p style="text-align: center;">Distress Thermometer</p> <ul style="list-style-type: none"> Used with several types of cancers Used in culturally diverse cancer patient populations Acceptable convergent and divergent validity Support for cutoff scores <p style="text-align: right;">(Dolbeault, et al., 2008)</p>	<p>Screening for Distress in Nova Scotia: Some Cancer Patients in all Health Districts are now being screened.</p> 																																		
<p>Most frequent cancer diagnoses in present sample:</p> <ul style="list-style-type: none"> Breast Lung Colorectal Oral/Head and Neck Prostate 	<p>Frequency of Mild, Moderate and High Distress on Distress Thermometer</p> 																																		
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<p>Healthcare Professional Survey</p> <p>The majority of respondents noted:</p> <ul style="list-style-type: none"> • Screening for Distress Tool is helpful in identifying patient concerns. • Comfortable discussing Distress Responses with Patients. • Think Screening for Distress leads to better person-centred care. 	<p>Time to Respond to Screen Per Patient</p> <p>Does not increase face-to-face time 14%</p> <p>Does increase face-to-face time by:</p> <table> <tr> <td>1 – 2 Minutes</td> <td>0%</td> </tr> <tr> <td>3 – 5 Minutes</td> <td>5%</td> </tr> <tr> <td>5 – 10 Minutes</td> <td>14%</td> </tr> <tr> <td>10 – 15 Minutes</td> <td>43%</td> </tr> <tr> <td>More than 15 Minutes</td> <td>24%</td> </tr> </table>	1 – 2 Minutes	0%	3 – 5 Minutes	5%	5 – 10 Minutes	14%	10 – 15 Minutes	43%	More than 15 Minutes	24%						
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<p>Other Chronic Illness Groups in Nova Scotia are interested in the Self-Report Symptom Tools we are using to screen Cancer patients</p>	<p>Summary</p> <ul style="list-style-type: none"> • Symptom Measures can be useful in identifying concerns throughout the illness continuum. • Can be used as screen and can facilitate assessment. • Helpful in managing patient distress and providing improved patient-centred care. 																
	<p>Acknowledgements</p> <ul style="list-style-type: none"> • Production of this presentation has been made possible in part through a financial contribution from Health Canada, through the Canadian Partnership Against Cancer. • Support of Cancer Care Nova Scotia, the Nova Scotia District Health Authorities, and Health Care Professionals is acknowledged. • The views expressed herein represent the views of presenters. 																

Appendix G – Patient (or Palliative) Outcome Scale

<p>“ Wow Me with Data “</p>  <p>Paul McIntyre and Glenna Thornhill</p>	<p>“ Know which abnormality you are going to follow during treatment. Pick something you can measure. ”</p> <p>Meador, A Little Book of Doctors’ Rules.</p>
<p>“Standards are not neutral ... They are as much about power and control as they are about ‘best practice’. For every standard adopted, something else shifts in the system – and it’s usually something we have neither predicted nor sought to measure. These issues are complex and subtle. It is small wonder that trials with deterministic designs and predefined outcome measures fail to capture them.</p> <p>Trish Greenlagh, British Medical Journal 2009</p>	<p>“ Box-ticking has often improved the care I provide my patients despite my assumption that my practice is already evidence-based. ”</p> <p>Trish Greenlagh, British Medical Journal 2009</p>
<p>Outcome</p> <p>“ ... any end result attributable to health services intervention ... “</p> <p>Measure should be clinically relevant, practical, valid, reliable, able to show change over time.</p>	<p>Implementing patient reported outcome measures (PROMs) in palliative care - users' cry for help.</p> <p>Bausewein Health Qual Life Outcomes 2011</p>
 <p>Outcome Measurement in Palliative Care <i>The Essentials</i> Bausewein C, Davison B, Benalia H, Simon ST, Higginson IJ</p>	<p>lit review outcomes in PC J Publ Health Med 1999</p> <p>reliability/validity POS Qual Health Care 1999 Health Qual Life Outcomes 2004</p> <p>Higginson, et al.</p>

