What outcomes should we measure to evaluate good supportive care?

IPPCN 2014

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How can good supportive care be evaluated?

Different Perspectives:

- Health system (broadly)
- Health sector (Primary healthcare)
- Practice organization level
- Provider level (?)
- Patient/family

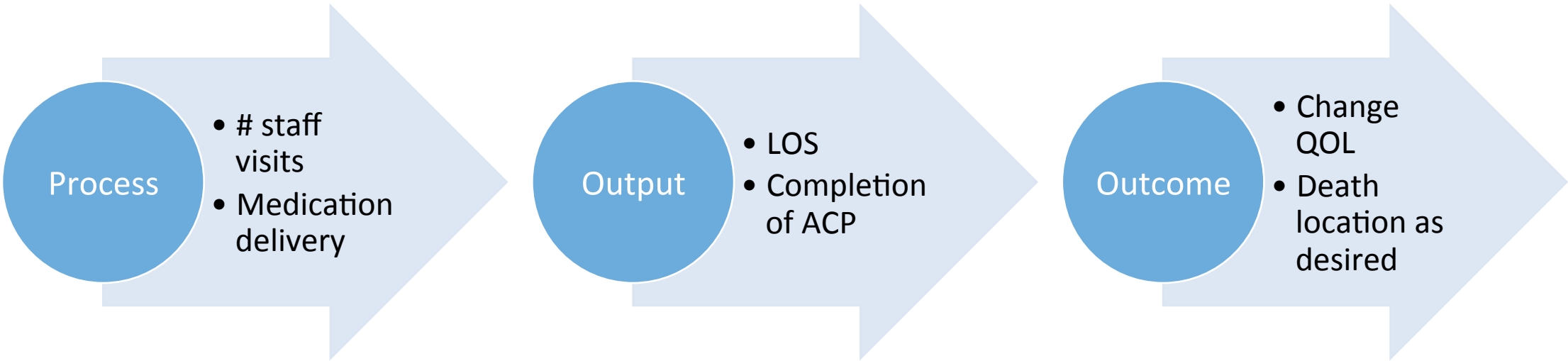
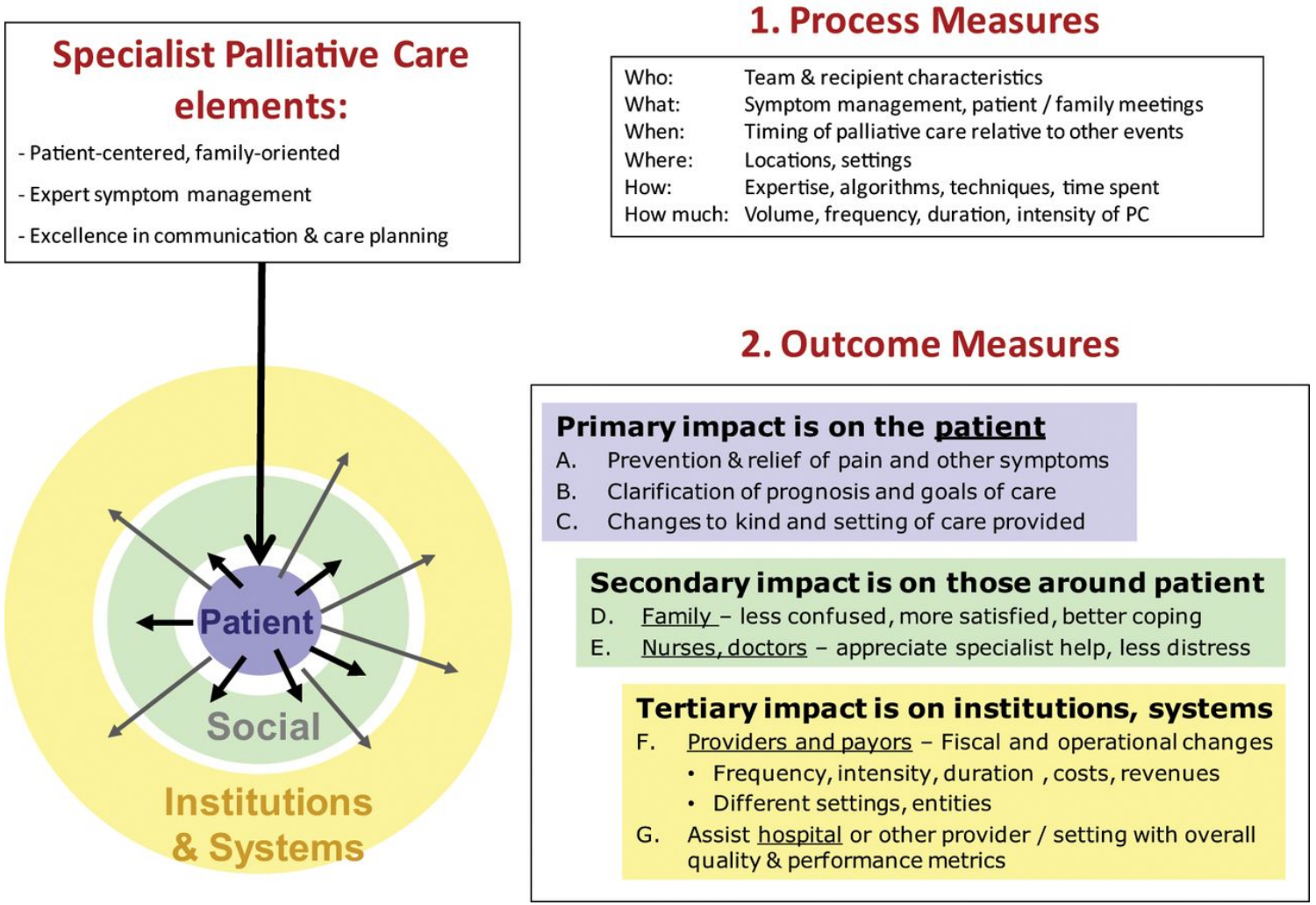

