



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	Barriers	Solutions
Housing <ul style="list-style-type: none">- Distance to TC- Time required- Percent of patients who relocate- Hours dedicated to housing	Housing <ul style="list-style-type: none">- Frequency of patient experience- Most common (top three barriers)	Housing <ul style="list-style-type: none">- Temporary housing- Resources/programs- Housing assistance funds- Solutions in place- Ideal solutions
Caregiver Availability <ul style="list-style-type: none">- Caregiver requirements- Percent of patients who don't go to transplant- Hours dedicated to caregiver availability	Caregiver Availability <ul style="list-style-type: none">- Frequency of patient experience- Most common (top three barriers)	Caregiver Availability <ul style="list-style-type: none">- Caregiver contract- Back-up caregiver plans- Resources/programs- Solutions- Ideal solutions

Results



Center and respondent characteristics

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

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



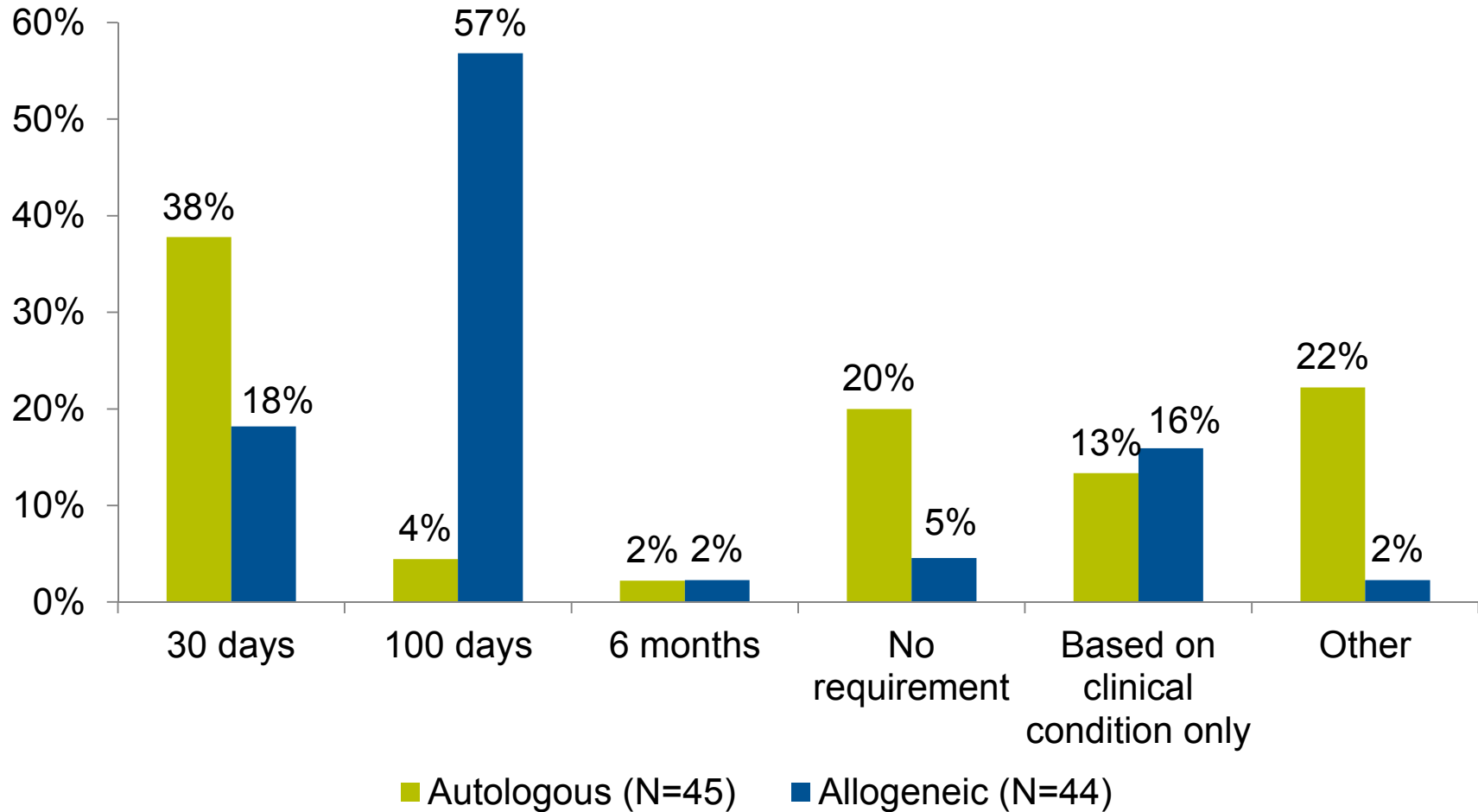
Housing

- 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."