	<p>Validation of a core outcome measure for palliative care in Africa: the APCA African Palliative Outcome Scale</p> <p>Harding Health Qual Life Outcomes 2010</p>
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<p>Psychological Well-Being and Quality of Care: A Factor-Analytic Examination of the Palliative Care Outcome Scale</p> <p>Siebert, et al JPSM 2010</p>	<p>Use of the Palliative Outcome Scale in Argentina: A Cross-Cultural Adaptation and Validation Study JPSM 2008</p> <p>Validation and Clinical Application of the German Version of the Palliative Care Outcome Scale JPSM 2005</p>
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 <p>POS use around the world</p>	<p>Doing secondary data-analysis on POS-datasets. & POS/ESAS/MSAS/interRAI LTC www.euro-impact.eu</p>
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<p>Palliative (Patient) Outcome Scale</p> <ul style="list-style-type: none"> <input type="checkbox"/> 10 items + open question <input type="checkbox"/> pt/family/staff versions <input type="checkbox"/> 12 language translations <input type="checkbox"/> modular optional versions <input type="checkbox"/> add-on symptom card 	 <p>Assessment Staff Training Team Comm Goal Attainment Audit Outcomes Research</p>
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“engagement by both patient and clinician in endlessly adaptive work of dealing with illness ... attention to here and now contextual detail is crucial. An excessive focus on standards reinforces the erroneous notion that the quality benchmark can be wholly established and expressed in the language of decision science.”

“Box-ticking has often improved the care I provide my patients despite my assumption that my practice is already evidence-based.” Trish Greenlagh, British Medical Journal 2009

<p>Is It Feasible and Desirable to Collect Voluntarily Quality & Outcome Data Nationally in Palliative Oncology Care?</p> <p>Currow, 2008.</p> 	<p>Establishing a Regional, Multisite Database for Quality Improvement and Service Planning in Community-Based Palliative Care and Hospice</p> <p>Bull, et al.</p> <p>Journal of Palliative Medicine 2009</p>
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	 <p>“Statistics & Stories “</p> <p>Cicely Saunders, in “Pioneers of Hospice” DVD</p>
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	<p>“ Being able to sit together and listen to meaningful music together allowed Mom and (our) family to express and feel pain and happiness and sadness without having to struggle to put it into words. ”</p> <p>CHIPCS Music Therapy Evaluation 2009</p>
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<p>Use of serial qualitative interviews to understand pts’ evolving experiences & needs.</p> <p>Murray, et al.</p> <p>British Medical Journal 2009 </p>	<p>Using POS as part of a multi-methods study of supportive care needs of non-cancer patients.</p> <p>Primary Palliative Care Research Group The University of Edinburgh</p>
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“Being able to sit together and listen to meaningful music together allowed Mom and (our) family to express and feel pain and happiness and sadness without having to struggle to put it into words.”

“create an environment of watchful concern that motivates everyone to reflect on how best to serve the community“

Appendix H – Abbey Pain Scale

Pain Assessment using the Abbey Pain Scale

Elsie Rolls, Director, Veterans' Services
Camp Hill Veterans Memorial Building
Capital Health
February 29, 2012



Pain Assessment



Photograph: ulrichkarjaho

- What is the Abbey Pain Scale
- Why are we using it at Camp Hill in Veterans Services?



Veterans' Services Story

- Results of satisfaction survey
- Length of stay information
- Percentage of Veterans living with dementia
- Accreditation recommendation
- Pain baseline data collection




Physical Pain in the Elderly

As many as 83% of residents experience pain at least some of the time.

Treatment of pain is lower amongst residents with cognitive impairment.

Spiritual pain can increase symptoms of physical pain and vice versa



Photograph: dachshund

References: Miller, L.L., 2002; Fekht, K.S., 1998; Ramage-Marin, P.L., 2008; Volker, L., 2002; Warden, V., 2003; Molony, S.L., 2005; Zwakhalen, S.M., 2006; Tuchs, H., 2003; Teno, J.M., 2003; Warden, V., 2003; Karnel, H.K., 2001; McCaffery, M., 1999; Brazil, K., 2006; Health Canada; Millsbaugh, D., 2005; Jackson, L., 2004; Canadian Hospice Palliative Care Association



Baseline Information Gathered

- 98% of the 49 residents reviewed had a diagnosis that could cause pain
- Average - 2.63 diagnoses that could cause pain, e.g. arthritis, wounds or skin breakdown, congestive heart failure, chronic obstructive pulmonary disease, osteoporosis, paralysis, diabetes, gum disease, joint replacements, etc.