Process
• # staff visits
• Medication delivery
Output
• LOS
• Completion of ACP
Outcome
• Change QOL
• Death location as desired

Figure 1. A measurement model for specialist palliative care.

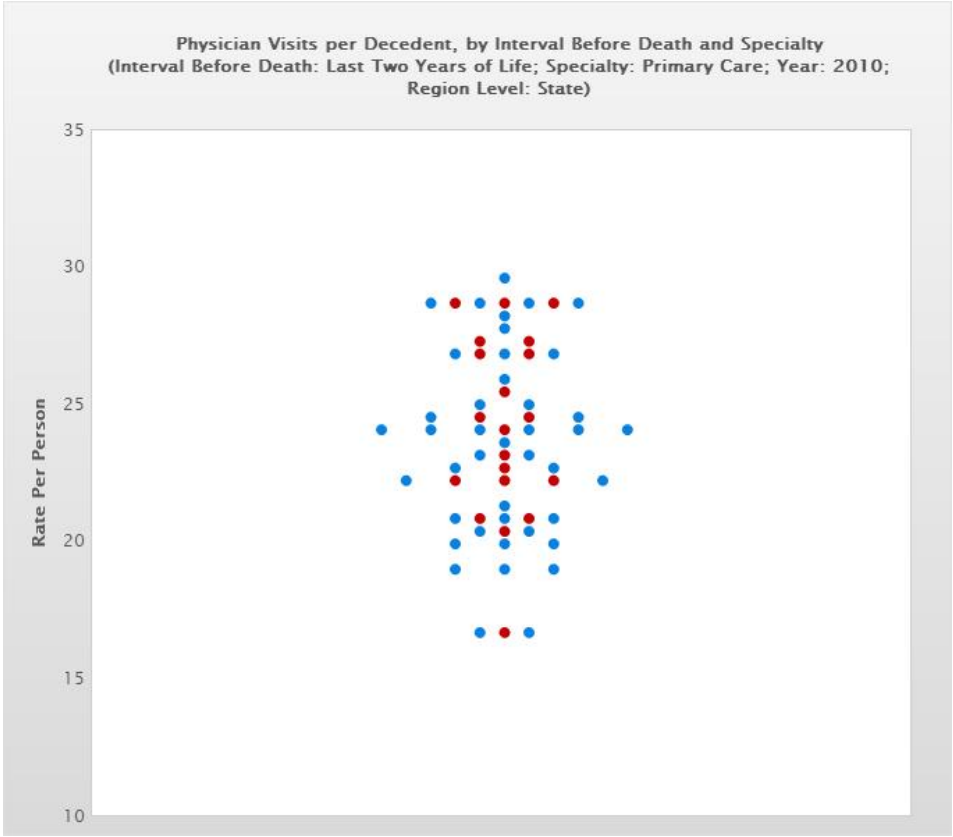


Cassel J B Palliat Med 2013;27:103-104

PALLIATIVE MEDICINE

Healthcare System

- Dartmouth Atlas of Health Care
  - Deaths in hospital
  - Deaths associated with ICU stay
  - Days in hospital in last 2 years of life (also last 6 months)
  - Days in ICU in last 2 yrs of life (also last 6 months)
  - % patients seeing > 10 different physicians in last 2 yrs (6 months)
  - Hospice days in last 6 months of life
  - Specialist input in last 2 yr and 6 mos life
  - Primary care input in last 2 yr and 6 mos life



THE DARTMOUTH INSTITUTE
FOR HEALTH POLICY & CLINICAL PRACTICE

Recommended metrics for palliative care programs

- Operational Metrics (# consults, disposition)
- Clinical Metrics (improvement in pain, dyspnea, distress)
- Customer Metrics (satisfaction – patient, family, referring provider)
- Financial Metrics (cost avoidance, billing revenue, LOS)

Weissman DE, Meier DE. Operational Features for Hospital Palliative Care Programs: consensus recommendations. JPM 2008;11(9):1190-1194

Health Sector (palliative care)

NQF measures

- Pain Screening
- Pain Assessment
- Patients treated with an Opioid who are given a bowel regimen
- Patients with advanced cancer assessed for pain at outpatient visits
- Hospice and Palliative Care- Dyspnea Treatment
- Hospice and Palliative Care – Dyspnea Screening
- Patients admitted to the ICU who have care preferences documented

- NQF measures (cont)
  - Hospice and Palliative Care- Treatment Preferences
  - Percentage of hospice patients with documentation in the clinical record of a discussion of spiritual/religious concerns or documentation that the patient/ caregiver did not want to discuss
  - Comfortable dying
  - Hospitalized patients who die an expected death with an ICD that has been deactivated
  - Family Evaluation of Hospice Care
  - Consumer Assessments and Reports of End of Life
  - Bereaved Family Survey

Univ. Colorado Health System Perspective (palliative care sector)

- LOS
- 30 day readmissions
- cost avoidance
- pain and non-pain symptom control (ESAS)
- ACP discussions/documentation
  - Inclusion of proxy in discussion
- time to consult

UCLA Health System Perspective (palliative care sector)

- Process measures (among patients with serious illness)
  - % patients with goals of care note completed
  - % patients with advance directive completed
  - % patients with Physician Orders for Life Sustaining Treatment (POLST) completed
  - % patients with palliative care involvement
- Outcome measures (among patients with serious illness)
  - % patients with moderate to severe symptoms and symptom trends over time
  - % patients referred to hospice before death and hospice length of stay
  - % decedents receiving chemotherapy during last 30 days and last 14 days (for advanced cancer)
  - ER/ICU/hospital utilization in the population overall and among decedents in the last 6 months of life (Dartmouth atlas)
  - Goal to also look at after death caregiver satisfaction, for example Bereaved Family Survey or Family Evaluation of Hospice Care

Areas in consideration

- Assessment of needs in patients with advanced illness
- Assessment of concordance with desired/delivered care
- Self determined life closure
- Family evaluation of bereavement services
- Family evaluation of palliative care services

LQI Demonstration Project – integration of supportive care in primary care practices

- Can practice improvement/transformation approaches be used to systematically integrate primary supportive services in primary care practices?
- What are the barriers?
- What is required by practices to implement?
- What are the impacts on practices? On patients and their loved ones? On the healthcare system?

