FACTORS OF SPECIALIZED PALLIATIVE CARE REFERRAL AND POTENTIALLY BURDENSOME TRANSITIONS FOR CHILDREN WITH LIFE-LIMITING CONDITIONS

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Abstract –

Purpose: We aimed to explore the factors associated with specialized palliative carereferral and their impact on potentially burdensome transitions at the end of lifeamong children and young adults with life-limiting conditions.

Methods: A population-based cohort study using the Health and Welfare DataScience Center database in Taiwan. All children and young adults aged 1-25 yearsrecorded in inpatient or outpatient data with a life-limiting condition diagnostic codewho subsequently died between 2009 and 2017 at age ≤ 25 years were recruited.The logistic regression was used to investigate associations between participantscharacteristics, including demographics and clinical variables, and the odd ratio ofaccessing SPC and the experience of potentially burdensome transition. A threshold$p$ value ($p \leq 0.1$) in the univariate analysis was included in the multivariable model.Multiple confounding factors, including age, sex, diagnoses, and townships digitaldevelopment, were accounted for in each analysis.

Results: Of the 6,863 children and young adults, 979 (14.3%) were referred forspecialized palliative care for at least three days before death. Specialized palliativecare was significantly more likely for those with oncological, gastrointestinal,metabolic, or hematological diseases. Age above 16 years old, had higher hospitaluse, psychotherapy recipient, and living in the highest digital development areaswere associated with increased likelihood of specialized palliative care referral. A lackof early referral was associated with an over three-fold increased odds of a latetransition and subsequent hospital death compared with early referral, whereasinpatient hospice and palliative home care had no impact.

Conclusions: Careful attention should be paid to a need for longer length of stayand dying in a medical setting late in life, despite early initiation of specialized palliative care. Many children and young adults still face in-hospital deaths, raisingconcerns about the need for greater availability of specialized palliative care in homesettings.