Baseline Pain Assessment - MDS

	Pain Frequency			Pain Intensity		
	No pain	Less than daily	Daily pain	Mild pain	Moderate pain	Horrible, excruciating pain
March 2009	57%	29%	14%	62%	28.5%	9.5%

NOTE: Pain intensity applies only to the 43% that were noted as having pain.



Appendix I – InterRAI Home Care (HC) Assessment in SEAscape

<p style="text-align: center;">interRAI Assessment in SEAscape</p> <p style="text-align: center;">Symptoms and Outcomes Measurement for End of Life Care in Nova Scotia Workshop February 29, 2012</p> <p style="text-align: center;">Present by Joanne Boudreau, SEAscape Manager Continuing Care Branch</p>	<p style="text-align: center;">SEAscape</p> <ul style="list-style-type: none"> • Continuing Care Electronic System • Supports Single Entry Access process • Clients – <ul style="list-style-type: none"> – Home Care – Long Term Care – Adult Protection • RAI-HC Assessment
<p style="text-align: center;">interRAI</p> <ul style="list-style-type: none"> • Researchers in over 30 countries • Promote evidence based clinical practice and policy • Common language in suite of 15 assessments • Assessments designed to work together • Each question has an intent and definition 	<p style="text-align: center;">interRAI Suite of Assessments</p> <ul style="list-style-type: none"> • Home Care • Palliative Care • Community Health • Wellness • Assisted Living • Long Term Care • Post Acute Care • Acute • Mental Health • Community Mental Health • Intellectual Disability • Mental Health for Correctional Facilities • Contact Assessment • Emergency Screener for Psychiatry • Self-Report Quality of Life
<p style="text-align: center;">RAI-HC Assessment</p> <ul style="list-style-type: none"> • Designed to inform and guide care planning in the current home care environment • Highlights function and quality of life • 19 Domains • Assessor asks client and caregiver questions • Assessment completed on laptop in client's home • Assessor is Health Care Professional 	<p style="text-align: center;">Domains- RAI-HC Assessment</p> <ul style="list-style-type: none"> • Cognitive Patterns • Vision Patterns • Mood and Behavior • Social Functioning • Informal Support Services • Physical Function • Continence
<p style="text-align: center;">Domains RAI-HC continued</p> <ul style="list-style-type: none"> • Disease Diagnosis • Health Conditions and Preventive Health Measures • Nutrition/Hydration Status • Dental Status • Skin Condition • Environment Assessment 	<p style="text-align: center;">Domains RAI-HC continued</p> <ul style="list-style-type: none"> • Service Utilization • Medications • Identification Information • Personal Items • Referral Items • Assessment Information

<p>RAI-HC Clinical Assessment Protocols (CAPs)</p> <ul style="list-style-type: none"> • Triggered by assessment questions • 30 Possible CAPs • Assist in the Care Planning Process along with the Clinical Judgment of the Assessor 	<p>RAI- HC CAPs Related to Palliative and End of Life</p> <ul style="list-style-type: none"> • Palliative Care • Pain • Cognition • Depression and Anxiety • Nutrition • Oral Health • Medication Management
<p>RAI-HC CAPs Related to Palliative and End of Life continued</p> <ul style="list-style-type: none"> • Bowel Management • Urinary Incontinence and Indwelling Catheter 	<p>RAI- HC Outcomes- Related to Palliative and End of Life</p> <ul style="list-style-type: none"> • Pain Scale- Indicates presence and intensity of pain • CHES- Change in Health, End Stage Disease and Signs and Symptoms • Depression Rating Scale- Used as a clinical screener for depression • ADL Self-Performance Hierarchy Scale • Cognitive Performance Scale • MAPLE- Method of Assigning Priority Level
<p>RAI-Palliative Care</p> <ul style="list-style-type: none"> • Purchased the RAI- Palliative Assessment • Currently not implemented in SEAscape • Developed in 2003 • Tested in Canada, Czech Republic, Iceland, Netherlands, Sweden, Spain, and United States • interRAI finalizing the CAPs for Palliative Care 	<p>RAI- Palliative Care</p> <ul style="list-style-type: none"> • Many similar domains as RAI-HC • Additional Domains are: <ul style="list-style-type: none"> – Psychosocial Well Being – Treatments and Procedures – Responsibility/Directive
<p>RAI-Palliative Care</p> <ul style="list-style-type: none"> • Some Domains Not Included: <ul style="list-style-type: none"> – Vision Patterns – Disease Diagnosis – Health Conditions and Preventative Health Measures – Dental Status – Environment Assessment 	<p>RAI-Palliative Care CAPs</p> <ul style="list-style-type: none"> • Pain • Mood, anxiety • Dyspnea • Bowel-GI • Skin ulcers • Sleep Disturbance • Fatigue • Life Completion • Advanced Care, Client Wishes • Delirium • Nutrition • Information Supports, Caregiver Distress
<p>Summary</p> <ul style="list-style-type: none"> • Currently use RAI- HC that has questions, CAPs, and Outcomes Related to End of Life Care • RAI-Palliative Care purchased, but not yet implemented, designed for persons with palliative and end of life needs • RAI assessments are designed to work together 	<p>Summary continued</p> <ul style="list-style-type: none"> • RAI-HC and RAI- Palliative Care Implemented in many countries • Ability to compare RAI assessment information with other countries

