years, 64% were male, 89% were white, 32% had received college or higher education and 66% had private insurance. 59% patients died in hospice (36% in inpatient hospice, and 23% in home hospice) and 40% in the hospital (23% in ICU and 17% on the floor). Figure shows indicators of intense EOL care in patients who died in hospital vs. hospice. Median duration of hospice was 3 (range 1-41) days. 72% had an advance directive on record and 37% were seen by palliative medicine. There was a higher rate of mechanical ventilation (p<0.001) and use of invasive procedures (p=0.01) in the last week of life for those that died in the hospital vs. in hospice. In the multivariable model, female gender (OR: 0.27, 95% CI: 0.10 to 0.7, p=0.01) and having an advance directive on record (OR: 0.24, 95% CI: 0.07 to 0.80, p=0.02) were associated with decreased odds of having >1 invasive care indicators. 

Conclusions: There is a high utilization of intensive care and procedures in the last days of life for patients dying in the hospital. Patients with advance directives were more likely to experience a value based EOL care including avoidance of intensive, and ultimately futile, medical care.

Methods: We conducted a landmark analysis of HCT survivors > 12 mos after allogeneic HCT seen at least once in our clinic between 1/1/02 & 6/30/18. We identified each pt's last point of contact with our institution (including admissions & death notifications). For pts not known to have died, we calculated ‘no-contact’ intervals since last points of contact. No-contact intervals of 12+ mos constituted being lost to f/u. We used the 75th percentile of driving distance (as done by Ragon et al) to delineate closer-living vs. furthest-living groups, calculating percentiles within f/u cohorts (1-4.9 yrs, 5-9.9 yrs, or 10+ yrs after HCT) to account for catchment area changes over time. 

Results: We analyzed 437 pts, of whom 22 (5%) had received HCTs at other centers. Compared to the closer-living group (median distance 24.1 mi, interquartile range [IQR] 13.9-33.3), the furthest-living group (median distance 78.4 mi, IQR 66.2-117.0) was more likely to be white but was otherwise comparable by age, gender, insurance, HCT indication, & GVHD distribution. The two groups had similar overall survival (median 32.0 vs. 31.0 mos, p = 0.94). Among patients not known to have died (n = 272), lost to f/u rates were almost 2x as high (17% vs. 9%) in the furthest-living group; however, this difference did not reach significance (p = 0.13). Only 1/4 of lost pts (n = 30) had documented reasons for ceasing contact, e.g. preference for local care or transfer to another center. The furthest-living group had significantly longer no-contact intervals than the closer-living group (p < 0.01): median 101 days (IQR 50-234) vs. 61 days (IQR 39-114).

Discussion: Our sample size was relatively small, and we were unable to assess HCT recipients not seen in our ambulatory LTFU clinic. Nevertheless, our single-center study suggests that long-distance pts may disproportionately become lost to f/u. LTFU clinics should ensure adequate inclusion, e.g. via telehealth, of long-distance HCT survivors in clinical care and research.

Figure. Indicators for high intensity EOL care in patients who died in hospital vs. hospice

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Long-Term Follow-up or Lost to Follow-up? Driving Distance and Continuity of Follow-up Care after Allogeneic Transplantation
Rahul Banerjee MD1, Alison W. Loren MD, MSCE2, 1 Department of Medicine, Hospital of the University of Pennsylvania, Philadelphia, PA; 2 Blood and Marrow Transplantation Program, Abramson Cancer Center and the Division of Hematology and Oncology, Hospital of the University of Pennsylvania, Philadelphia, PA

Introduction: Long-term follow-up (LTFU) clinics overcome any potential survival disadvantage from long driving distances in hematopoietic stem cell transplant (HCT) recipients (Ragon et al, 2014; Khera et al, 2017). However, omitting pts who are lost to follow-up (f/u) – defined as no phone/electronic communication or appointment requests in 12+ mos – may introduce selection bias. We hypothesized that long driving distances lead to higher ‘lost’ rates in HCT survivors.

Methods: We conducted a landmark analysis of HCT survivors > 12 mos after allogeneic HCT seen at least once in our clinic between 1/1/02 & 6/30/18. We identified each pt’s last point of contact with our institution (including admissions & death notifications). For pts not known to have died, we calculated ‘no-contact’ intervals since last points of contact. No-contact intervals of 12+ mos constituted being lost to f/u. We used the 75th percentile of driving distance (as done by Ragon et al) to delineate closer-living vs. furthest-living groups, calculating percentiles within f/u cohorts (1-4.9 yrs, 5-9.9 yrs, or 10+ yrs after HCT) to account for catchment area changes over time. 

Results: We analyzed 437 pts, of whom 22 (5%) had received HCTs at other centers. Compared to the closer-living group (median distance 24.1 mi, interquartile range [IQR] 13.9-33.3), the furthest-living group (median distance 78.4 mi, IQR 66.2-117.0) was more likely to be white but was otherwise comparable by age, gender, insurance, HCT indication, & GVHD distribution. The two groups had similar overall survival (median 32.0 vs. 31.0 mos, p = 0.94). Among patients not known to have died (n = 272), lost to f/u rates were almost 2x as high (17% vs. 9%) in the furthest-living group; however, this difference did not reach significance (p = 0.13). Only 1/4 of lost pts (n = 30) had documented reasons for ceasing contact, e.g. preference for local care or transfer to another center. The furthest-living group had significantly longer no-contact intervals than the closer-living group (p < 0.01): median 101 days (IQR 50-234) vs. 61 days (IQR 39-114).

Discussion: Our sample size was relatively small, and we were unable to assess HCT recipients not seen in our ambulatory LTFU clinic. Nevertheless, our single-center study suggests that long-distance pts may disproportionately become lost to f/u. LTFU clinics should ensure adequate inclusion, e.g. via telehealth, of long-distance HCT survivors in clinical care and research.

Figure. Landmark analysis of HCT survivors > 12 mos after allogeneic HCT, stratified by the 75th percentile of driving distance. (b) No-contact intervals (since last points of contact) for patients not known to have died. No-contact intervals of 12+ mos constituted being ‘lost.’

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Nutrition Practices in Hematopoietic Stem Cell Transplantation (HSCT): A Comparison between Guidelines and Clinical Practice
Yen P Lowder RD, CNSC1, Meredith Moyers MS, RD2, Jenna Seckar MS, RD2, Elisabeth Gorecki MS, RD, CNSC, CSO4, Kelli Oldham MS, RD2, Jennifer Frutchey MPH, RD, CSO4, Kara Beasley MS, RD5, Anya Guy RD6, Christina Proch RD7, Teisha Lightbourne MPH, RD, LDN, CNSC, IBCLC10, Samuel Del Verne RD8,11, Kathleen Stockmann MS, RD, CSO12, Mitchell E. Horwitz MD13, Nelson J. Chao MD, MBA14, Anthony D. Sung MD14, 1 Hematologic Malignancies & Cell Therapy, Duke University Hospital, Durham, NC; 2 UNC Health, Chapel hill, NC; 3 University of Florida Health Shands, Gainesville, FL; 4 Froedtert Hospital, Menomonee Falls, WI; 5 UT Southwestern Simmons Cancer Center, Dallas, TX; 6 USC Norris Comprehensive Cancer Center, Los Angeles, CA; 7 Massachusetts General Hospital, Boston, MA; 8 Mayo Clinic- Jacksonville, Jacksonville, FL; 9 duke university hospital, durha, NC; 10 Duke University Hospital,