Outpatient Palliative Care:
Oxymoron or Innovation?

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Objectives

- To discuss the relevance of palliative care to contemporary oncology practice
- To present preliminary baseline data from an RCT of early vs. usual palliative care involvement
- To discuss socio-demographic determinants of health-related quality of life (HRQL) in patients with advanced cancer

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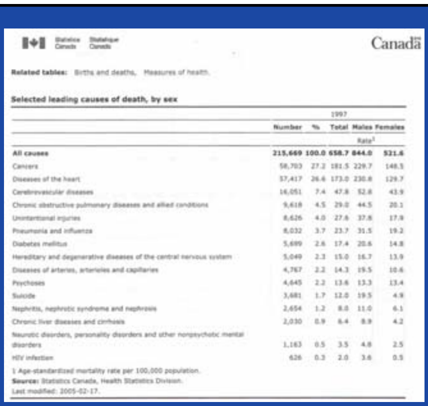


Statistics Canada Statistique Canada Canada

Related tables: Births and deaths, Measures of health.

Selected leading causes of death, by sex

	1997				
	Number	**%**	**Total**	**Males**	**Females**
				Rate[1]	
All causes	**215,669**	**100.0**	**658.7**	**844.0**	**521.6**
Cancers	58,703	27.2	181.5	229.7	148.5
Diseases of the heart	57,417	26.6	173.0	230.8	129.7
Cerebrovascular diseases	16,051	7.4	47.8	52.8	43.9
Chronic obstructive pulmonary diseases and allied conditions	9,618	4.5	29.0	44.5	20.1
Unintentional injuries	8,626	4.0	27.6	37.8	17.9
Pneumonia and influenza	8,032	3.7	23.7	31.5	19.2
Diabetes mellitus	5,699	2.6	17.4	20.6	14.8
Hereditary and degenerative diseases of the central nervous system	5,049	2.3	15.0	16.7	13.9
Diseases of arteries, arterioles and capillaries	4,767	2.2	14.3	19.5	10.6
Psychoses	4,645	2.2	13.6	13.3	13.4
Suicide	3,681	1.7	12.0	19.5	4.9
Nephritis, nephrotic syndrome and nephrosis	2,654	1.2	8.0	11.0	6.1
Chronic liver diseases and cirrhosis	2,030	0.9	6.4	8.9	4.2
Neurotic disorders, personality disorders and other nonpsychotic mental disorders	1,163	0.5	3.5	4.8	2.5
HIV infection	626	0.3	2.0	3.6	0.5

1 Age-standardized mortality rate per 100,000 population.
Source: Statistics Canada, Health Statistics Division.
Last modified: 2005-02-17.

- 50% of patients with cancer will die of their disease (NCIC, 2005)

- 80% of patients with cancer experience pain before death (Bruera and Kim, JAMA, 2003)

- Patient and family needs often not met by standard outpatient care (Cleeland *et al.* NEJM, 1994)

WHO definition of palliative care

- "an approach that *improves the quality of life* of patients and their families…

- by means of *early identification* and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (WHO, 2003)

CCO Palliative Care Program Goals

1. Seamless integration of palliative care into the overall patient care system of the Regional Cancer Programs (RCP)

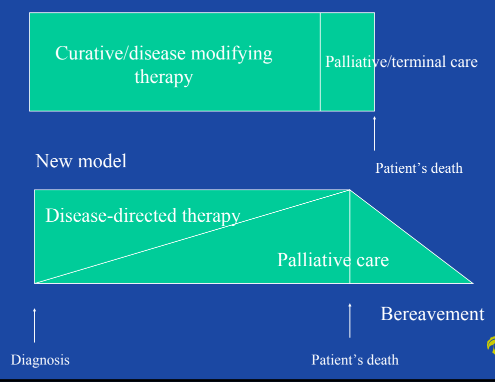
2. Coordination of RCP palliative services with the regional EOL Care Networks

