Chronic Graft-versus-Host Disease and Hematopoietic Cell Transplant Survivorship Care Models

Mary E.D. Flowers, MD
Full Member, Fred Hutch
Professor of Medicine, UW, Seattle, WA

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No conflict of interest to disclose
Disclosures

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- **Major Shareholder**: No disclosure

*Ibrutinib is the only FDA approved therapy for chronic GVHD that failed corticosteroids*
Outline

- What is chronic Graft-versus-Host Disease (GVHD)
- Challenges of patients with chronic GVHD
- Quality of life and functional of hematopoietic cell transplant (HCT) recipients with chronic GVHD
- Quality of life and functional of caregivers of transplant recipients
- HCT Survivorship Care Models
Chronic Graft-versus-Host-Disease (GVHD)

- Major barrier of otherwise successful allogeneic hematopoietic stem cell transplantation (HCT)
- Results from an immunological assault of the allogeneic “graft” against the transplant recipient (host)
- ~40% cumulative incidence by 1 year after transplant
- Median onset 6 months after HCT (10% > 1 year after HCT)
- Median duration of treatment 2-3 years (some cases require systemic immunosuppression beyond 10 years)
- Associated with poor quality of life
- Associated with lower risk of relapse of original malignancy
Sites affected by chronic GVHD
At time of initiation of systemic treatment

Diagnosis per NIH criteria

Flowers et al, Blood 2002
Flowers et al Biol Blood Marrow Transplant 2008
What are the severe manifestations of cGVHD

- Severe ocular sicca (eyes)
- Sclerotic features (skin)
- Joint contractures/Fasciitis (muscle/joint)
- Esophageal stricture (difficult swallowing)
- Bronchiolitis obliterans (lungs)
- Severe oral sicca and ulcers (mouth)

Flowers M et al. *Blood* 2002; 100: 415-419
Impact of severity of chronic GVHD on NRM, OS and *Graft-vs.-Leukemia*

A) Non-relapse mortality

B) Overall mortality

C) Recurrent malignancy

<table>
<thead>
<tr>
<th>NIH global score</th>
<th>N. of patients*</th>
<th>Non-relapse mortality HR(^1) (95% CI)</th>
<th>(P)</th>
<th>N. of patients*</th>
<th>Overall mortality HR(^1) (95% CI)</th>
<th>(P)</th>
<th>N. of patients*</th>
<th>Recurrent malignancy HR(^1) (95% CI)</th>
<th>(P)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>196</td>
<td>1.00 (reference)</td>
<td></td>
<td>196</td>
<td>1.00 (reference)</td>
<td></td>
<td>194</td>
<td>1.00 (reference)</td>
<td></td>
</tr>
<tr>
<td>Moderate</td>
<td>455</td>
<td>4.27 (0.99-18.4)</td>
<td>0.051</td>
<td>455</td>
<td>2.79 (1.24-6.30)</td>
<td>0.013</td>
<td>447</td>
<td>1.26 (0.68-2.35)</td>
<td>0.46</td>
</tr>
<tr>
<td>Severe</td>
<td>320</td>
<td>17.1 (4.12-71.3)</td>
<td>&lt;0.001</td>
<td>320</td>
<td>7.59 (3.42-16.9)</td>
<td>&lt;0.001</td>
<td>314</td>
<td>1.27 (0.64-2.52)</td>
<td>0.49</td>
</tr>
</tbody>
</table>

\*Total number of patients contributing to the category at one or more visits. \*Models were adjusted for time after transplantation, transplant center, patients' age, stem cell source, disease risk, cytomegalovirus status, HLA and donor type, gender mismatch, conditioning intensity, prior acute GVHD and thrombocytopenia at the visit. \*Models were adjusted for time after transplantation, transplant center and disease risk.

Inamoto Y et al, Haematologica 2014: 99:1619
Challenges Faced by Patients with Chronic GVHD

Neuropsychologic effects
- Depression, anxiety
- Post-traumatic stress disorder
- Neurocognitive deficits

Pulmonary diseases
- Bronchiolitis obliterans syndrome
- Cryptogenic organizing pneumonia
- Pulmonary hypertension

Kidney diseases
- Thrombotic microangiopathy
- Nephrotic syndrome
- Idiopathic CKD
- Persistent acute kidney injury
- RK virus nephropathy

Impact on quality of life

Bone diseases
- Osteopenia
- Osteoporosis
- Avascular necrosis

Endocrine diseases
- Thyroid dysfunction
- Gonadal dysfunction
- Diabetes
- Dyslipidemia
- Metabolic syndrome
- Adrenal insufficiency

