Barriers to Palliative Care in Cystic Fibrosis (S863)

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Objectives

1. Identify barriers to palliative care for individuals with cystic fibrosis from the perspectives of patients, caregivers, and CF providers.
2. Describe ways to overcome barriers to palliative care in cystic fibrosis.

Original Research Background. In the absence of clear guidelines for palliative care (PC) in cystic fibrosis (CF), little is known about PC provision to individuals with CF and barriers to PC.

Research Objectives. To identify barriers to PC in CF.

Methods. CF care team members ("providers"), adults with CF ("patients"), and family caregivers ("caregivers") recruited from listservs maintained by the Cystic Fibrosis Foundation completed an online survey about barriers to PC in CF. Responses were analyzed using descriptive statistics.

Results. Surveys were completed by 70 patients, 100 caregivers, and 350 providers. All providers and 96% of patients and caregivers expressed beliefs that PC is valuable for individuals with CF. Nearly half of patients and caregivers recalled knowing someone who received PC, but rarely had personal experience. While 73% of providers reported introducing PC to patients, only 26% of patients and 12% of caregivers recalled learning about PC from providers. From a list of common barriers to PC, all groups identified the same top three: perception that palliative care is only for dying people, lack of access to outpatient PC, and lack of PC training for CF providers. Nearly 1/3 of providers felt patient reluctance to engage in PC conversations is an important barrier, versus 5% of patients and caregivers. Many patients (64%) and caregivers (74%) were not aware of availability of PC specialists, and 19% of providers did not know if PC specialists were available to their patients.

Conclusion. Patients with CF and caregivers report little experience with PC despite a majority of providers reporting they introduce PC to their patients. The most common barriers to PC reflect gaps in knowledge and provider concerns about patient willingness to engage in PC conversations.

Implications for Research, Policy, or Practice. PC education and tools to promote patient-provider communication may help alleviate barriers to PC in CF.

Non-Surgical Patients with Advanced Gynecologic Cancer Discharged to Subacute Rehabilitation Centers Have Low Rates of Subsequent Chemotherapy (S864)

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Objectives

1. Interpret survival data presented as median days after discharge.
2. Interpret significant of results from a univariate analysis.

Original Research Background. Women with advanced gynecologic cancer are often enticed by the promise of additional chemotherapy even when the potential for prolonged life or a cure is slim. Furthermore, many of these patients don't qualify for additional chemotherapy due to preclusive weakness or medical comorbidities. Despite these observations, they are often discharged from the hospital to skilled rehabilitation centers (SRC) to recuperate the strength to qualify for additional chemotherapy.

Research Objectives. We sought to characterize prognosis and rates of subsequent chemotherapy among non-surgical patients with advanced gynecologic cancer who were discharged to SRC.

Methods. Patients with stage III/IV or recurrent gynecologic malignancy who were admitted to the Kaiser Permanente Southern California health care system and discharged to SRC over a ten-year period were included in this retrospective cohort. Patients who had surgery during their admission or who were enrolled in hospice prior to discharge were excluded. A univariate analysis was performed to identify patient characteristics that might be predictive of receiving future chemotherapy. Statistical significance was ascertained in all analyses through a Fisher's exact test.

Results. 35 patients met inclusion criteria. The majority were Caucasian (75%), and the median age was 70. Survival after discharge ranged from 5 to 1463 days, with a median survival of 57.5 days. Seven patients (20%) received future chemotherapy after discharge. None of the examined patient or admission factors (age, primary site of malignancy, upfront vs recurrent disease, indication for admission) was predictive of future chemotherapy. Trends toward longer survival

were seen in patients with age ≤75 (p=0.27), cervical cancer (p=0.11), non-recurrent disease (p=0.69) and a non-infectious admission indication (p=0.49).

Conclusion. In this cohort of non-surgical patients with advanced gynecologic malignancy discharged to SRC, only 20% received additional chemotherapy, and the median survival was 58 days.

Implications for Research, Policy, or Practice. This may be an appropriate population to target for advanced care planning prior to discharge.

Why Do Some Patients Regret Their Decision to Initiate Dialysis? (S865)

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Objectives

1. Discuss the importance of patient autonomy in dialysis decision-making.
2. Discuss the impact of a physician's paternalistic style of decision making on patients' inner peace with the decision.

Original Research Background. Nearly 25% of patients receiving maintenance dialysis withdraw from dialysis each year. Many patients regret their decision to start dialysis.

Research Objectives. To identify factors associated with dialysis regret.

Methods. A forty-one item questionnaire was administered to adult patients receiving maintenance dialysis in seven dialysis units located in Cleveland, Ohio and its suburbs. Of the 450 patients who were asked to participate in the study, 423 agreed. The questionnaire items assessed patients' knowledge of their kidney disease, attitudes toward chronic kidney disease (CKD) treatment, and preference for end-of-life (EoL) care. A single question was used to assess dialysis regret, "Do you regret your decision to start dialysis?" We used logistic regression to identify predictors of decisional regret. Candidate predictors were patient demographics, attitudes toward CKD treatment, beliefs about the dialysis decision-making process, and EoL care preferences.

Results. Eighty of 395 respondents (20.2%) reported dialysis regret. Three variables were associated with dialysis regret: (1) patients chose dialysis over conservative management to please doctors or family members (adjusted odds ratio (AOR) 3.33, confidence interval 1.73, 6.37), p=<0.0001; (2) patients thought it was important for their families to be actively involved in dialysis decision-making (AOR 1.97, CI 1.73, 6.37), p=0.0001; (3) patients reported not having prognostic discussions with the kidney doctors (AOR 2.60, CI 5.85,1.15, CI), p=0.0414.

Conclusion. Dialysis regret was not uncommon in this sample. Regret is associated with beliefs about the dialysis decision-making process. There was no evidence of demographic (age, gender, race, income) differences in regret.

Implications for research. Future research involving multiple stakeholders (e.g., patients, caregivers, physicians) is warranted to identify modifiable risk factors for dialysis regret and to improve dialysis decision-making.

Trends in Hospital-Based Specialty Palliative Care: Insights from a National Palliative Care Quality Improvement Collaborative (S866)

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Objectives

1. Describe at least two trends in processes of care provided by inpatient palliative care (PC) teams over time.
2. Describe one major change in a clinical outcome achieved by inpatient PC teams over time.
3. Discuss how these trends relate to evolving expectations of and norms within the field.

Background. The field of palliative care (PC) is growing and evolving rapidly in response to increased demand and recognition of its benefits.

Objectives. Describe how processes of care and outcomes achieved by inpatient PC teams have changed over time.

Methods. Data for this study were extracted from the Palliative Care Quality Network database on 03/06/2018 and pertain to 135,197 patients referred to 88 inpatient PC consult teams between 01/01/2013 and 12/31/2017.

Results. The most common diagnoses leading to inpatient PC consult were cancer (32.0%, range between teams: 11.3%−93.9%), cardiovascular disease (13.2%, 0%−29.0%), and pulmonary disease (11.3%, 0%−26.0%). The percentage of referred patients with cancer decreased between 2013 and 2017 (39.0% to 30.0%, p<0.0001), while there was an increase in the percentage of patients with cardiovascular disease (12.0% to 14.0%, p<0.0001) and pulmonary disease (10.0% to 12.0%, p<0.0001).