## Learnings From *The Costs and Medical Care of Patients with Advanced Serious Illness in Singapore (COMPASS)* Cohort Study

31 AUGUST 2020 (MONDAY) 10 - 11AM





## COMPASS Background

Initial Funding: Singapore Millennium Foundation 2015-SMF-0003 24/12/15 – 23/12/18 SGD \$749,922

**Ongoing Funding:** Lien Centre for Palliative Care

Institution	Investigators	
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## **Background (cont.)**

- Primary objective:
  - To better understand the end of life experience for late stage cancer patients in Singapore
- Design
  - Surveys of 600 advanced cancer patients and their family caregivers
  - Followed up every 3 months until death, <u>from</u> <u>2015 till present</u>
  - Multiple sources of data:
    - ✓ Patient surveys
    - ✓ Caregiver surveys
    - ✓ Physician surveys
    - ✓ Medical records
    - ✓ Billing records
    - ✓ Death records



## **Background (cont.)**

Teo et al. BMC Cancer (2018) 18:459 https://doi.org/10.1186/s12885-018-4356-z

#### STUDY PROTOCOL

Cost of Medical Care of Patients with Advanced Serious Illness in Singapore (COMPASS): prospective cohort study protocol

#### Cost and Medical Care of Patients with Advanced Serious Illness in Singapore (COMPASS) Study



National Cancer Centre Singapore

SingHealth





Approached 1510 participants

2 study sites: NCCS and NUH

Recruited 1027 participants (patients and caregivers)



850 days spent in clinics for data collection

**BMC** Cancer

**Open Access** 

CrossMark



1100 trips made for home visits



Completed 7200 surveys to date



## Baseline: Patient Characteristics (N=600)

Age	M = 60.9 (SD=10.6)
Gender	54% Female 46% Male
Marital status	73% Married
Highest Education	15% University 30% Secondary 29% Primary
Cancer (primary site)	28% Respiratory 16% Breast 15% Colorectal 13% Genito-urinary 28% Others

## **Research Outputs To Date**



- **4 Published Papers**
- **5 Manuscripts under review**
- **6 Manuscripts In Progress**
- **Many posters and presentations**

## Today's Program: Research Highlights



Semra Ozdemir, Asst Professor, Lien Centre for Palliative Care

- Awareness of palliative care services
- Discordance between experienced and preferred role in decision making



Chetna Malhotra, Asst Professor, Lien Centre for Palliative CareInstability in preferences for end of life care

EOL suffering



Irene Teo, Asst Professor, Lien Centre for Palliative Care

- Caregiving for advanced cancer patients: Psychological outcomes and protective factors
- Bereavement adjustment of caregivers



**Eric Finkelstein**, Professor and Executive Director, Lien Centre for Palliative Care

Healthcare costs at the end of life

# Awareness of hospice palliative care services



Semra Ozdemir Asst Professor Lien Centre for Palliative Care

## Awareness of hospice palliative care (PC) services among patients



## More than half of patients do not know about hospice palliative care services.

## Predictors for being aware of PC among patients

	Odds Ratio	P Value
Higher education (higher than secondary education)	2.927	0.000
Higher income (higher than median income)	1.798	0.005

## Patients with higher education and higher income had higher odds of being aware of PC services.

## Awareness of PC services among patient-caregiver dyads (N=290)

	Patients	Caregivers
Aware of PC services	43%	53%
(If aware) Physician recommended PC	10%	20%
Whether patient received PC	7%	15%

## Caregivers seem to be better informed about hospice palliative care services.

## Discordance between perceived and preferred roles in decision making



Semra Ozdemir Asst Professor Lien Centre for Palliative Care

### Patients' Perceived and Preferred Role in Decision Making



## Most commonly reported perceived and preferred role was collaborative, followed by patient-led decision making.

### Patients' Perceived and Preferred Role in Decision Making

	N (%)
Discordance in decision making	93 (16%)
Types of Discordance	
Involved less than preferred	31 (33%)
Involved more than preferred	44 (47%)
No change in patient involvement	18 (19%)

Overall, 16% patients reported discordance in decision making – which is pretty good!

### Association of Discordance with Perceived Quality of Care

	Anxiety	Quality of physician communication	Quality of care coordination
Involved less than preferred	0.550	-9.413***	-11.633***
Involved more than preferred	0.456	2.298	-0.446

\* p < 0.1; \*\* p < 0.05; \*\*\* p < 0.01

After controlling for patient characteristics, involvement at a lesser level than preferred was associated with:

- poorer quality of physician communication
- poorer quality of care coordination

compared to concordance and other types of discordance.





## Instability in patient preference for place of death



Chetna Malhotra Asst Professor Lien Centre for Palliative Care

## Imagine going for grocery shopping empty stomach



Our prediction for how much food we need for the week is biased by our state of hunger.

### **Projection bias**



This is problematic when there is a mismatch between how we are feeling right now and how we will feel in the future.

