Housing and Caregiver Challenges: A Study of HCT Centers

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Study conducted by CIBMTR Health Services Research Program in partnership with Be the Match Patient and Health Professional Services

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Learning Objectives

At the conclusion of this session, attendees will be able to:

• Describe the requirements for housing near transplant centers
• Describe transplant requirements for a caregiver
• Identify three of the top HCT housing and caregiver barriers
• Identify current practices in place to address housing and caregiver barriers
System Capacity Initiative

- System Capacity Initiative
  - Assess health system’s ability to accommodate expected increase in transplants
  - Planning for future growth
  - Benchmarking
  - Collaboration between NMDP and ASBMT
Methods

- Mixed-methods study
  - 3 focus groups of HCT social workers (N=15)
    - 2 adult, 1 pediatric
    - Various US geographic areas and center sizes
  - Held via teleconference
  - 1.5 hours in length
  - $50 gift card incentive
  - Recoded and transcribed for analysis by two independent reviewers
Methods (continued)

• Survey
  - Web-based 45-item
  - Directed towards primary BMT social worker at each U.S. center
  - Provided $25 incentive
    • Administered between August and December 2013
      - 2 reminder emails
      - 1 follow-up phone call with follow-up email
      - 1 final reminder email
## Survey Domains

### TC Requirements

**Housing**
- Distance to TC
- Time required
- Percent of patients who relocate
- Hours dedicated to housing

**Caregiver Availability**
- Caregiver requirements
- Percent of patients who don’t go to transplant
- Hours dedicated to caregiver availability

### Barriers

**Housing**
- Frequency of patient experience
- Most common (top three barriers)

**Caregiver Availability**
- Frequency of patient experience
- Most common (top three barriers)

### Solutions

**Housing**
- Temporary housing
- Resources/programs
- Housing assistance funds
- Solutions in place
- Ideal solutions

**Caregiver Availability**
- Caregiver contract
- Back-up caregiver plans
- Resources/programs
- Solutions
- Ideal solutions
Results
## Center and respondent characteristics

<table>
<thead>
<tr>
<th></th>
<th>Adult (N=46)</th>
<th>Pediatric (N=22)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>2012 Annual Volume (%(n))</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>25.0% (12)</td>
<td>54.5% (12)</td>
</tr>
<tr>
<td>Medium</td>
<td>33.3% (16)</td>
<td>27.3% (6)</td>
</tr>
<tr>
<td>High</td>
<td>41.7% (20)</td>
<td>18.2% (4)</td>
</tr>
<tr>
<td><strong>Region (%(n))</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Northeast</td>
<td>15.6% (7)</td>
<td>30.0% (6)</td>
</tr>
<tr>
<td>Midwest</td>
<td>33.3% (15)</td>
<td>25.0% (5)</td>
</tr>
<tr>
<td>South</td>
<td>31.1% (14)</td>
<td>30.0% (6)</td>
</tr>
<tr>
<td>West</td>
<td>20.0% (9)</td>
<td>15.0% (3)</td>
</tr>
<tr>
<td><strong>Social Work FTES  (median (range))</strong></td>
<td>1.0 (0.2-4.8)</td>
<td>1.0 (0.5-5.0)</td>
</tr>
<tr>
<td><strong>Average hours per week spent on housing (median (range))</strong></td>
<td>5 (1-32)</td>
<td>3 (0-20)</td>
</tr>
<tr>
<td><strong>Average hours per week identifying a caregiver (median (range))</strong></td>
<td>4 (0-25)</td>
<td>3 (0-8)</td>
</tr>
</tbody>
</table>

Adult TC volume: Low: ≤70 transplants/year; Medium: 71-150 transplants/year; High: >150 transplants /year.
Pediatric TC volume: Low: ≤50 transplants/year; Medium: 51-150 transplants/year; High: >150 transplants /year.
Housing
Housing

a. “Housing is not an issue.”

b. “The majority of our patients that require housing are on Medicaid and a fixed income. They can barely afford the gas to come back and forth to appointments, let alone afford housing in our area for up to three months.”

c. “Our center is located in an expensive area which increases difficulty in obtaining housing.”

d. “Nearly all of our patients are traveling a distance from home.”
How close to your TC are your patients required to stay?

