

Appendix 2: Recent examples of research and research methods related to palliative care outside of cancer

Study (country)	Concept/setting	Study design/evaluation	Comments
Downar et al., 2012 ¹	Duration of survival among patients with a noncancer diagnosis admitted to a palliative care unit (Canada)	Retrospective study in four palliative care units in Toronto over one year; 1000 patients, 21% with noncancer diagnosis	Noncancer patients (older, worse functional status and prognosis) had shorter length of stay (14 v. 24 d) and similar likelihood of being discharged alive than patients with cancer. Authors suggested: "Referring physicians and PCUs should not reject or restrict end-stage noncancer referrals out of concern that these patients are 'oversurviving' and having a detrimental impact on PCU bed utilization."
Bakitas et al., 2013 ²	Palliative care consultations for patients with heart failure (United States)	Retrospective chart review; 1320 patients, 1763 admissions with heart failure	Palliative care consultations for only 132 patients
Higginson et al., 2014 ³	An integrated palliative respiratory care service for patients with advanced disease and refractory breathlessness (United Kingdom)	RCT; primary outcome was mastery domain of chronic respiratory questionnaire	First study to report survival advantage for patients with noncancer diagnosis in the intervention group. Survival rate at six months was better in the group receiving breathlessness support service than in the control group (94% [50/53] v. 75% [39/52]) and in overall survival ($p = 0.048$).
Cook et al., 2015 ⁴	Personalization of the dying process in a 21-bed medical-surgical intensive care unit (Hamilton, Ont.)	Mixed-methods study; 40 patients near death, a family member and bedside clinicians who together elicited 159 "wishes" that, when facilitated, would honour the dying patient	Interpretation of qualitative component: "For patients, eliciting and customizing the wishes honored them by celebrating their lives and dignifying their deaths. For families, it created positive memories and individualized end-of-life care for their loved ones. For clinicians, it promoted interprofessional care and humanism in practice. The 3 Wishes Project facilitated personalization of the dying process through explicit integration of palliative and spiritual care into critical care practice."
Kimbell et al., 2015 ⁵	Patient experience in advanced liver disease	Scoping literature review	Only 2 studies (of 121 reviewed) explored the holistic patient experience. "Qualitative longitudinal research has great potential for contributing to our understanding of the complex needs and experiences of patients living with advanced liver disease."
George et al., 2016 ⁶	Palliative care screening and assessment in the emergency department (United States)	Systematic review	"The [emergency department] screening of patients for [palliative care] referrals and resources is feasible and may offer benefits." "...[C]onclusions are limited by the heterogeneity intrinsic to each of the studies included in our systematic (scoping) review analysis, the paucity of existing literature investigating screening triggers for [palliative care] in [emergency department] patients, and the lack of standardization in the outcomes assessed."
Oliver et al., 2016 ⁷	A collaboration between the European Association of Palliative Care and the European Academy of Neurology	A consensus review on the development of palliative care for patients with chronic and progressive neurologic disease	"Overall there is limited evidence to support the recommendations but there is increasing evidence that palliative care and a multidisciplinary approach to care do lead to improved symptoms (Level B) and quality of life of patients and their families (Level C)."

Note: PCU = palliative care unit, RCT = randomized controlled trial.

References

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