Possible Process – LQI project

- Identify population at risk for having supportive care needs
- Screen that population for supportive needs
- Evaluate those screening positive for likely supportive needs
- Target few PC elements for improvement – develop outcome measures
- Develop specific patient supportive care plans –
  - Internal practice resources
  - External practice resources
- Monitor outcome measures
  - for patient
  - for practice

Elements of Supportive Care – LQI project

- Communication
  - Delivering bad news
  - Establishing goals of care
  - Transitions to comfort focused care
- Advance Care Planning
  - Documentation using advance directives
- Evaluating and managing symptoms – pain

Elements of Supportive Care – LQI project

- Evaluating and addressing emotional and mental health issues - depression
- Evaluating and addressing social issues and support
- Evaluating and enhancing spiritual issues and support
- Bereavement

Potential Multidimential Outcome Measures – screening

- Palliative Outcome Scale
- Distress thermometer
- Edmonton Symptom Assessment Scale
- Memorial Symptom Assessment Scale
- Hospital Anxiety and Depression Scale
- EORTC QOL-C30
- PROMIS (global, pain, fatigue, emotional distress, physical function, social function) (stress response and coping; shifts in self-concept, social interactions, and spirituality)
- NEST13+

Practice level

- % patients in registry who are approached about ACP
- % patients in registry who complete at least one AD
- % patients with initial and repeat pain assessment
- Change in pain scores
- % patients with initial and repeat depression assessment
- Change in depression

' QLQ – GI.NET21

patients report that they have the following symptoms or problems. Please indicate the extent you have experienced these symptoms or problems during the past week. Please answer by number that best applies to you.

the past week:		Not at all	A little	Quite a bit	Very much
you have hot flushes?		1	2	3	4
you sweated or been told by others that you looked flushed/red?		1	2	3	4
you have night sweats?		1	2	3	4
you have abdominal discomfort?		1	2	3	4
you have a bloated feeling in your abdomen?		1	2	3	4
you had a problem with passing wind/gas/flatulence?		1	2	3	4
you had acid indigestion or heartburn?		1	2	3	4
you had difficulties with eating?		1	2	3	4
you had side-effects from your treatment? are not on treatment please circle N/A	N/A	1	2	3	4
you had a problem from repeated injections? having injections please circle N/A	N/A	1	2	3	4
you worried about the tumour occurring in other parts of the body?		1	2	3	4
you concerned about disruption of home life?		1	2	3	4
you worried about your health in the future?		1	2	3	4
distressing has your illness or treatment been to those close to you?		1	2	3	4
ought love been a problem for you?		1	2	3	4
ought sex been a problem for you?		1	2	3	4
you worry about the results of your tests? have not had tests please circle N/A	N/A	1	2	3	4
you had aches or pains in your muscles or bones?		1	2	3	4
you have any limitations on your ability to travel?		1	2	3	4
past four weeks:					
you had problems receiving adequate information your disease and treatment?		1	2	3	4
ur disease or treatment affected your sex life (for the worse)? applicable please circle N/A	N/A	1	2	3	4