### We examined change in patients' preferred place of death over time every 6 months (n=466)





Change in colour of lines shows that patients' preference changes over time

Draft, do not cite or distribute

## Change is not consistent in one direction



# Instead, it is based on how the patients' mood and health at the time the preference was elicited

- Patients psychologically distressed at the time of survey were more likely to change their preferred place of death to home (RRR: 1.81; 95% CI: 1.16-2.82) and to institution (RRR 2.00; 95% CI: 1.17-3.42).
- Patients hospitalized in the last 6 months were more likely to change their preference to home (RRR 1.53; 95% CI 1.04-2.24) and less likely to change to institution (RRR 0.53; 95% CI 0.30-0.9

(relative to no change in preference)

### This has implications for Advance Care Planning

- Can't assume what is written in an ACP, for example, is what patient will want when the time comes
- ACP should be an ongoing process

## Trajectories of suffering in the last year of life among patients with a solid metastatic cancer



Chetna Malhotra Asst Professor Lien Centre for Palliative Care

### Suffering at the end of life



## Objective

 To delineate and describe the course of illness (joint trajectories) of psychological, spiritual, physical and functional suffering during last year of life of patients with a solid metastatic cancer

### Joint trajectories of psychological, spiritual, physical and functional suffering during last year of life (N=345 decedents)



## Patients with very high suffering: 18% of sample



Compared to persistently low suffering group, they had **more**:

- Education (secondary or more)
- ✓ Hospital admissions in last year of life
- Hospital days in last year of life
- $\checkmark$  Likely to die in hospice

## Course of suffering is related to hospitalizations

- Some patients experience suffering earlier in their last year of life
- Clinical decisions to reduce suffering will have implications not only for patients' well-being but also health care costs.
  - Should we systematically screen patients for suffering?

## Caregiving for advanced cancer patients: Outcomes and protective factors



Irene Teo Asst Professor Lien Centre for Palliative Care

### **Caregiver and caregiving characteristics (N = 287)**

Age	M = 51 (SD=14, range 20-78)	
Gender	63% Female	
Relationship to patient	51% Spouse 36% Child	
Living with patient	77%	
Employment status	51% Full-time 12% Homemaker 12% Not working 16% Retired	
Have additional help	69%	
Duration of caregiving	M = 32.5 months (SD = 39)	
Caregiving tasks	26% Basic ADLs 80% Instrumental ADLs 95% Healthcare-related tasks	

**Caregiver psychological outcomes** 



### **Caregiving esteem**



### **Time spent caregiving & Caregiver Outcomes**

- Average time spent caregiving is 17.4 hours/week (SD = 9 hours)
- Time spent caregiving was not directly associated with: Anxiety (r = 0.02, p = n.s.) Depression (r = 0.02, p = n.s.) CG esteem (r = 0.06, p = n.s.)



### **Protective role of Perceived Competency**



Self-reported competency buffered the effect of caregiving hours on caregivers anxiety (p<0.05)

Teo et al. 2019. BMJ Supportive & Palliative Care. doi: 10.1136/bmjspcare-2019-001979

### **Protective role of Meaning-making**



Teo et al. 2019. BMJ Supportive & Palliative Care. doi: 10.1136/bmjspcare-2019-001979

### **Patterns of Caregiving Trajectories**



## Bereavement Adjustment of Caregivers



Irene Teo Asst Professor Lien Centre for Palliative Care

### At 8 weeks Post-death (N=157)



On average, what has your mood been like in the last week?

At 8 weeks Post-death (N=157)



How much regret do you have about patient's EOL care?

### Caregiver Perceptions & Well-being at 8 weeks Post-death (N=157)

CG perceptions (CEQUEL)	Mood	Regret
Perceived prolongation of death	n.s.	n.s.
Perceived preparedness for patient death	n.s.	-0.21**
Perceived suffering of patient	n.s.	0.38**

\*\*Correlation is significant at the 0.01 level (2-tailed)

### Caregivers with Bereavement Adjustment Difficulties (BGQ≥ 5) at 6 months (N=172)



- Bereavement adjustment difficulty was associated with
  - anxiety (r = 0.48, p <.001)</p>
  - depression (*r* = .0.39, *p* < .001)</p>



## Healthcare costs at the End-of-life



Eric Finkelstein Professor and Executive Director Lien Centre for Palliative Care

## Aims

- Quantify healthcare costs in last 1, 3, 6, 9, and 12 months of life
- Determine whether preferences for 1) minimizing costs vs. 2) maximizing life extension influence these costs

## Data

- Billing data was obtained from NUHS and IHIS (for SGH) for all deceased participants from enrollment to death
- These data include inpatient, outpatient, and emergency department records, and include:
  - Non-subsidized costs
  - Diagnosis codes
  - Procedure codes
  - Dates and length of service
  - Among other variables
- These data were linked to baseline patient surveys

### **Preferences for Life Extension/Cost**

• Patients stratified into three groups based on responses to the following baseline survey question:

If you had to make a choice now, would you prefer treatment that extends life as much as possible, or would you want treatment that costs you less? Please choose a point in the scale below.



## **Preferences (cont.)**



## Methods

- For each participant we sum across service types to generate costs in the 1, 3, 6, 9 and 12-months before death
- Run a regression model to quantify differences in costs as a function of preferences for life extension/cost controlling for:
  - age, gender, housing type, marital status, ethnicity, and type of cancer type

### **Results**

#### Mean Monthly Cost by Preferences



#### Trends

- Overall trend shows increasing mean monthly cost closer to death
- Expected costs in the last year of life are \$61,680 for these patients

### **Preferences for Life Extension/Cost**



### Results

Mean Monthly Cost by Preferences



#### **Findings**

- Lifetime costs for those who prefer to extend life even at higher costs total \$65,280
- Falls to \$55,560 for those whose preference is to minimize costs vs. maximize life extension.
  - This group has much lower costs in the months leading to death
  - Partly because they are far less likely to die in the hospital (28% vs. 46%)

## Discussion

- EOL costs are expensive, averaging roughly \$5K per patient per month
- Costs are higher for those who prefer to try to extend life
  - Partly due to an increase in hospitalizations at EOL
  - Unclear whether the efforts to extend life pay off
- Efforts should be made to educate patients and the public on these costs so they can make informed treatment/insurance/savings decisions

# **Closing Comments/ Discussion**







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