3. Ensure RCP palliative services are of consistently high quality

Principles of palliative care

- Pain and symptom management as central
- Holistic care
- Multidisciplinary team
- Family as the unit of care
- Emphasis on community linkages and home care

Canadian Hospice Palliative Care Association, 2002



UHN Palliative Care Program organizational structure

- Consultation service
  - Inpatient consultations (TGH, TWH, PMH)
    - Inpatient wards, emergency room
  - Outpatient consultations (PMH)
    - Scheduled appointments to palliative medicine clinic
    - Urgent on-site referrals to outpatient clinics
- Palliative Care Unit
  - Admissions from home, hospitals, emergency

SUPPORTIVE CARE INTERNATIONAL

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Bringing palliative care to a Canadian cancer center: the palliative care program at Princess Margaret Hospital

Abstract It is increasingly recognized that complete care of the patient with cancer includes palliative care, which is applicable early in the course of illness, in conjunction with life-prolonging treatment. Princess Margaret Hospital (PMH) is Canada's largest center for cancer care and research, and it is an international referral center for patients with cancer. The Palliative Care Program at PMH has developed into a comprehensive clinical, educational, and research program, with an acute palliative care unit, daily palliative care clinics, a cancer pain clinic, and a consultation service that sees urgent consultations on a same-day basis in inpatient and outpatient areas. We will describe the components, successes, and challenges of our program, which may be useful for others, who are developing palliative care programs in an academic setting.

Keywords Palliative care · Cancer · Oncology · Program development

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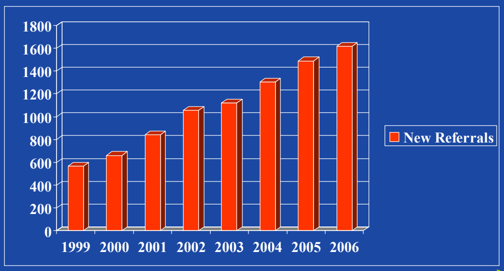
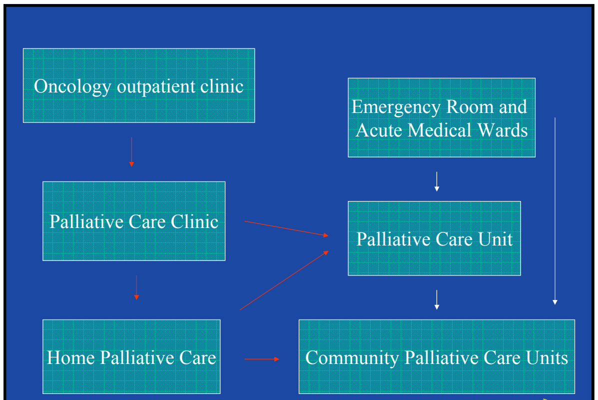
Referrals to UHN palliative care service





Oncology outpatient clinic

Emergency Room and Acute Medical Wards

Palliative Care Clinic

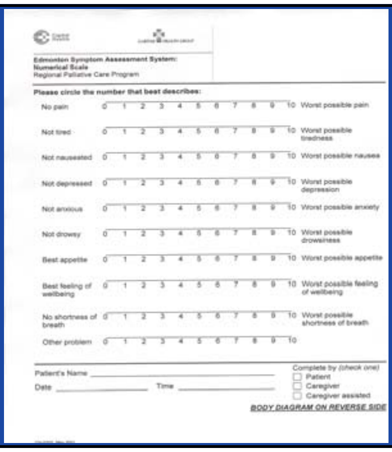
Palliative Care Unit

Home Palliative Care

Community Palliative Care Units

Palliative care clinics

- 15 half-day clinics weekly
- Staffed by physician, RN Case manager, social worker
- Referrals to other disciplines as necessary
- Completion at every visit:
  - Edmonton symptom assessment scale
  - Assessment of performance status
  - Referral check-list (CCAC, PCU back-up papers, specialists, home palliative care physician,)



Edmonton Symptom Assessment System:
Numerical Scale
Regional Palliative Care Program

Please circle the number that best describes:

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

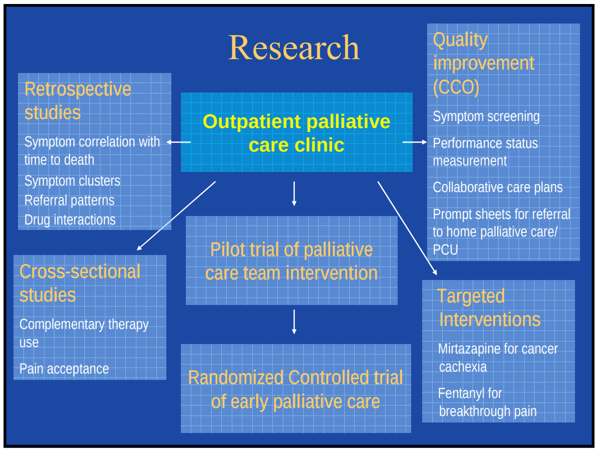
Patient's Name ____________________

Date ____________ Time ____________

Complete by (check one)
☐ Patient
☐ Caregiver
☐ Caregiver assisted

BODY DIAGRAM ON REVERSE SIDE

Research



Outpatient palliative care clinic

Retrospective studies
- Symptom correlation with time to death
- Symptom clusters
- Referral patterns
- Drug interactions

Quality improvement (CCO)
- Symptom screening
- Performance status measurement
- Collaborative care plans
- Prompt sheets for referral to home palliative care/ PCU

Cross-sectional studies
- Complementary therapy use
- Pain acceptance

Pilot trial of palliative care team intervention

Randomized Controlled trial of early palliative care

Targeted Interventions
- Mirtazapine for cancer cachexia
- Fentanyl for breakthrough pain

RCT of early vs. routine palliative care involvement

Timing of palliative care involvement

- Palliative care team involvement for patients with advanced cancer and their families
  - Generally begins in the last 2 months of life
  - Patients usually have stopped chemotherapy

Costantini et al, *J Pain Sympt M*, 1999; Cristakis and Escarce, *NEJM*, 1996; Lamont and Cristakis, *Cancer*, 2002

Timing of palliative care at PMH

- Approximately 30% of cancer deaths referred to UHN palliative care service
- Only 7% (11/151 deaths; 11/110 GI, 0/41 lung) were referred >6 months before death

Reasons for lack of early involvement of palliative care

- Territoriality, both on part of palliative care physicians and oncologists
  - (McGorty and Bornstein, J Eval Clin Pract, 2003)
- Discomfort discussing terminality
  - (Gattelari et al, Soc Sci Med, 2001; Lamont and Christakis, Ann Int Med, 2001)
- Perception of defeatism
  - (Auret et al, Int Med J, 2003)
- No sound evidence that early referral results in better care for patients

Studies so far

- Few RCTs and those that have been done have been criticized for methodological reasons
- No completed Canadian RCT
- No trial examining early palliative care versus conventional care

Research Hypotheses

- Compared to conventional care, early intervention by a palliative care team in patients with metastatic cancer will be associated with:
  - (i) better patient health related quality of life (HRQL) (primary outcome measure)
  - (ii) greater patient and caregiver satisfaction with care; (iii) better symptom control; (iv) improved communication with health care providers; and (v) improved caregiver quality of life

    (ii-v are secondary outcomes)