MEMORIAL SYMPTOM ASSESSMENT SCALE

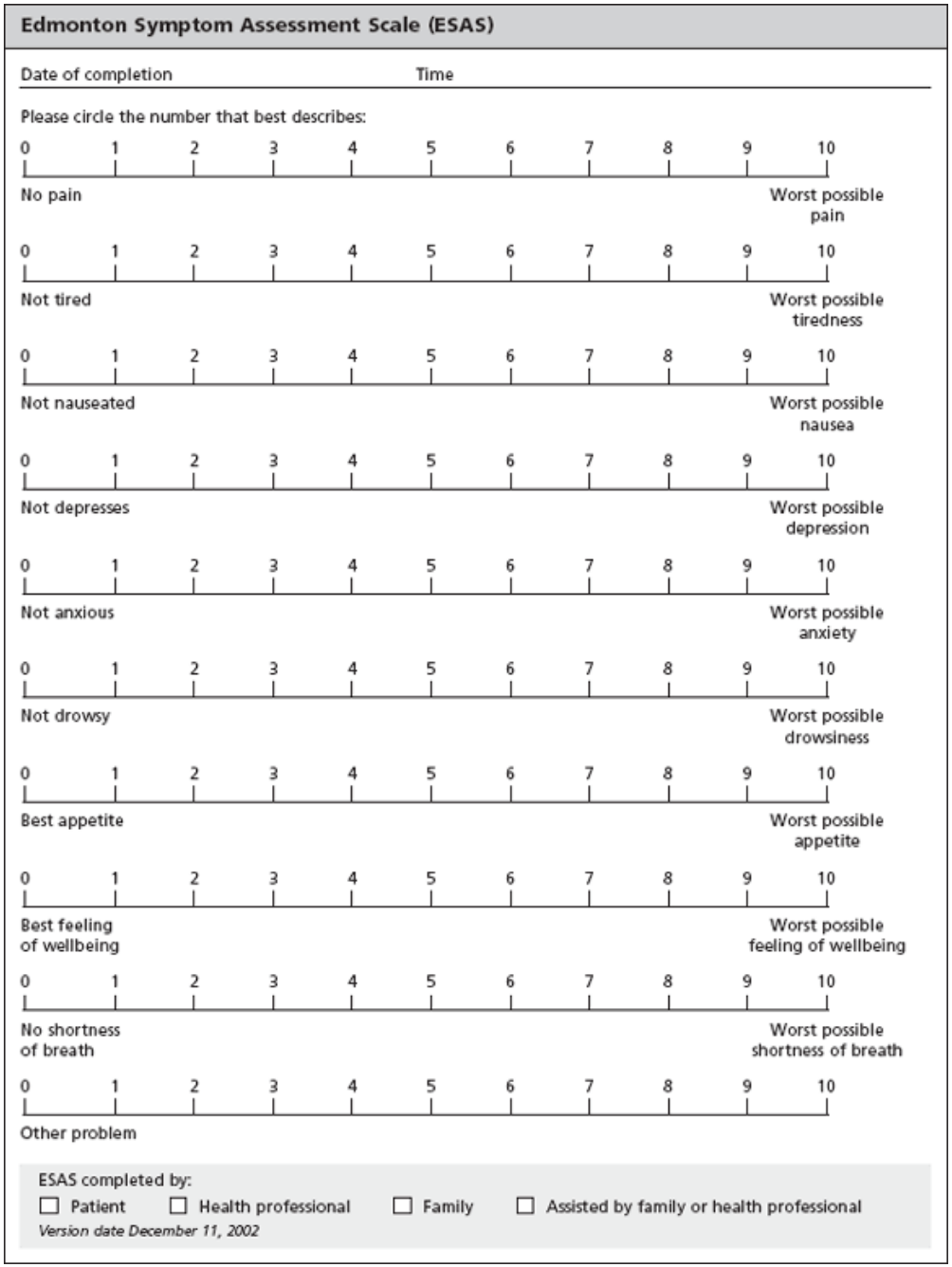
Name Date

Section 1

Instructions: We have listed 24 symptoms below. Read each one carefully. If you have had the symptom during this past week, let us know how OFTEN you had it, how SEVERE it was usually and how much it DISTRESSED or BOTHERED you by circling the appropriate number. If you DID NOT HAVE the symptom, make an "X" in the box marked "DID NOT HAVE."

DURING THE PAST WEEK Did you have any of the following symptoms?	DID NOT HAVE	IF YES How OFTEN did you have it?				IF YES How SEVERE was it usually				IF YES How much did it DISTRESS or BOTHER you?				
		Rarely	Occasionally	Frequently	Almost Constantly	Slight	Moderate	Severe	Very Severe	Not at all	A Little Bit	Somewhat	Quite a Bit	Very Much
Difficulty concentrating		1	2	3	4	1	2	3	4	0	1	2	3	4
Pain		1	2	3	4	1	2	3	4	0	1	2	3	4
Lack of energy		1	2	3	4	1	2	3	4	0	1	2	3	4