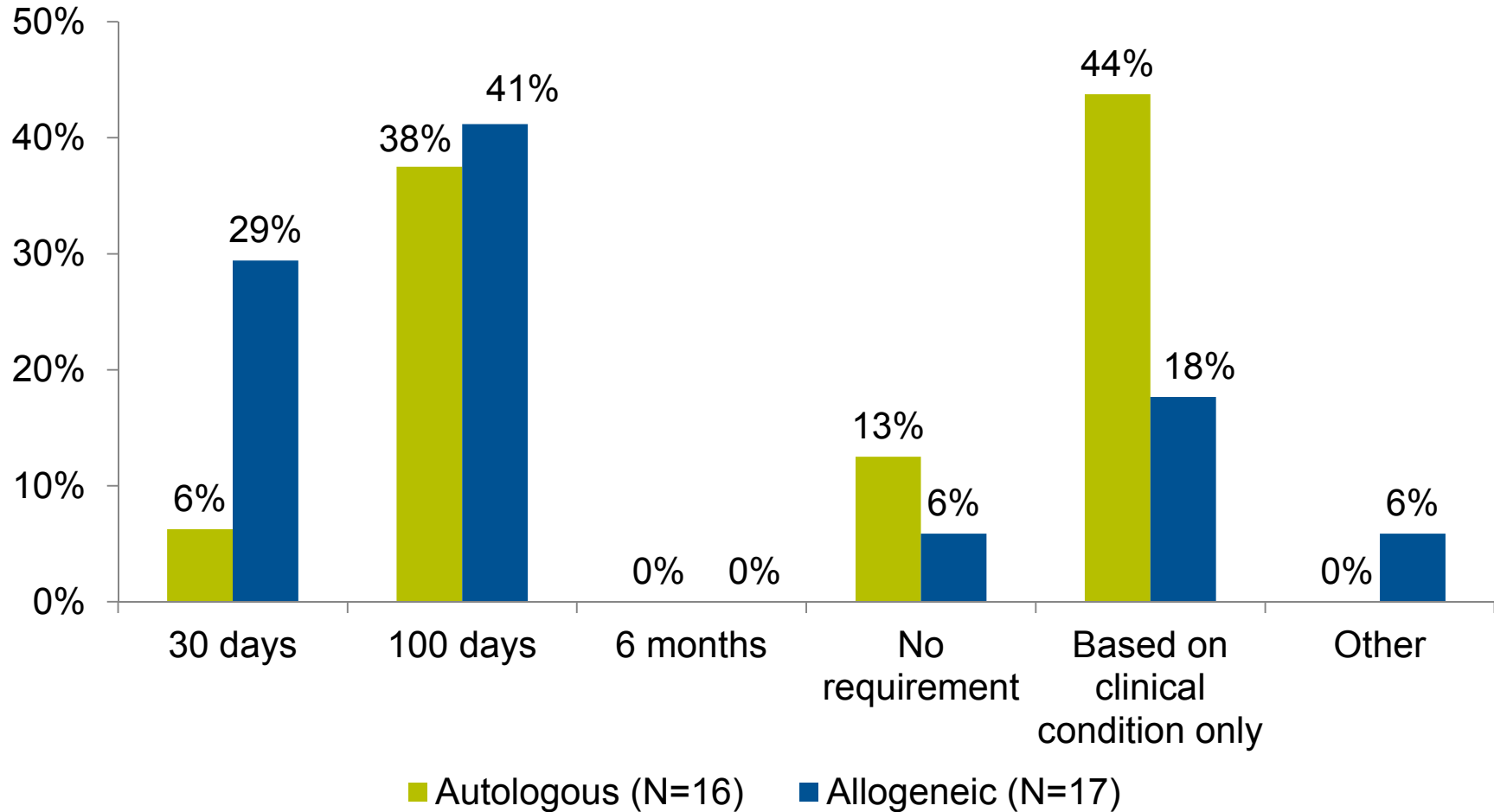
How close to your TC are your patients required to stay?