Current study

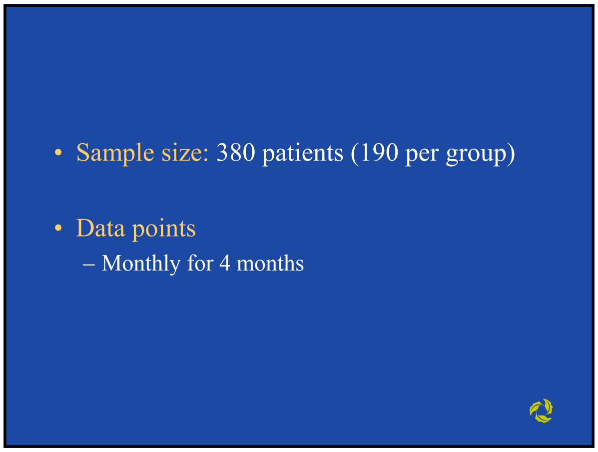
- Design:
  - Stratified, cluster-randomized, controlled clinical trial
  - Unit of randomization: medical oncology clinic
  - Unit of inference: Patient/caregiver
- Population:
  - PMH patients with metastatic cancer; prognosis > 6 months-2 years; ECOG ≤ 2
- Recruitment:
  - from 5 tumour sites: Lung, GI, GU, Breast, Gynecology

- Intervention**:**
  - Consultation and ongoing follow-up by the palliative care team
  - Process evaluation measures: Palliative Care Assessment Checklist (for physicians); Log of telephone calls (palliative care nurse)
- Control:
  - Conventional care

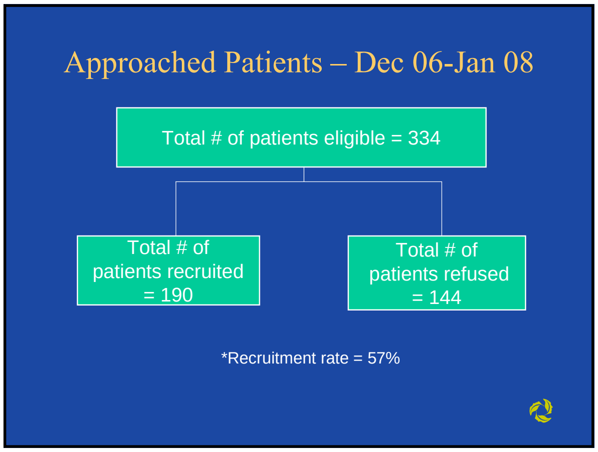
- Primary outcome:
  - Health-related quality of life **(FACT-G; FACIT-Sp; QUAL-E)**
- Secondary outcomes:
  - Patient and family: Satisfaction with care **(FAMCARE)**
  - Patient only (i) Symptom control **(ESAS)**

    (ii) Communication with health care providers (**CARES: Medical Interaction Subscale)**
  - Family member only (i) Caregiver quality of life **(Caregiver QOL Index-Cancer)**

    (ii) Caregiver health and functioning **(Medical Outcomes Study Short Form (SF-36))**



- **Sample size:** 380 patients (190 per group)
- **Data points**
  - Monthly for 4 months