Solid cancers
- Oral cavity
- Skin
- Breast
- Thyroid
- Other sites

Cardiovascular diseases
- Cardiomyopathy
- Congestive heart failure
- Valvar dysfunction
- Arrhythmia
- Pericarditis
- Coronary artery disease

Liver diseases
- Hepatitis B, Hepatitis C, liver cirrhosis
- Nodular regenerative/focal nodular hyperplasia

Gonadal dysfunction/infertility

Infectious diseases
- *Pneumocystis jiroveci*
- Encapsulated bacteria
- Fungi
- Varicella-zoster virus
- Cytomegalovirus
- Respiratory syncytial virus
- Influenza virus
- Parainfluenza virus

Adapted from Inamoto Y, Lee SJ. Haematologica 2017
Chronic GVHD impacts overall health and quality of live (QOL) after transplantation
Patient-reported outcomes and health status associated with chronic GVHD

Study objectives:

- Describe the quality of live (QOL) scores and health status of patients with chronic GVHD of differing severity compared to those with resolved chronic GVHD or those who had never had chronic GVHD.
- Investigate the PROMIS* measures in chronic GVHD relative to established measures of QOL in long-term transplant survivors.

*Patient-Reported Outcomes Measurement Information System is a set of person-centered measures that evaluates and monitors physical, mental, and social health.

Lee. S et al. Haematologica 2018, 103(9):1535-1541
We surveyed allogeneic transplant recipients about their quality of life, symptoms, health status, comorbid conditions and medication.

Of 3027 surveys sent to recipients surviving \( \geq 1 \) year after transplantation, 1377 (45%) responded.
Patient-reported outcomes and health status associated with chronic GVHD

- Of 1377 responders, they reported their chronic GVHD as
  - Mild (18.7%)
  - Moderate (8.0%)
  - Severe (1.8%)
- Another 377 (27.4%) never had chronic GVHD
- And 280 (20.3%) had chronic GVHD but it had resolved.

Lee. S et al. Haematologica 2018, 103(9):1535-1541
Patient-reported outcomes and health status
(n = 1377)

<table>
<thead>
<tr>
<th>Population characteristics</th>
<th>Never</th>
<th>Resolved</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
<th>P-value</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>(n=377)</td>
<td>(n=280)</td>
<td>(n=257)</td>
<td>(n=110)</td>
<td>(n=25)</td>
<td></td>
</tr>
<tr>
<td>Female, n (%)</td>
<td>209 (55.4)</td>
<td>135 (48.2)</td>
<td>113 (44.0)</td>
<td>49 (44.5)</td>
<td>9 (36.0)</td>
<td>0.02</td>
</tr>
<tr>
<td>Age, mean years (SD)</td>
<td>53.9 (13.5)</td>
<td>58.8 (12.3)</td>
<td>57.2 (12.6)</td>
<td>58.3 (10.8)</td>
<td>57.6 (15.0)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Matched related</td>
<td>212 (56.2)</td>
<td>136 (48.6)</td>
<td>88 (34.2)</td>
<td>40 (36.4)</td>
<td>7 (28.0)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Mismatched related</td>
<td>16 (4.2)</td>
<td>19 (6.8)</td>
<td>4 (1.6)</td>
<td>1 (0.9)</td>
<td>1 (4.0)</td>
<td></td>
</tr>
<tr>
<td>Haplo-identical related</td>
<td>11 (2.9)</td>
<td>7 (2.5)</td>
<td>10 (3.9)</td>
<td>2 (8.1)</td>
<td>1 (4.0)</td>
<td></td>
</tr>
<tr>
<td>Matched unrelated</td>
<td>95 (25.2)</td>
<td>81 (28.9)</td>
<td>114 (44.4)</td>
<td>54 (49.1)</td>
<td>11 (44.0)</td>
<td></td>
</tr>
<tr>
<td>Mismatched unrelated</td>
<td>17 (4.5)</td>
<td>33 (11.8)</td>
<td>31 (12.1)</td>
<td>13 (11.8)</td>
<td>4 (16.0)</td>
<td></td>
</tr>
<tr>
<td>Cord</td>
<td>19 (5.0)</td>
<td>4 (1.4)</td>
<td>9 (3.5)</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Syngeneic</td>
<td>6 (1.6)</td>
<td>0</td>
<td>1 (0.4)</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Peripheral blood, n (%)</td>
<td>150 (39.8)</td>
<td>110 (39.3)</td>
<td>187 (72.8)</td>
<td>97 (88.2)</td>
<td>20 (80.0)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Myeloablative, n (%)</td>
<td>309 (82.0)</td>
<td>242 (86.4)</td>
<td>172 (66.9)</td>
<td>64 (58.2)</td>
<td>14 (56.0)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>High dose TBI, n (%)</td>
<td>133 (35.3)</td>
<td>131 (46.8)</td>
<td>59 (23.0)</td>
<td>18 (16.4)</td>
<td>3 (12.0)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Years since HCT, mean, (SD)</td>
<td>14.9 (11.3)</td>
<td>17.5 (8.4)</td>
<td>8.4 (7.5)</td>
<td>7.2 (5.8)</td>
<td>9.0 (8.1)</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>
SF-36 Physical (PCS) and Mental (MCS) Component Score and PROMIS Global Health Health Physical (GH-Phys) and Mental score (GH-Ment)

