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?8 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
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.
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

Eligible patients ($N=433$)

Patients refused to participate ($n=53$)
1. Too weak ($n=25$)
2. Uninterested ($n=22$)
3. Other reasons ($n=6$)

Patients recruited ($n=380$)

Patients excluded:
1. Enrolled before introducing EOL care discussion assessments ($n=36$)
2. EOL care discussions assessed >6 months before death ($n=11$)
3. Independent variables missing ($n=3$)

Patients with sufficient data for analyses ($n=303$)

EOL-care discussions assessed once only ($n=47$)

Final sample with EOL-care discussions assessed ≥ twice ($n=256$)
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

<table>
<thead>
<tr>
<th>Potential predictor</th>
<th>AOR</th>
<th>95% CI</th>
<th>Z</th>
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<td>Time proximity to patient death (days)</td>
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<tr>
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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 facilitate 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 ??