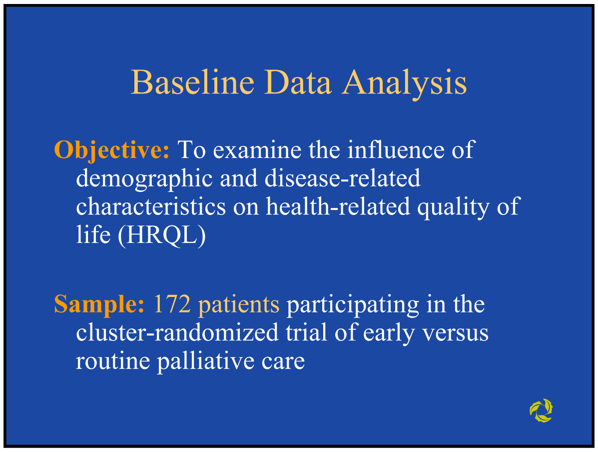
Approached Patients – Dec 06-Jan 08

Total # of patients eligible = 334

Total # of patients recruited = 190

Total # of patients refused = 144

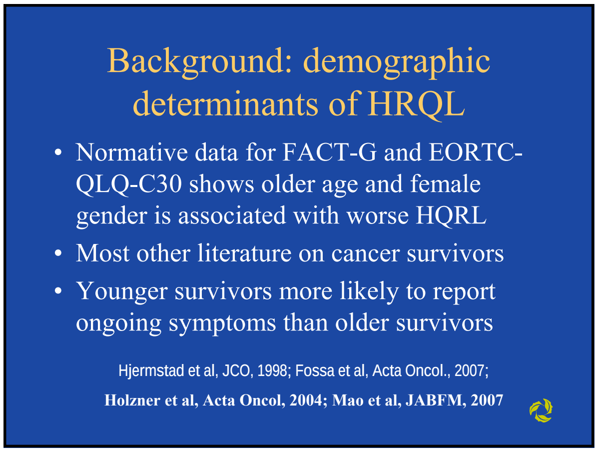
*Recruitment rate = 57%



Baseline Data Analysis

Objective: To examine the influence of demographic and disease-related characteristics on health-related quality of life (HRQL)

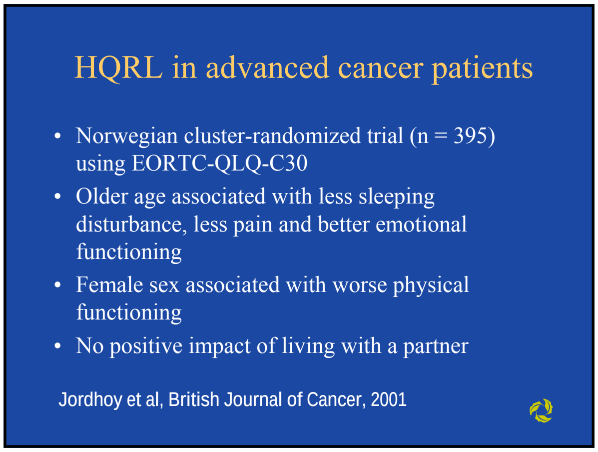
Sample: 172 patients participating in the cluster-randomized trial of early versus routine palliative care



Background: demographic determinants of HRQL

- Normative data for FACT-G and EORTC-QLQ-C30 shows older age and female gender is associated with worse HQRL
- Most other literature on cancer survivors
- Younger survivors more likely to report ongoing symptoms than older survivors

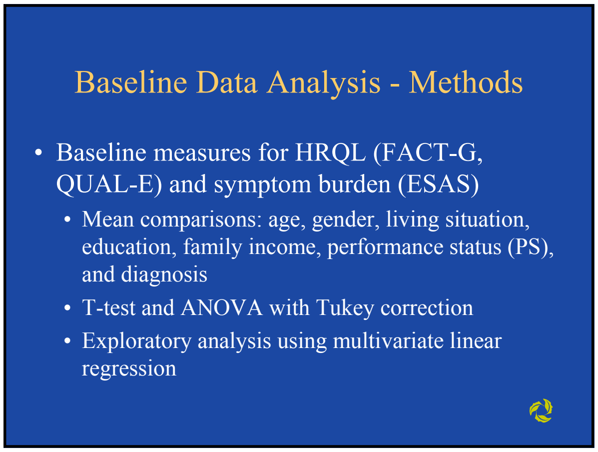
Hjermstad et al, JCO, 1998; Fossa et al, Acta Oncol., 2007;
Holzner et al, Acta Oncol, 2004; Mao et al, JABFM, 2007



HQRL in advanced cancer patients

- Norwegian cluster-randomized trial (n = 395) using EORTC-QLQ-C30
- Older age associated with less sleeping disturbance, less pain and better emotional functioning
- Female sex associated with worse physical functioning
- No positive impact of living with a partner

Jordhoy et al, British Journal of Cancer, 2001



Baseline Data Analysis - Methods

- Baseline measures for HRQL (FACT-G, QUAL-E) and symptom burden (ESAS)
  - Mean comparisons: age, gender, living situation, education, family income, performance status (PS), and diagnosis
  - T-test and ANOVA with Tukey correction
  - Exploratory analysis using multivariate linear regression

