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**Accurate prognostic awareness facilitates, whereas better quality of life and more anxiety symptoms hinder end-of-life discussions**

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# Importance of Physician-Patient EOL-Care Discussions

- High quality end-of-life (EOL) care depends on honoring terminally ill cancer patients' values and treatment preferences.
- Aligning clinical practice to cancer patients' values, goals, and preferences for EOL care requires effective physician-patient discussions.
- Omitted, delayed, or inadequate physician-patient EOL-care discussions lead to physicians misunderstanding patients' EOL-care preferences and patients overestimating the benefits of life-sustaining treatments (LSTs).
  - increase the likelihood of patients' preferring and receiving LSTs at EOL
  - without or late hospice/palliative care referral
  - receive EOL care frequently at odds with patients' preferences
  - unsatisfactory EOL care and poorer EOL-care quality
  - consume more EOL-care resources



# Gaps of Current Clinical Practice

- National guidelines recommend that EOL-care discussions be initiated early in the disease trajectory for patients with incurable cancer.
- Terminally ill cancer patients either don't engage in EOL-care discussions or do so only when death is imminent.
- Most existing studies on patient-reported EOL-care discussions are cross-sectional without exploring changes in EOL-care discussions as death approached.
- Cross-sectional studies also cannot disentangle the impacts of EOL-care discussions on patients' prognostic awareness, psychological well-being, and quality of life or whether these factors facilitate/hinder EOL-care discussions.



# Purposes of This Study

- To explore the evolution of patient-reported physician-patient EOL-care discussions over cancer patients' last 6 months
- To identify factors facilitating or hindering such discussions by arranging time-variant, modifiable independent variables and EOL-care discussions in a distinct time sequence.
  - prognostic awareness,
  - physical symptom distress and functional dependency
  - psychological well-being, and
  - quality of life
  - controlling for:
    - Patient age, gender, education, and physician-patient EOL-care discussion in the previous wave of assessment



# Methods

- Design: observational, longitudinal study extends our earlier study (conducted in 2009-2012) on the quality of death and dying in Taiwanese cancer patients over their dying process by following patients through December 2015.
- Sample: 256 terminally ill cancer patients:
  - recognized by their oncologist that their disease continually progressed and was unresponsive to current curative treatments
- Outcome variable: physician-patient EOL-care discussion:
  - Have you and your doctor discussed what kind of care you would want if your disease continued to progress, your condition continually deteriorated, and you were dying?<sup>8</sup> This care includes being resuscitated, receiving treatments if your heart stopped beating or if you could not breathe on your own, or being kept comfortable without aggressive treatments.
  - Yes or no



# Methods (continued)

- Factors facilitating or hindering physician-patient EOL-care discussions
  - Modifiable by effective palliative care
  - Prognostic awareness was evaluated by asking patients if they knew their prognosis, and if so, whether their disease (1) was curable; (2) might recur in the future, but their life was not currently in danger; or (3) could not be cured, and they would probably die in the near future.
    - Patients were recognized as accurately understanding their prognosis only if they chose option 3.
  - Functional dependence was measured by the 10-item Enforced Social Dependency Scale
    - Total score range=10-51; higher scores reflect greater dependence on help for personal and social functioning.
  - Physical symptom distress was measured by the 13-item Symptom Distress Scale
    - Score range=13-65; higher scores indicate greater distress.



# Methods (continued)

- Factors facilitating or hindering physician-patient EOL-care discussion:
  - Psychological symptom distress (anxiety and depressive symptoms) was measured by anxiety and depression subscales of the Hospital Anxiety and Depression Scale (HADS), respectively.
    - Total anxiety (HADS-A) and depression (HADS-D) subscale scores range=0-21; higher scores indicate greater anxiety and depressive symptoms, respectively.
  - Quality of life was measured by a modified 13-item McGill Quality of Life Questionnaire (MQOL).
    - physical, psychological, social, and existential well-being
    - omitting 3 items (the three most distressing symptoms), but retaining the item on overall physical well-being to avoid overlap with physical symptom distress
    - Total scores for the 13-item MQOL range=0-130; higher scores indicate better QOL.