Appendix J – Extended Care Paramedics (ECP)

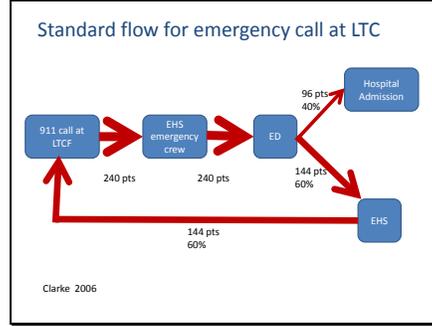
Extended Care Paramedics:
A Novel Long Term Care Paramedic Program



ECP Approach to End of Life Care

Jan L. Jensen
Dr. Andrew H. Travers





Impact of ED visits on elderly

Ambulance ride
Unfamiliar surroundings
Long waits



Loud & bright surroundings
Difficult to move from stretcher

Better Care Sooner
the plan to improve emergency care

OBJECTIVES:
Enhance paramedic training and equipment; expand services provided by 811 registered nurses.

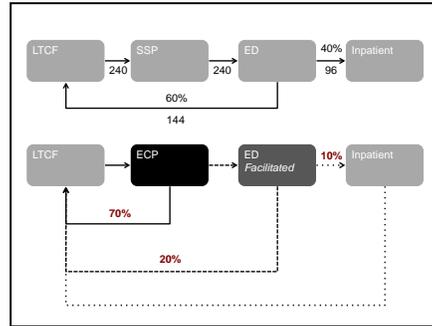
ACTIONS:

- The scope of practice for paramedics across Nova Scotia will be expanded to enable them to deliver life-saving clot-busting drugs.
- A new Extended Care Paramedic Program is being introduced that will bring the emergency department to nursing home residents—reducing the need for transfers to hospitals. Current transfer services will be reviewed and adjusted to ensure appropriate levels of supervision and care.

Extended Care Paramedic Program



- Started Feb 15th 2011
- Initially hired 7 Advanced Care Paramedics, now up to 16
- 1 week of in-class training, 1 day clinical at teaching LTCF, 1 day in ED
- Work in non-transport capable vehicle
- Broadened scope of practice
- Respond to 15 CBD LTCFs in Halifax region
- Hours of work: 0900-2100, 7 days/week
- Consult with LTC and EHS physician for every call



With the ECP program, there are more disposition options.

- Some patients who the ECP sees may require an urgent ambulance transport to the ED
- The ECP can arrange a transfer to ED or other location for things like diagnostic imaging, at times which the wait can be minimized
- Or, the ECP can assess the patient, in collaboration with nursing staff, make a consult with the EHS physician and nursing home physician, and treat the patient on site. Often, the ECP will arrange for a follow up visit.