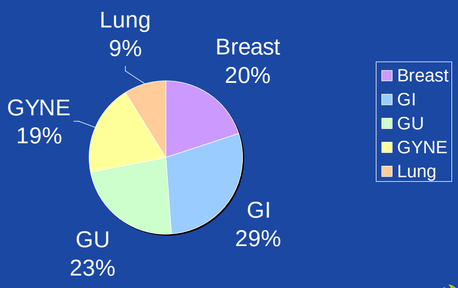
HQRL scales

- FACT-G
  - Physical
  - Social
  - Emotional
  - Functional
- QUAL-E
  - Impact
  - Relationship
  - Preparation
  - Life completion

Baseline Data Analysis: N = 172

Characteristic	*N* (%)
Female	103 (59.9)
Mean Age *yrs* (min-max)	59.7 (23-88)
Median ECOG (min-max)	1 (0-2)
Marital status	
Married/Common law	129 (75.0)
Single	21 (12.2)
Separated/Divorced	15 (8.7)
Widowed	7 (4.1)
Living alone	33 (19.2)
College/University education	124 (72.5)

# Participants by Site
n=172



Characteristic	*N* (%)
Employment status	
Unemployed	24 (14.0)
On disability	36 (20.9)
Employed	43 (25.0)
Retired	69 (40.1)
Household Income	
< $14,999	4 (2.3)
$15,000 – 29,999	10 (5.8)
$30,000 – 59,999	28 (16.3)
> $60,000	62 (36.0)
Not answered	68 (39.5)

FACT-G: age differences

FACT-G subscales (range)	Mean (SD)		General pop'n[1]	
	Age < 60 n = 86	Age ≥ 60 n = 86	Age < 60 n = 662	Age ≥ 60 n = 264
Physical (0-28)	18.1 (5.8)**	21.0 (5.2)	25.2	24.3
Social (0-28)	22.7 (3.9)	22.3 (4.6)	21.0	18.4
Emotional (0-28)	16.4 (4.7)*	18.3 (4.5)	24.6	19.1
Functional (0-24)	16.7 (5.9)*	18.8 (5.4)	21.9	20.3
Total score (0-108)	73.8 (14.6)*	80.4 (14.3)	88.0	82.6

*p<0.05 **p<0.0005

[1] Holzner et al, Acta Oncol, 2004

FACT-G: gender differences

FACT-G subscales (range)	Mean (SD)		General pop'n[1]	
	Women n = 103	Men n = 69	Women n = 447	Men n = 479
Physical (0-28)	18.5 (6.0)*	21.0 (4.8)	24.5 (4.4)	25.3 (3.7)
Social (0-28)	23.0 (4.0)	21.8 (4.5)	20.4 (5.9)	20.1 (5.7)
Emotional (0-28)	16.2 (5.1)**	19.1 (3.5)	19.0 (4.9)	20.1 (4.0)
Functional (0-24)	17.1 (6.0)	18.6 (5.4)	21.2 (5.7)	21.6 (5.3)
Total score (0-108)	74.8 (15.6)*	80.5 (13.0)	85.5 (16.4)	87.3 (14.1)

*p<0.05 **p<0.0005

[1] Holzner et al, Acta Oncol, 2004

FACT-G: performance status

FACT-G subscales (range)	**Mean (SD)**			
	ECOG 0 **n = 76**	**ECOG 1** **n = 91**	**ECOG 2** **n = 5**	***p*-value**
Physical (0-28)	20.9 (0.6)	19.0 (4.8)	8.3 (2.4)	<0.00001
Social (0-28)	22.7 (0.5)	22.4 (0.5)	21.1 (1.9)	0.703
Emotional (0-28)	17.8 (0.5)	17.2 (0.5)	12.8 (2.1)	0.066
Functional (0-24)	18.8 (0.6)	17.3 (0.6)	9.4 (2.5)	0.001
Total score (0-108)	80.2 (1.6)	75.8 (1.5)	51.6 (6.3)	<0.0001