Cough		1	2	3	4	1	2	3	4	0	1	2	3	4
Feeling nervous		1	2	3	4	1	2	3	4	0	1	2	3	4
Dry mouth		1	2	3	4	1	2	3	4	0	1	2	3	4
Nausea		1	2	3	4	1	2	3	4	0	1	2	3	4
Feeling drowsy		1	2	3	4	1	2	3	4	0	1	2	3	4
Numbness/tingling in hands/feet		1	2	3	4	1	2	3	4	0	1	2	3	4
Difficulty sleeping		1	2	3	4	1	2	3	4	0	1	2	3	4
Feeling bloated		1	2	3	4	1	2	3	4	0	1	2	3	4
Problems with urination		1	2	3	4	1	2	3	4	0	1	2	3	4
Vomiting		1	2	3	4	1	2	3	4	0	1	2	3	4
Shortness of breath		1	2	3	4	1	2	3	4	0	1	2	3	4
Diarrhea		1	2	3	4	1	2	3	4	0	1	2	3	4
Feeling sad		1	2	3	4	1	2	3	4	0	1	2	3	4
Sweats		1	2	3	4	1	2	3	4	0	1	2	3	4
Worrying		1	2	3	4	1	2	3	4	0	1	2	3	4
Problems with sexual interest or activity		1	2	3	4	1	2	3	4	0	1	2	3	4
Itching		1	2	3	4	1	2	3	4	0	1	2	3	4
Lack of appetite		1	2	3	4	1	2	3	4	0	1	2	3	4
Dizziness		1	2	3	4	1	2	3	4	0	1	2	3	4
Difficulty swallowing		1	2	3	4	1	2	3	4	0	1	2	3	4
Feeling irritable		1	2	3	4	1	2	3	4	0	1	2	3	4