<table>
<thead>
<tr>
<th>Program Type</th>
<th>Adult (median (range))</th>
<th>Pediatric (median (range))</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autologous</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Miles</td>
<td>45 (0-180)</td>
<td>30 (20-100)</td>
</tr>
<tr>
<td>Minutes</td>
<td>45 (10-180)</td>
<td>30 (20-60)</td>
</tr>
<tr>
<td>Allogeneic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Miles</td>
<td>30 (0-90)</td>
<td>30 (8-100)</td>
</tr>
<tr>
<td>Minutes</td>
<td>33.75 (10-120)</td>
<td>30 (20-90)</td>
</tr>
</tbody>
</table>
Period of time most patients are required to stay close to the TC (Adult)

- 38% for 30 days
- 57% for 100 days
- 2% for 6 months

Based on clinical condition only:
- 13% for Autologous
- 16% for Allogeneic

Other:
- 22% for Autologous
- 2% for Allogeneic

HCT in 2020 System Capacity Initiative
Period of time most patients are required to stay close to the TC (Pediatric)

Based on clinical condition only

Autologous (N=16) Allogeneic (N=17)

- 30 days: 6% (6%), 29% (29%)
- 100 days: 38% (41%), 13% (6%)
- 6 months: 0% (0%), 18% (6%)
- No requirement: 13% (6%)
- Based on clinical condition only: 44% (18%)
- Other: 0% (0%), 6% (6%)

HCT in 2020
System Capacity Initiative
### Percent of adult patients required to relocate (N=45)

<table>
<thead>
<tr>
<th>% of patients required to relocate</th>
<th>Number of TCs</th>
</tr>
</thead>
<tbody>
<tr>
<td>0%</td>
<td>3 TCs</td>
</tr>
<tr>
<td>1-25%</td>
<td>17 TCs</td>
</tr>
<tr>
<td>26-50%</td>
<td>13 TCs</td>
</tr>
<tr>
<td>51-75%</td>
<td>7 TCs</td>
</tr>
<tr>
<td>76-100%</td>
<td>5 TCs</td>
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</tbody>
</table>
Percent of pediatric patients required to relocate (N=20)

<table>
<thead>
<tr>
<th>% of patients required to relocate</th>
<th>Number of TCs</th>
</tr>
</thead>
<tbody>
<tr>
<td>0%</td>
<td>2 TCs</td>
</tr>
<tr>
<td>1-25%</td>
<td>4 TCs</td>
</tr>
<tr>
<td>26-50%</td>
<td>6 TCs</td>
</tr>
<tr>
<td>51-75%</td>
<td>2 TCs</td>
</tr>
<tr>
<td>76-100%</td>
<td>6 TCs</td>
</tr>
</tbody>
</table>
Temporary housing barriers (rank score)

- Cost/affordability of housing: 26.6
- Lack of insurance benefits for lodging: 11.6
- Housing options full/long waiting lists: 8.3
- Lack of housing options available: 8.0
- Other: 4.7
- Restrictions placed by housing provider: 2.3
- Restriction on persons who can stay in housing: 2.3
- Eligibility for housing: 1.7
- Age of patient: 0.3

Adult vs. Pediatric
Types of housing available

- Discounted hotel rates
  - Adult (N=45): 80%
  - Pediatric (N=17): 71%

- Local hotel/motel
  - Adult (N=45): 58%
  - Pediatric (N=17): 41%

- Housing owned in collaboration with another entity
  - Adult (N=45): 36%
  - Pediatric (N=17): 24%

- Hope Lodge
  - Adult (N=45): 31%
  - Pediatric (N=17): 24%

- Other
  - Adult (N=45): 29%
  - Pediatric (N=17): 24%

- Discounted apartments
  - Adult (N=45): 24%
  - Pediatric (N=17): 12%

- Housing fully owned and operated by the hospital
  - Adult (N=45): 16%
  - Pediatric (N=17): 12%

- Ronald McDonald House
  - Adult (N=45): 13%
  - Pediatric (N=17): 82%
Programs/resources offered to assist patients with finding housing