Physical functioning scales

Mental Functioning

Lee. S et al. Haematologica 2018, 103(9):1535-1541
PROMIS 29 subscales of physical and social functioning

![Box plot showing scores for physical and social functioning with p-values for comparison.]

Lee. S et al. Haematologica 2018, 103(9):1535-1541
Patients with moderate or severe cGVHD reported worse quality of life, lower performance status, a higher symptom burden and were more likely to be taking prescription medications for pain, anxiety and depression compared to those with resolved cGVHD.

Self-reported measures were similar between patients with resolved cGVHD and those who never had it.

Our data suggest that the PROMIS measures can replace the SF-36 in cGVHD assessment.

Between 26.7-39.4% of people with active cGVHD were unable to work due to health reasons, compared with 12.1% whose cGVHD had resolved and 15.4% who never had cGVHD.

Mouth, eye and nutrition symptoms persisted after resolution of cGVHD.

These results show that better prevention of and treatment for cGVHD is needed to improve survivorship after allogeneic transplantation.

Lee. S et al. Haematologica 2018, 103(9):1535-1541
Quality of live of Caregivers of Recipients of Hematopoietic Cell Transplantation (HCT)
Caregiver burden is a well-recognized problem when patients have chronic illnesses. Caregiver burden is defined as the emotional, physical, social, and financial suffering that they experience as a result of providing care. Studies have found that early after HCT, caregivers experience significant levels of distress and burden and declining quality of life (QOL). Given the complex care needs and prolonged recovery for transplant recipients, effects on caregiver health and QoL are expected. We surveyed allogeneic transplant recipients about their quality of life, symptoms, health status, comorbid conditions and medication.

Jamani, K et al. BBMT 2018 (24):2271-2276
Quality of Life (QoL) of Caregivers of Hematopoietic Cell Transplant (HCT) Recipient

- In this study we surveyed 4446 caregiver-recipient pairs in the post-HCT period to describe their QoL and its determinants.
- Survey was sent between July 2015 to July 2016
- 849 caregiver-recipient pairs at a median of 6 years (range, 0.4 to 44) after autologous or allogeneic HCT responded (~20%).
## Characteristics of Caregiver Population

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Recipient</th>
<th>Caregiver</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, median (range) years</td>
<td>62 (18-87)</td>
<td>63 (18-90)</td>
</tr>
<tr>
<td>Sex, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>502 (56)</td>
<td>290 (33)</td>
</tr>
<tr>
<td>Female</td>
<td>390 (44)</td>
<td>594 (67)</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-Hispanic</td>
<td>863 (97)</td>
<td>764 (86)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>15 (2)</td>
<td>14 (2)</td>
</tr>
<tr>
<td>Missing</td>
<td>14 (2)</td>
<td>114 (13)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;High school</td>
<td>11 (1%)</td>
<td></td>
</tr>
<tr>
<td>2 year college/trade degree</td>
<td>97 (11%)</td>
<td></td>
</tr>
<tr>
<td>4 year college/trade degree</td>
<td>228 (26%)</td>
<td></td>
</tr>
<tr>
<td>Graduate degree</td>
<td>254 (28%)</td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>24 (3%)</td>
<td></td>
</tr>
<tr>
<td>2 year college/trade degree</td>
<td>97 (11%)</td>
<td></td>
</tr>
</tbody>
</table>