ECP Research

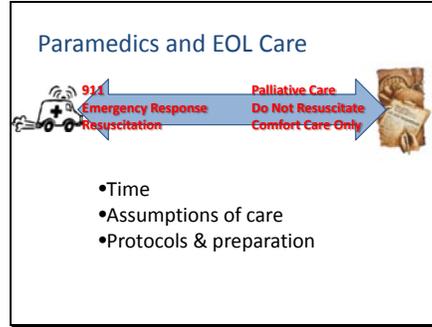


Qualitative

- Implementation & operation of a novel program
- Focus groups
 - ECPs, paramedics & COs, managers, ECP physicians
- Thematic analysis
- Main themes:
 - Implementation
 - ECP Process of Care
 - Communications
 - End of Life Care

Quantitative

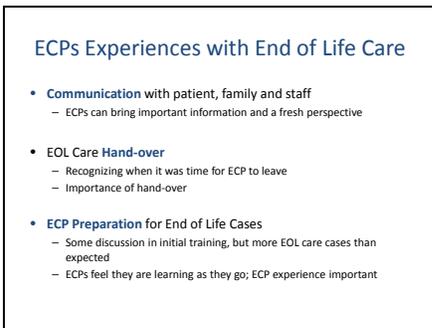
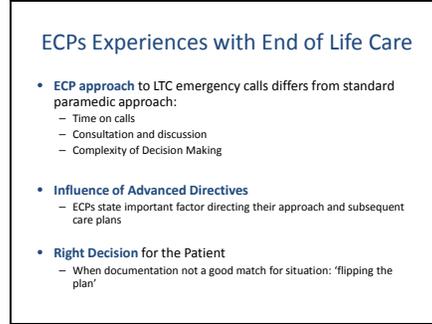
- Pilot study of dispatch determinants, call outcomes, EOL cases
- ECPs most often requested specifically by LTC staff
- 48% absolute risk reduction in transport
 - 6% relapse rate after ECP no transport
- 11 EOL cases
- 60.7% AD documentation rate
- Larger before-and-after study planned



Typical paramedic response differs dramatically from EOL care

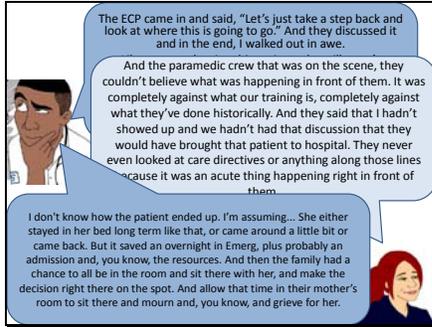
Factors leading to this juxtaposition:

- Time (EMS calls usually quick, timed; EOL requires lots of time)
- Assumptions of care (public assumes EMS will always resuscitate; paramedics trained for this)
- Protocols & preparation (no specific EOL protocols in place; paramedics likely not comfortable with these situations)

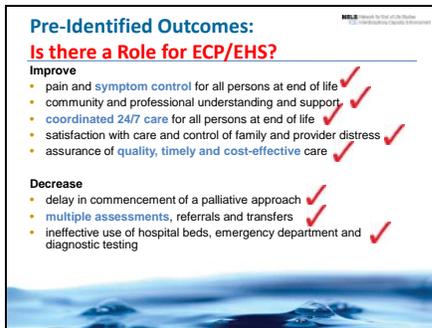
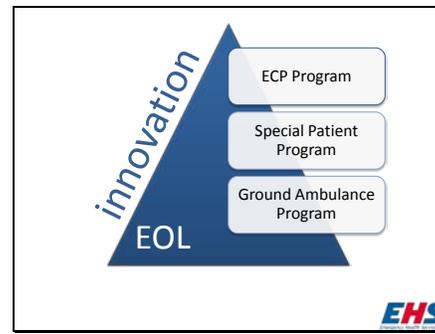