- Print materials/resources: 84% (Adult), 88% (Pediatric)
- Housing/accommodations department within center: 33% (Adult), 35% (Pediatric)
- Waiting lists: 20% (Adult), 24% (Pediatric)
- Website: 20% (Adult), 12% (Pediatric)
- Other: 20% (Adult), 29% (Pediatric)
- None: 2% (Adult), 2% (Pediatric)
### TC housing assistance funds

<table>
<thead>
<tr>
<th>TC provides housing assistance funds</th>
<th>Adult (N=45)</th>
<th>Pediatric (N=17)</th>
</tr>
</thead>
<tbody>
<tr>
<td>40% (18)</td>
<td></td>
<td>10% (2)</td>
</tr>
</tbody>
</table>

### Types of assistance

<table>
<thead>
<tr>
<th>Types of assistance</th>
<th>Adult (N=45)</th>
<th>Pediatric (N=17)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assistance for hotels</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rent for local apartments on a sliding fee scale</td>
<td></td>
<td></td>
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<tr>
<td>Financial assistance program</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grant funding</td>
<td></td>
<td></td>
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<tr>
<td>Donation fund</td>
<td></td>
<td></td>
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<tr>
<td>Assistance with nightly costs for Ronald McDonald House stay</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Connections to a fund that will assist with expenses at home</td>
<td></td>
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</tbody>
</table>

### Requirements to receive housing assistance

<table>
<thead>
<tr>
<th>Requirements to receive housing assistance</th>
<th>Adult (N=45)</th>
<th>Pediatric (N=17)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insurance status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Income level</td>
<td></td>
<td></td>
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<tr>
<td>Specific diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nothing specified</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Housing solutions in place (Adult)

- Financial
- Foundation partnerships
- Apartments
Housing solutions in place (Pediatric)

- Family resource specialist position created
- Houses with isolation rooms
- Exceptions to requirements
Ideal housing solutions (Adult)

Process
• Put names on wait list early in process
• Reduce mileage requirements

Resources
• BMT specific housing for patients/families
  – Transplant house similar to Hope Lodge
  – On campus Hope Lodge
  – Lodging within hospital
• Housing offered for free for the first 100 days, then a reduced rate
• Insurance to cover lodging costs
Ideal housing solutions (Pediatric)

**Process**
- Don’t require background checks
- Waive mileage requirement for Ronald McDonald House
- Hospitality Coordinator that could assist families with housing (not just for BMT)

**Resources**
- Additional apartments
  - Hospital-run hotel
  - A hospital owned lodging alternative
  - Housing within the hospital
- Financial assistance
- Easier reimbursement for families with private insurance to find lodging
Caregiver Availability

“Making sure a defined caregiver plan is available and in place is a significant requirement.”
– Survey respondent (adult)

“I do not face caregiver availability as much in pediatrics, but it does happen. Caregivers/families have to sacrifice a lot and usually they just do whatever it takes. We help them with problem solving.”
– Survey respondent (pediatric)
Caregiver Availability

a. “Being in a rural area, and having patients from a variety of communities, including rural, urban, and suburban, makes this a wide spread problem.”

b. “Thankfully, we have not had this problem occur in the last year.”

c. “We consider the caregiver to be critical to the transplant and we try to make them feel the importance of their role. We pledge to take care of the caregiver, too, and see patient/family as a unit.”
Caregiver required for a patient to proceed to transplant

- The majority of TCs (adult-89%; pediatric-89%) require a caregiver to proceed to transplant
- Centers without a requirement strongly recommend a caregiver

“As a social worker I wish they would require one because patients fare better with that type of support.”
Caregiver requirements (Adult)

- Autologous:
  - Requirements range from 10 days to up to 50 days post-HCT
  - Limited occasions no caregiver— but requires patient to remain inpatient

- Allogeneic:
  - Requirements range from a couple weeks to 100 days post-HCT

“There is no official requirement, but we strongly encourage identification of one caregiver who will be primary, at bedside, learning care to transition home.”
Caregiver requirements (Pediatric)

- 24/7 supervision
  - All pediatric patients must have a caregiver at all times
- Parents encouraged to be present or have a family member or friend with the patient
Barriers to having a caregiver (rank score)