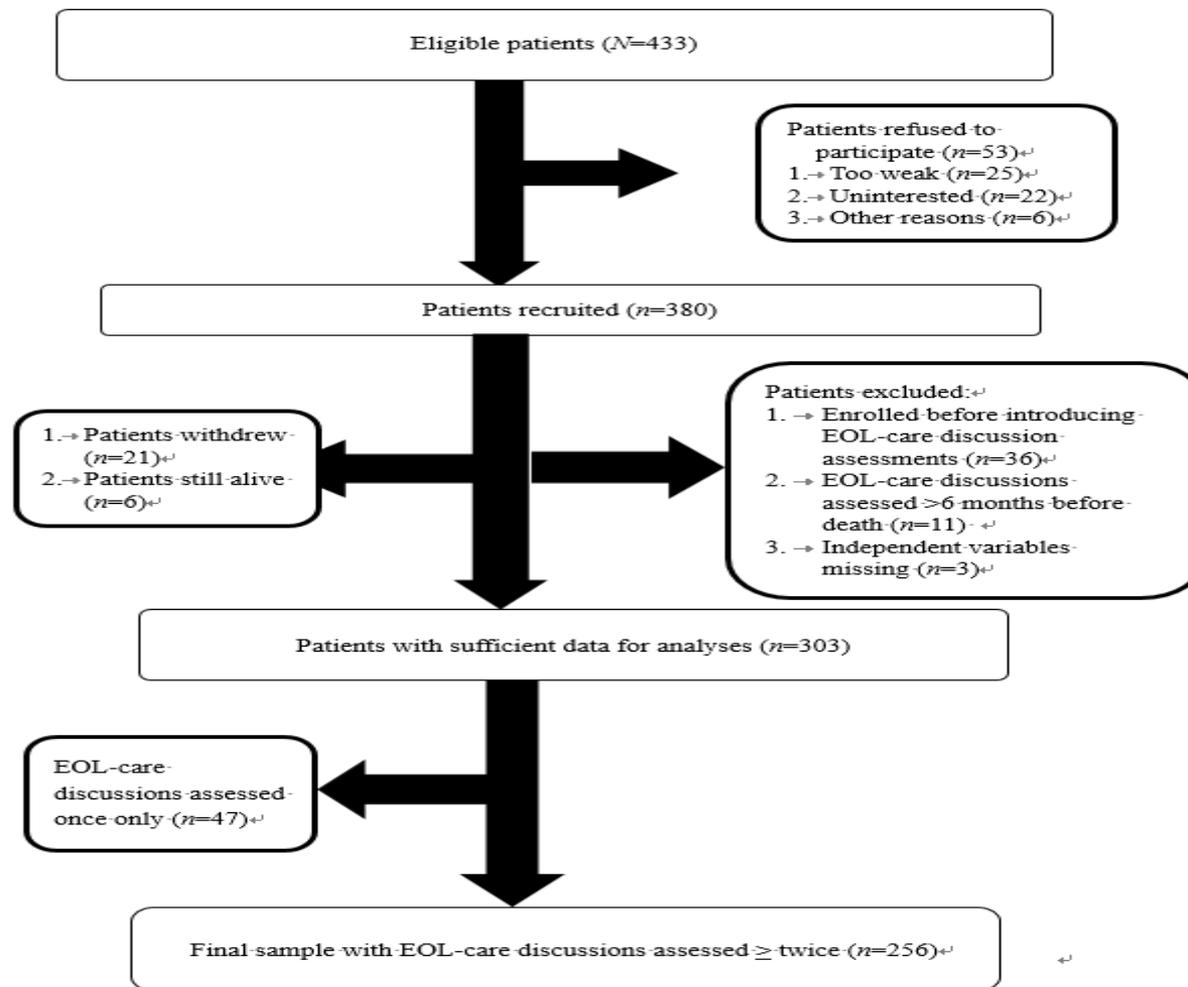


# Methods (continued)

- Data collection: Trained, experienced oncology nurses interviewed patients approximately every 2 weeks until patients declined to participate or died.
- Time proximity to patient death: the period between death and assessment, as 1-30, 31-90, and 91-180 days, conventional periods for estimating cancer patients' survival.
- Changes in and associations of identified independent variables with physician-patient EOL-care discussions were tested using hierarchical generalized linear modeling (HGLM) with logistic regression while controlling for confounding variables.
  - lagged time-varying predictors (accurate prognostic awareness, functional dependence, physical and psychological symptom distress, and QOL) in the previous wave of assessment
    - arranging time-variant, modifiable independent variables and EOL-care discussions in a distinct time sequence to ensure a clear time sequence