ESAS



Edmonton Symptom Assessment Scale (ESAS)

Date of completion Time

Please circle the number that best describes:

	0	1	2	3	4	5	6	7	8	9	10	
No pain												Worst possible pain
Not tired												Worst possible tiredness
Not nauseated												Worst possible nausea
Not depresses												Worst possible depression
Not anxious												Worst possible anxiety
Not drowsy												Worst possible drowsiness
Best appetite												Worst possible appetite
Best feeling of wellbeing												Worst possible feeling of wellbeing
No shortness of breath												Worst possible shortness of breath
Other problem												

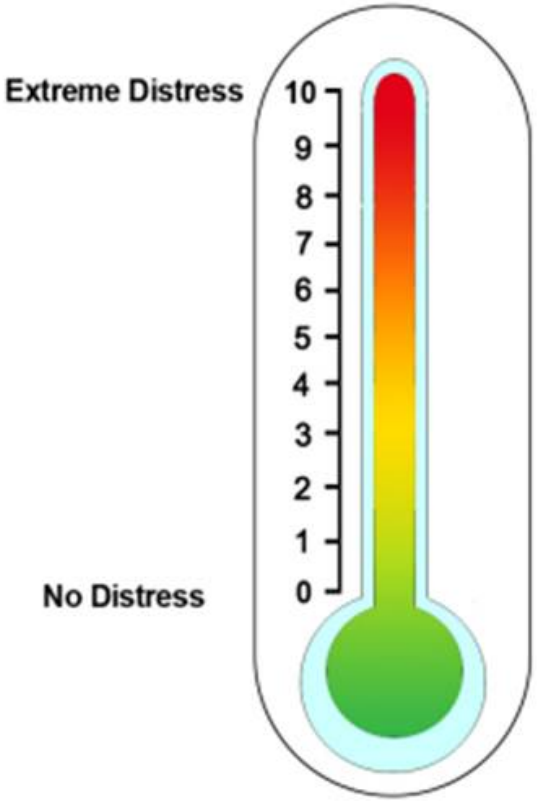
ESAS completed by:

☐ Patient ☐ Health professional ☐ Family ☐ Assisted by family or health professional

Version date December 11, 2002

The Distress Thermometer

First please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.



Second, please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.

YES	NO	Practical Problems
☐	☐	Child Care
☐	☐	Housing
☐	☐	Insurance/financial
☐	☐	Transportation
☐	☐	Work/school
		Family Problems
☐	☐	Dealing with children
☐	☐	Dealing with partner
☐	☐	Dealing with close
☐	☐	Friend/relative
		Emotional Problems
☐	☐	Depression
☐	☐	Fears
☐	☐	Nervousness
☐	☐	Sadness
☐	☐	Worry
☐	☐	Loss of interest in usual activities
☐	☐	**Spiritual/religious concerns**

YES	NO	Physical Problems
☐	☐	Appearance
☐	☐	Bathing/dressing
☐	☐	Breathing
☐	☐	Changes in urination
☐	☐	Constipation
☐	☐	Diarrhoea
☐	☐	Eating
☐	☐	Fatigue
☐	☐	Feeling Swollen
☐	☐	Fevers
☐	☐	Getting around
☐	☐	Indigestion
☐	☐	Memory/concentration
☐	☐	Mouth sores
☐	☐	Nausea
☐	☐	Nose dry/congested
☐	☐	Pain
☐	☐	Sexual
☐	☐	Skin dry itchy
☐	☐	Sleep
☐	☐	Tingling in hands/feet

Other problems

_____

_____

_____