- Patient has limited social ties: 22.3
- Caregiver's loss of income: 20.9
- Caregiver cannot commit to the required time period: 13.6
- Patient independence: 10.3
- Caregiver's employer does not provide PTO/LOA: 6.3
- Caregiver has other family members to take care of: 6.3
- Caregiver's loss of insurance benefits: 4.0
- No transportation available for caregiver: 2.0
- Caregiver capability to travel to transplant center: 1.7
- Cost of hiring a caregiver: 1.3
- Health care needs of caregiver: 1.0
- No housing available for caregiver: 0.7
- Other, please describe: 0.3

Adult
Pediatric
<table>
<thead>
<tr>
<th></th>
<th>Adult</th>
<th>Pediatric</th>
</tr>
</thead>
<tbody>
<tr>
<td>Signed contract</td>
<td>32%</td>
<td>6%</td>
</tr>
<tr>
<td>Guidelines on roles/responsibilities but not a signed contract</td>
<td>15%</td>
<td>25%</td>
</tr>
<tr>
<td>No contract</td>
<td>53%</td>
<td>69%</td>
</tr>
</tbody>
</table>
What happens if a caregiver plan falls through after the patient has received a transplant? (Adult)
What happens if a caregiver plan falls through after the patient has received a transplant? (Adult)

- Work with patient/family (n=30)
- Medical Facility (n=21)
  - Delay discharge
  - Readmit
  - Nursing facility (SNF, CBRF)
- Rarely happens (n=5)
What happens if a caregiver plan falls through after the patient has received a transplant? (Adult- continued)

- Community resources (n=4)
  - “Sometimes we can engage community services such as VNA (Visiting Nurse Association) or other resources to supplement. This is always a difficult situation.”

- Hire caregiver (n=3)
  - “It is a last resort to have patients hire caregivers.”

- Have back-up plan in place (n=2)
What happens if a caregiver plan falls through after the patient has received a transplant? (Pediatric)
What happens if a caregiver plan falls through after the patient has received a transplant? (Pediatric)

- Identify alternative caregiver options (n=12)
- Child Protective Services (n=9)
- Extend hospitalization (n=2)
- Rarely happens (n=1)
- Back-up plan in place (n=1)
Programs/resources offered to assist patients with finding a caregiver

- Allowed to have multiple caregivers
- Hire a caregiver using private funds
- Hire a caregiver using public/government insurance
- Hire a caregiver using private insurance benefits
- Other
- Community volunteers

Adult (N=45) vs Pediatric (N=16)
Caregiver Availability Solutions
(Adult)

- Multiple caregivers
- Parking cost assistance
- Lifeline/Medalert buttons
- Help with FMLA
- Assisted living partnership
- Employment board at local nursing school

Allison, caregiver to her husband Sean
Caregiver availability solutions (Pediatric)

- Financial assistance
- Parking cost assistance

David Sr., caregiver to his son, David Jr.
Ideal caregiver availability solutions
(Adult)

Process
• Caregiver contract (to formalize responsibilities)
• Have a requirement that a caregiver is needed to proceed to transplant
• Better education for referring physician’s office
• More education and resources for caregivers

Resources
• Financial assistance
  – Child care costs
  – Respite care
• Hospital owned facility with professional caregivers on staff
• FMLA coverage to include extended family or friends
• Caregivers be given special accommodations from their employer
Ideal caregiver availability solutions (Pediatric)

**Process**
- Formalized training
- Distance criteria for staying at Ronald McDonald House would be waived
- Establish a primary and a back-up caregiver
- Trained volunteers for BMT unit

**Resources**
- Increased support network
- Financial assistance
  - Child care costs for siblings
  - Respite care
  - Paid travel expenses for caregiver who does not qualify for Ronald McDonald House
  - Inexpensive or free meal tickets for caregivers
Conclusions

• Housing is often a burden to patients, caregivers and families
  – Requirements to stay near a TC vary in time and distance, as well as in time required to stay near the TC after transplant

• Caregiver requirements vary by TC, and by patient characteristics (e.g., age, complications)

• Some TCs have solutions in place that other TCs can learn from and implement in their TCs
Protocol Team

- Kent Walters, MBA, CMPE
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