# Participant flow chart

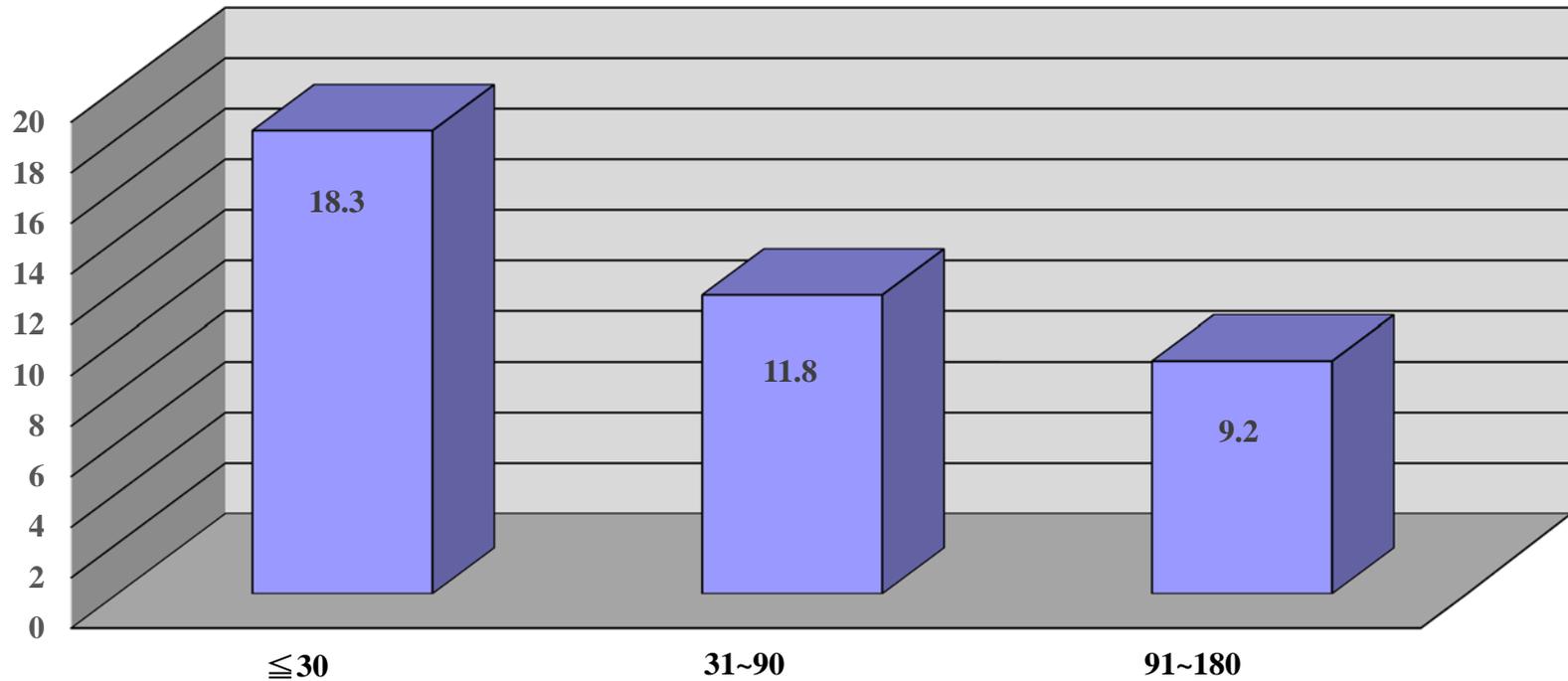


# Characteristics of study participants

- Participants were predominantly:
  - male (57.4%), over 55 years old (56.7%), married/cohabiting (80.1%), had < a junior high-school education (59.9%), with metastatic disease (73.7%)
- Most common cancer sites:
  - liver-pancreas (32.8%), stomach (17.6%), lung (9.4%), and head and neck (8.6%)
  - had been diagnosed on average 19.51 (SD=34.47) months ago
- After enrollment, participants survived on average 194.51 (SD=214.52; median=117.5; range=17-1506) days.
  - completed on average 5.88 (SD=2.85; median=5.5, range=2-12) follow-up assessments in the last 6 months.
  - separated on average by 18.49 (SD=7.62; median=15; range=8-82) days
  - The last assessment was made on average 25.65 (SD=25.23; median=18; range=1-166) days before death.



# Results: Prevalence of EOL-care discussion



Potential predictor	AOR	95% CI		Z	p
Time proximity to patient death (days)					
1-30	3.09	1.89	5.05	4.50	<0.001
31-90	1.43	0.93	2.21	1.63	0.102
91-180	Reference				