Jamani, K et al. BBMT 2018 (24):2271-2276
### Characteristics of Caregivers Population (Continue)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Caregiver relationship, n (%)</strong></td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>698 (78)</td>
</tr>
<tr>
<td>Live in partner</td>
<td>21 (2)</td>
</tr>
<tr>
<td>Parent</td>
<td>92 (10)</td>
</tr>
<tr>
<td>Child</td>
<td>28 (3)</td>
</tr>
<tr>
<td>Other</td>
<td>33 (4)</td>
</tr>
<tr>
<td>Friend</td>
<td>9 (1)</td>
</tr>
<tr>
<td>Paid caregiver</td>
<td>2 (0)</td>
</tr>
<tr>
<td>Missing</td>
<td>9 (1)</td>
</tr>
<tr>
<td><strong>Caregiver still living with HCT recipient, n (%)</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>760 (85)</td>
</tr>
<tr>
<td>Missing</td>
<td>21 (2)</td>
</tr>
<tr>
<td><strong>Caregiver still providing care of HCT recipient, n (%)</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>608 (68)</td>
</tr>
<tr>
<td>Missing</td>
<td>32 (4)</td>
</tr>
</tbody>
</table>
Quality of Life (QoL) of Caregivers of HCT Recipient

Results

- Of 849 responding caregivers, 67% were women and 68% were still providing care to the HCT recipient.
- Mean and median QoL measures of caregivers were at or above general population norms; but approximately 20% of reported poor QoL relative to general population norms.
- Multivariate analysis revealed that caregiver age, gender, and educational attainment, were important determinants of caregiver QoL.
- Other determinants of caregiver QoL were recipient QoL, relapse after autologous HCT, and ongoing use of immunosuppression after allogeneic HCT.
- Prevalence of depression and sleep disorders appeared to be higher in caregivers than in the general population.
Quality of Life (QoL) of Caregivers of HCT Recipient

Conclusions

- We identified a population of caregivers who may benefit from interventions aimed at improving QoL and health outcomes.

- HCT clinical practice should also consider caregiver well-being
Autologous and Allogeneic HCT survivors have higher risk of chronic health problems compared with siblings
HCT survivors have higher risk of chronic health problems in compared with siblings.

Chronic problems

Relative risk (RR) compared with HCT siblings

<table>
<thead>
<tr>
<th>Chronic problems</th>
<th>RR</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall</td>
<td>1.88</td>
<td>1.39-2.11</td>
</tr>
<tr>
<td>Grade 3-5 Overall</td>
<td>3.52</td>
<td>2.31-5.38</td>
</tr>
</tbody>
</table>

Sun CL et al, Blood 2010
Gaps in the Care of HCT survivors

- Lack of evidence of care delivery models for HCT survivors
- Models of care delivery for HCT survivors vary and depend on many factors.

Phases in the HCT continuum and Main stakeholders

**Evaluation**

**PCP**

**Hematology/Oncology**
- Diagnosis and initial treatment
- Referral to transplant center
- Treatment while awaiting HCT

**Pre-HCT**

- Transplant Center
  - HCT consultation
  - Pre HCT evaluation: medical and psychological
  - Donor search

**Transplantation**

- Transplant Center
  - HCT
  - Early post HCT care
  - Management of specific post HCT complications

**Follow-Up Care**

- Transplant Center
  - All post HCT care by transplant physician and/or LTFU clinic

**Hematology/Oncology**

- Majority of post HCT care with referral back to Transplant Center (LTFU clinic) for specific issues

**PCP**

- General preventive care
- Comorbidities management

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Khera et al. Blood Advances 2017
Opportunities in HCT Survivorship Care

- Patient-centered care coordination in hematopoietic cell transplantation has been reviewed\(^1\)

- ASBMT Practice Guidelines Committee Survey on Long Term Follow-Up Clinics for HCT Survivors has recently been published\(^2\)

\(^1\) Khera, N. et al. *Blood Advances*, 2017

\(^2\) Hashmi, S. et al. *Biol Blood Marrow Transplant*, 2018
Survey on Long-Term Follow-Up Clinics for Hematopoietic Cell Transplant Survivors

- Among 77 programs (38.5%) that responded, 45% indicated that they had a LTFU clinic, however, their care models varied with respect to services provided, specialist availability, type of patients served, and staffing.

- Among 55% of programs without an LTFU clinic, 100% agreed that allogeneic HCT survivors have unique needs separate from graft-versus-host disease and that complications could arise during the transition of care either from pediatric to adult settings or away from the HCT center.

- Obstacles identified to establish HCT survivorship care clinic included lack of expertise, logistics and financial issues.