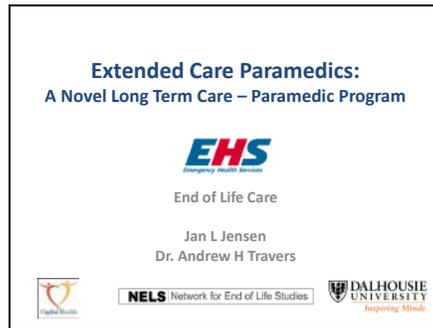
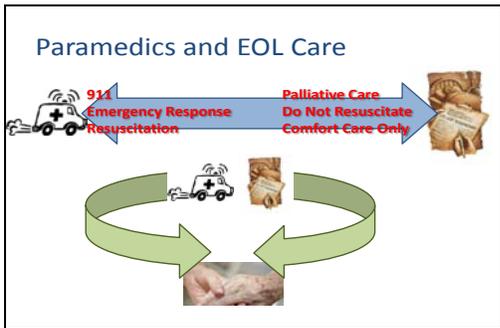
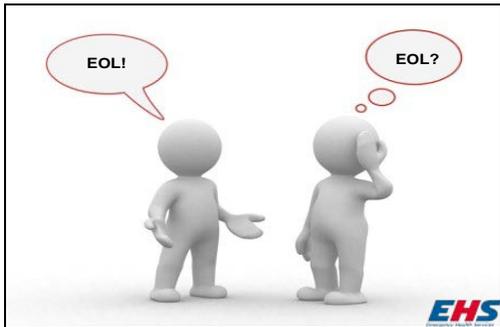
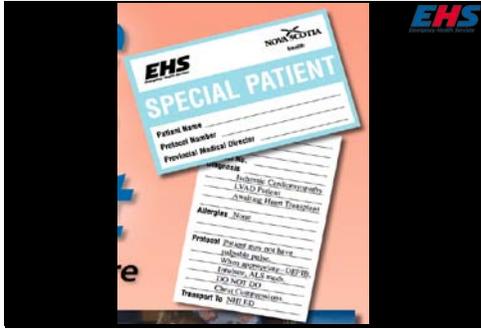
To give you a better understanding of paramedic & ECP care, I want to tell you about a case that was described by a paramedic that was eye-opening to him about the ECP program. In the ECP focus group, one of the ECP spontaneously brought up the same case. I will use their words.

Report of Symptoms and Outcomes Measurement for End of Life Care in Nova Scotia, 2012



- Paramedic 'in awe' of what was happening -> breaking traditional practice
- Slowing things down; Discussions
- ECP brought new perspective
- Paramedic saw value in avoiding ED transport, but ALSO in patient being left with family so they are together during this time.
- Focus shifted away from quickly administering treatment towards holistic decision-making
- Very powerful.





Appendix K – Primary Palliative Care

Outcomes

Improve

- pain and symptom control for all persons at end of life
- community and professional understanding and support
- coordinated 24/7 care for all persons at end of life
- satisfaction with care and control of family and provider distress
- assurance of quality, timely and cost-effective care

Decrease

- delay in commencement of a palliative approach
- multiple assessments, referrals and transfers
- ineffective use of hospital beds, emergency department and diagnostic testing

What else?



Outcome Measures for EOLC in Primary Care

- Have we identified those who should be identified as potentially palliative?
- Have we assessed their needs well?
- Has care been coordinated with others well?
- Have we provided good care?
 - Access
 - Patient-centred: patient goals, information sharing, joint decision-making
 - Physical comfort
 - Practical support

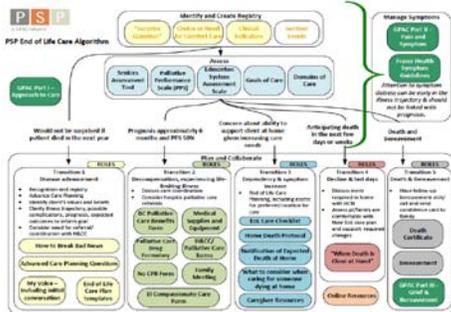
Primary Care

- Measures of patient outcomes?
 - POS or ESAS
 - PPS
 - Satisfaction: information, shared decision making
- Measures of access
 - To Primary Care–Family reported/patient reported/other Health Care Provider
 - To other services: palliative care, etc
- Markers of good care
 - Low Emergency Room use, minimal hospitalization, use of community resources, Advance Care Planning documentation

Primary Care

See Table in Appendix C which Elaine Loney prepared from a literature review on Outcome measures in Primary Care

Next Slide shows the end of life care algorithm for the Practice Support Program (PSP) developed in British Columbia for general practice. Appendix D has a larger view of this page. The functional PDF algorithm can be obtained from the BC website



Outcomes

Improve

- pain and symptom control for all persons at end of life
- community and professional understanding and support
- coordinated 24/7 care for all persons at end of life
- satisfaction with care and control of family and provider distress
- assurance of quality, timely and cost-effective care

Decrease

- delay in commencement of a palliative approach
- multiple assessments, referrals and transfers
- ineffective use of hospital beds, emergency department and diagnostic testing

What else?