# Results: Predictors of EOL-care discussions

Potential predictor <sup>↔</sup>	AOR <sup>↔</sup>	95% CI <sup>↔</sup>	Z <sup>↔</sup>	p <sup>↔</sup>	*
Accurate prognostic awareness <sup>↔</sup>					
Yes <sup>↔</sup>	<b>1.83</b>	<b>1.19</b> <b>2.80</b>	2.77	<b>0.006</b>	*
No <sup>↔</sup>	Reference				*
Physical symptom distress <sup>†↔</sup>	0.97	0.95 1.00	-1.91	0.056	*
Functional dependence <sup>‡↔</sup>	1.01	0.98 1.04	0.72	0.469	*
Quality of life <sup>§↔</sup>	<b>0.98</b>	<b>0.96</b> <b>0.99</b>	-4.30	<b>&lt;0.001</b>	*
Depressive symptoms <sup>  ↔</sup>	0.99	0.93 1.04	-0.49	0.626	*
Anxiety symptoms <sup>l↔</sup>	<b>0.93</b>	<b>0.87</b> <b>0.99</b>	-2.33	<b>0.020</b>	*
Confounding variables <sup>↔</sup>					
Gender <sup>↔</sup>					
Male <sup>↔</sup>	0.88	0.57 1.36	-0.57	0.572	*
Female <sup>↔</sup>	Reference				*
Age <sup>↔</sup>	0.99	0.97 1.01	-0.86	0.390	*
Educational level <sup>↔</sup>					
< Senior high school <sup>↔</sup>	Reference				*
≥ Senior high school <sup>↔</sup>	1.30	0.83 2.04	1.16	0.248	*
Prior end-of-life care discussion <sup>↔</sup>					
Yes <sup>↔</sup>	12.43	7.86 19.63	10.78	<b>&lt;0.001</b>	*
No <sup>↔</sup>	Reference				*



# Discussions

- The prevalence of EOL-care discussions for Taiwanese terminally ill cancer patients increased but remained exceptional even as death approached (9.2-18.3%).
  - at the lowest end of worldwide statistics: 6-7.8%, **20-22%**, 31-39%, 53%, 71.3%
  - cultural practices of not disclosing prognosis or requiring family consent for prognostic disclosure
    - Without adequate prognostic disclosure, it is difficult if not impossible to initiate EOL-care discussions
- Accurate prognostic awareness facilitates EOL-care discussions:
  - AOR (95% CI): 1.83 (1.19, 2.80),  $p=0.006$
  - are more likely to
    - treat EOL-care decision making as relevant (Heyland, et al., Chest, 2006)
    - become more receptive to engaging in physician-patient EOL-care discussions (Wright, et al., JAMA, 2008; Mack, et al., JCO, 2010)



# Discussions (continued)

- Better QOL hindered terminally ill cancer patients' likelihood of reporting EOL-care discussions with physicians in the subsequent assessment:
  - Patients with better QOL may not sense the urgency or necessity to discuss their EOL-care preferences.
  - physicians are more likely to delay discussing EOL-care issues until late in patients' disease trajectory when their QOL is compromised (Lopez-Acevedo, et al., *Gynecol Oncol.* 2013; Zakhour, et al., *Gynecol Oncol*, 2015)
    - they may not benefit from EOL-care discussions to make value-/preference-based decisions.
- More anxiety symptoms hindered EOL-care discussions:
  - difficult for terminally ill cancer patients not only to confront their forthcoming death and the subsequent EOL care issues.
  - physicians may “titrate” EOL-care discussions with patients who are highly anxious by deferring communication about EOL care issues to avoid overwhelming them.



# Limitations of this study

- Representativeness and generalizability of our findings to national and international target populations may have been compromised by convenience sampling from a single medical center in Taiwan.
- A remarkable proportion of patients withdrew or was excluded from analysis, limiting generalization of our findings to those patients.
- We investigated the occurrence of patient-reported physician-patient EOL-care discussions, but we did not explore whether the lack of such discussions was due to physicians' not initiating the conversation or patients' refusing to discuss EOL-care issues when the topic was raised by their physician.
- We did not evaluate the timing, depth, or quality of physician-patient EOL-care discussions.
- We can never exclude the possible impact of unmeasured residuals commonly found in observational studies on patient-reported EOL-care discussions with physicians.



# Conclusions

- Physician-patient EOL-care discussions remain exceptional for terminally ill Taiwanese cancer patients even when death approaches.
- Accurate prognostic awareness facilitated subsequent physician-patient EOL-care discussions.
- Terminally ill cancer patients who enjoy better QOL or suffer from more severe anxiety symptoms may not feel ready to discuss EOL-care issues with their physician.
- Physicians may choose not to discuss EOL-care issues with patients whose QOL is too good or are too anxious to engage in emotion-laden EOL-care discussions to avoid disturbing/overwhelming them.
  - High anxiety was reported to predispose patients to want future EOL-care discussions.



# Clinical implications

- Healthcare professionals should cultivate accurate prognosis awareness to facilitate physician-patient EOL-care discussions in a timely manner to promote preference-based EOL decisions.
- To facilitate early EOL-care discussions in the patient's disease trajectory, healthcare professionals should recognize and overcome their own and patients' barriers to discuss EOL care issues when the patient still enjoys a better QOL.
- Sensitivity to the source and nature of patients' anxiety symptoms can guide interventions tailored to their anxieties, thus facilitating EOL-care discussions for making informed EOL-care decisions.
- Providing value-concordant EOL care to facilitate a good death that is in accordance with patients' wishes (IOM, 1997; 2014).





*Thanks for your attention  
Any comments or questions ??*



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