Hashmi, SK. et al *Biol Blood Marrow Transplant* 2018
Availability of specialty services at centers with already established HCT-LTFU Clinics

- Complementary Alternative Medicine: 94%
- Medical Photography: 91%
- Neurology: 91%
- Dentistry: 84%
- Orthopedics: 84%
- Fertility counseling: 84%
- Psychology: 81%
- Gynecology: 78%
- Nephrology: 78%
- Vaccinations: 75%
- Social worker: 72%
- Cardiology: 72%
- Physical therapy: 59%
- Pulmonology: 59%
- Dermatology: 47%
- Endocrinology: 16%
- Ophthalmology: 6%

Hashmi, SK. et al. *Biol Blood Marrow Transplant* 2018
Results of Survey among HCT Centers with Established LTFU Clinics

<table>
<thead>
<tr>
<th>Statements</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Helpful in providing preventive ASBMT guidelines for HCT survivors (n=34)</td>
<td>3%</td>
<td>6%</td>
<td>6%</td>
<td>32%</td>
<td>53%</td>
</tr>
<tr>
<td>Advance practice practitioners (NP/PA) are essential part of LTFU Clinic (n=34)</td>
<td>3%</td>
<td>3%</td>
<td>6%</td>
<td>18%</td>
<td>70%</td>
</tr>
<tr>
<td>All allogeneic HCT survivors are seen/followed lifelong (n=32)</td>
<td>6%</td>
<td>9%</td>
<td>9%</td>
<td>31%</td>
<td>44%</td>
</tr>
<tr>
<td>All Autologous HCT survivors are seen/followed lifelong (n=32)</td>
<td>16%</td>
<td>31%</td>
<td>25%</td>
<td>16%</td>
<td>12%</td>
</tr>
<tr>
<td>Provides survivorship care plans for longitudinal care and transitional of care of HCT survivors (n=33)</td>
<td>3%</td>
<td>6%</td>
<td>3%</td>
<td>45%</td>
<td>44%</td>
</tr>
</tbody>
</table>

Hashmi, SK. et al  *Biol Blood Marrow Transplant* 2018
Results of this survey hopefully will help policymakers, HCT providers, and institutions in establishing HCT survivorship care models.

Many studies have documented substantial morbidity and mortality from late effects after HCT, thus, delivering recommended screening and expert management of any detected late effects is paramount in HCT survivors.

The American Society of Blood and Marrow Transplantation (ASBMT) Clinical Practice Committee recommends that delivering guidelines-driven screening and expert management of late effects is the goal of first-rate HCT survivorship care.

Hashmi, SK. et al *Biol Blood Marrow Transplant* 2018
Fred Hutch/SCCA
Transplant Timeline - Clinical Care

- **Arrival Conference**
- **HCT Outpatient inpatient**
- **Data Review Conference**
- **HCT**
- **BMT Discharge**
- **LTFU Pre-Discharge Consult**
- **LTFU for Life**
- **TTC**
- **Continuous primary care for complex patients**

- **HCT Consult**
- **Intake**
- **~ 2-6 weeks**
- **Allo ~ 3 months**
- **Auto ~ 1-2 months**

Long-Term Follow-Up:
- Annual Evaluations
- Telemedicine
- GVHD Clinic
- Outcomes Research
- TTC

Fred Hutch/CURES START HERE®
Seattle Cancer Care Alliance
HCT Long-Term Follow Up (LTFU) Survivorship Clinical Care and Research Model

Fred Hutch/ SCCA Model

Research

Clinical Service
Fred Hutch/SCCA LTFU Population in 2014
N = 4,819
### LTFU Patients currently being followed*