ESAS: gender and age differences

Symptom (0-10)	**Mean (SD)**		**Mean (SD)**	
	Women **n = 103**	**Men** **n = 69**	**Age < 60** **n = 86**	**Age ≥ 60** **n = 86**
Pain	2.5 (2.9)	2.2 (3.6)	2.9 (2.9) *	1.9 (2.6)
Dyspnea	1.7 (2.5)	2.1 (1.9)	1.8 (2.5)	1.9 (2.5)
Appetite	3.3 (3.0) *	2.1 (1.9)	2.7 (2.7)	2.9 (2.9)
Nausea	1.2 (2.1)	0.8 (1.7)	1.5 (2.3) **	0.7 (1.5)
Fatigue	4.1 (2.5)	3.4 (2.5)	4.2 (2.4) *	3.4 (2.6)
Drowsiness	2.3 (2.6)	2.4 (2.4)	2.8 (2.8) *	1.9 (2.2)
Insomnia	3.1 (2.8)	2.9 (3.0)	3.7 (3.0) **	2.4 (2.6)
Anxiety	2.4 (2.8) *	1.5 (2.0)	2.6 (2.7) *	2.5 (2.0)
Depression	2.1 (2.6) *	1.3 (2.1)	2.2 (2.4) *	1.4 (2.3)
Wellbeing	4.0 (2.6) **	2.8 (1.9)	3.6 (2.4)	3.5 (2.5)

*p<0.05 **p<0.005

ESAS: performance status

Symptom (0-10)	**Mean (SD)**			
	ECOG 0 **n = 76**	**ECOG 1** **n = 91**	**ECOG 2** **n =5**	***p*-value**
Pain	1.9 (0.3)	2.6 (0.3)	7.2 (1.2)	<0.0001
Dyspnea	1.5 (0.3)	2.1 (0.3)	4.0 (1.1)	<0.05
Appetite	1.9 (0.3)	3.4 (0.3)	4.6 (1.2)	<0.001
Nausea	0.8 (0.2)	1.2 (0.2)	4.0 (0.9)	<0.005
Fatigue	3.2 (0.3)	4.2 (0.3)	6.4 (1.1)	<0.005
Drowsiness	1.8 (0.3)	2.5 (0.3)	5.8 (1.1)	<0.005
Insomnia	2.7 (0.3)	3.2 (0.3)	3.6 (1.3)	0.432
Anxiety	1.8 (0.3)	2.1 (0.3)	5.4 (1.1)	<0.01
Depression	1.4 (0.3)	1.9 (0.2)	5.2 (1.0)	<0.005
Wellbeing	3.0 (0.3)	3.8 (0.3)	6.0 (1.1)	<0.01

Multivariate regression analyses

Poor performance status was associated with:

- worse HRQL (FACT-G, *p* < 0.0001)
- higher symptom burden (ESAS, *p* < 0.0001)
- more concern about death preparation (QUAL-E, *p* = 0.02)

Young age (< 60 yrs) was associated with:

- worse HRQL (FACT-G, *p*<0.0001)
  physical and emotional well-being p<0.001
- higher symptom burden
  ESAS: pain, nausea, depression, anxiety, drowsiness, *p*<0.005
- more concern about death preparation (QUAL-E, *p*<0.0000001)

Female gender was associated with:

- worse emotional well-being (FACT-G, *p*=0.001)
- worse appetite and general well-being (ESAS, p<0.005)

Lower family income (< $30,000) was associated with:

- worse social well-being (FACT-G, *p*=0.01)

Being on disability was associated with:

- worse functional well-being (FACT-G, *p*=0.01)

- Living with others was associated with:
  - a higher sense of life completion (QUAL-E, *p*=0.001)
  - better social well-being (FACT-G, *p*=0.05)
- Being married was associated with:
  - better functional well-being (p<0.01)
- No differences between cancer sites for HRQL or symptom burden

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Baseline Data Analysis - Conclusions

Socio-demographic characteristics are important determinants of HRQL in patients with metastatic cancer

Certain groups of patients may benefit more from early palliative care referral

Research is necessary to determine whether early referral can prevent/alleviate deterioration of HQRL as performance status declines

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