<table>
<thead>
<tr>
<th>Diagnoses</th>
<th>&lt; 1</th>
<th>1-4</th>
<th>5-9</th>
<th>10-14</th>
<th>15-19</th>
<th>20-24</th>
<th>25+</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute Leukemias</td>
<td>40</td>
<td>331</td>
<td>274</td>
<td>223</td>
<td>127</td>
<td>118</td>
<td>2889</td>
<td>1402</td>
</tr>
<tr>
<td>Aplastic Anemia</td>
<td>9</td>
<td>39</td>
<td>24</td>
<td>22</td>
<td>12</td>
<td>23</td>
<td>175</td>
<td>304</td>
</tr>
<tr>
<td>MDS</td>
<td>26</td>
<td>124</td>
<td>101</td>
<td>87</td>
<td>69</td>
<td>41</td>
<td>31</td>
<td>479</td>
</tr>
<tr>
<td>CML</td>
<td>3</td>
<td>19</td>
<td>22</td>
<td>60</td>
<td>181</td>
<td>181</td>
<td>278</td>
<td>744</td>
</tr>
<tr>
<td>Lymphoma</td>
<td>44</td>
<td>275</td>
<td>274</td>
<td>188</td>
<td>93</td>
<td>79</td>
<td>67</td>
<td>1020</td>
</tr>
<tr>
<td>Multiple Myeloma</td>
<td>55</td>
<td>299</td>
<td>214</td>
<td>77</td>
<td>33</td>
<td>6</td>
<td>3</td>
<td>687</td>
</tr>
<tr>
<td>CLL</td>
<td>0</td>
<td>7</td>
<td>16</td>
<td>12</td>
<td>10</td>
<td>2</td>
<td>1</td>
<td>48</td>
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<td>Solid Tumors</td>
<td>4</td>
<td>27</td>
<td>23</td>
<td>16</td>
<td>35</td>
<td>49</td>
<td>7</td>
<td>161</td>
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<tr>
<td>Other**</td>
<td>8</td>
<td>81</td>
<td>81</td>
<td>30</td>
<td>29</td>
<td>7</td>
<td>24</td>
<td>260</td>
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<tr>
<td>Multiple diagnoses</td>
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<td>24</td>
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<td>10</td>
<td>6</td>
<td>5</td>
<td>0</td>
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<tr>
<td><strong>Total</strong></td>
<td>189</td>
<td>1226</td>
<td>1069</td>
<td>725</td>
<td>595</td>
<td>511</td>
<td>875</td>
<td>5190</td>
</tr>
</tbody>
</table>

* As of 4/11/18, sent a PRQ since 2014  
** Neoplasms, disorders of hematopoietic or immunologic and metabolic inborn errors
Fred Hutch/SCCA HCT Survivorship Care Model

- Utilizes primary care providers and/or non-transplant hemo/oncologist in the care of HCT survivors but require coordination and collaboration.
Traditional Management Model

Transplant Center

Patient

Information

Advice
Geographic Dispersion of Patients Transplanted at Fred Hutch/SCCA

Allogeneic Transplants by State
7/01/99 - 4/30/02
- 6 to 149 (13)
- 5 to 6 (2)
- 4 to 5 (7)
- 3 to 4 (6)
- 1 to 3 (13)
Collaborative Management Model

Transplant Center

Patient

Referring Physician

Information

Advice

Information
Collaborative Care Model
Fred Hutch / SCCA HCT Survivorship Care Delivery
“Collaborative Care Model”

- **Consultation Service**
  - Pre-discharge Home LTFU Consultation Clinic (*between days 80-100 posttransplant*)
  - Telemedicine consultation to patients and primary care providers
  - Chronic GVHD Clinic
  - Comprehensive annual evaluation

- **Primary care (Transitional Transplant Clinic)**
  - Transitional continuity of care to HCT survivors with severe or lingering complications that requires complex management by experts
  - Alleviate the high burden of care by primary care providers
FHCRC/SCCA HCT Survivors Care Delivery Model

- Multidisciplinary long-term hematopoietic stem cell transplant care model
- Consultation
- Primary care for complex health needs (transitional transplant clinic)
- Collaborative management with non-transplant primary care providers
Reasons for HCT Survivorship Care Delivery Model

Collaborative Management Model

- Geographical dispersion of HCT survivors
- Necessary for long-term follow up continuity of care
- Important for research
Does a dedicated HCT-LTFU Model matter?
Survival after chronic GVHD over time
What may account for difference in survival in patients with high risk CIBMTR chronic GVHD score?

CIBMTR (n=1128)*  Seattle (n=268)†  Toronto (n=108)†

* Arora M, Flowers, Pavletic S. et al BBMT 2015 (Supp. Figure)
†Inamoto, Kim, Flowers et al. BLOOD 2014
What accounts for difference in survival in patients with high risk CIBMTR chronic GVHD score?

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† Inamoto, Kim, Flowers et al. BLOOD 2014

Could a dedicate LTFU service account for better survival?
Conclusions

- Increased interest in HCT survivorship care in the past 5 years

- Future studies are needed to evaluate HCT survivorship care delivery models

- Severity of chronic GVHD needs to be considered when evaluating HCT survivorship care models

- Collaboration between the transplant center and patient PCP are important for care of HCT survivors
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