Program Type		Adult (median (range))	Pediatric (median (range))
Autologous			
 Miles		45 (0-180)	30 (20-100)
 Minutes		45 (10-180)	30 (20-60)
Allogeneic			
 Miles		30 (0-90)	30 (8-100)
 Minutes		33.75 (10-120)	30 (20-90)

Period of time most patients are required to stay close to the TC (Adult)



Period of time most patients are required to stay close to the TC (Pediatric)



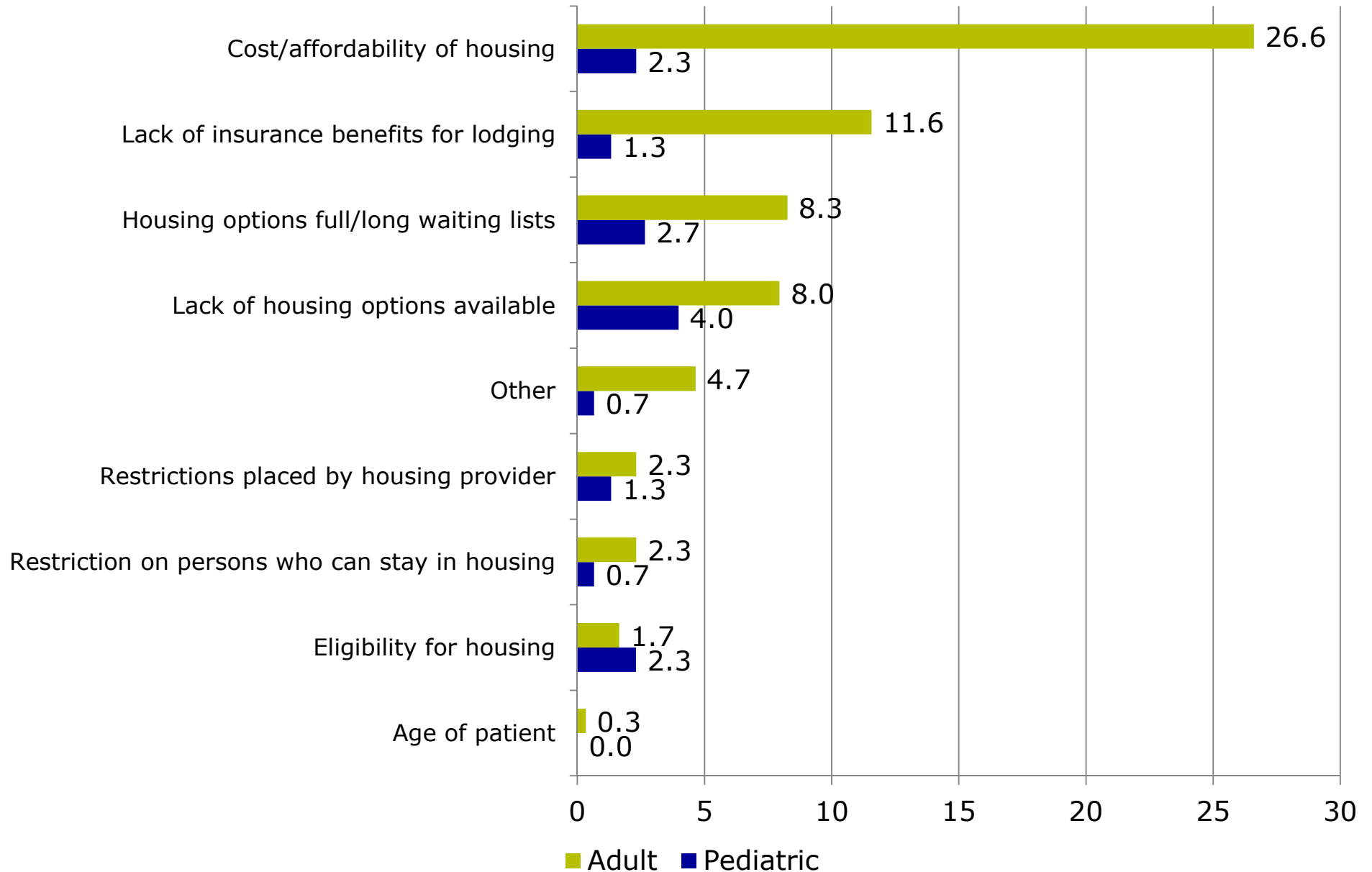
Percent of adult patients required to relocate (N=45)

% of patients required to relocate	Number of TCs
0%	3 TCs
1-25%	17 TCs
26-50%	13 TCs
51-75%	7 TCs
76-100%	5 TCs

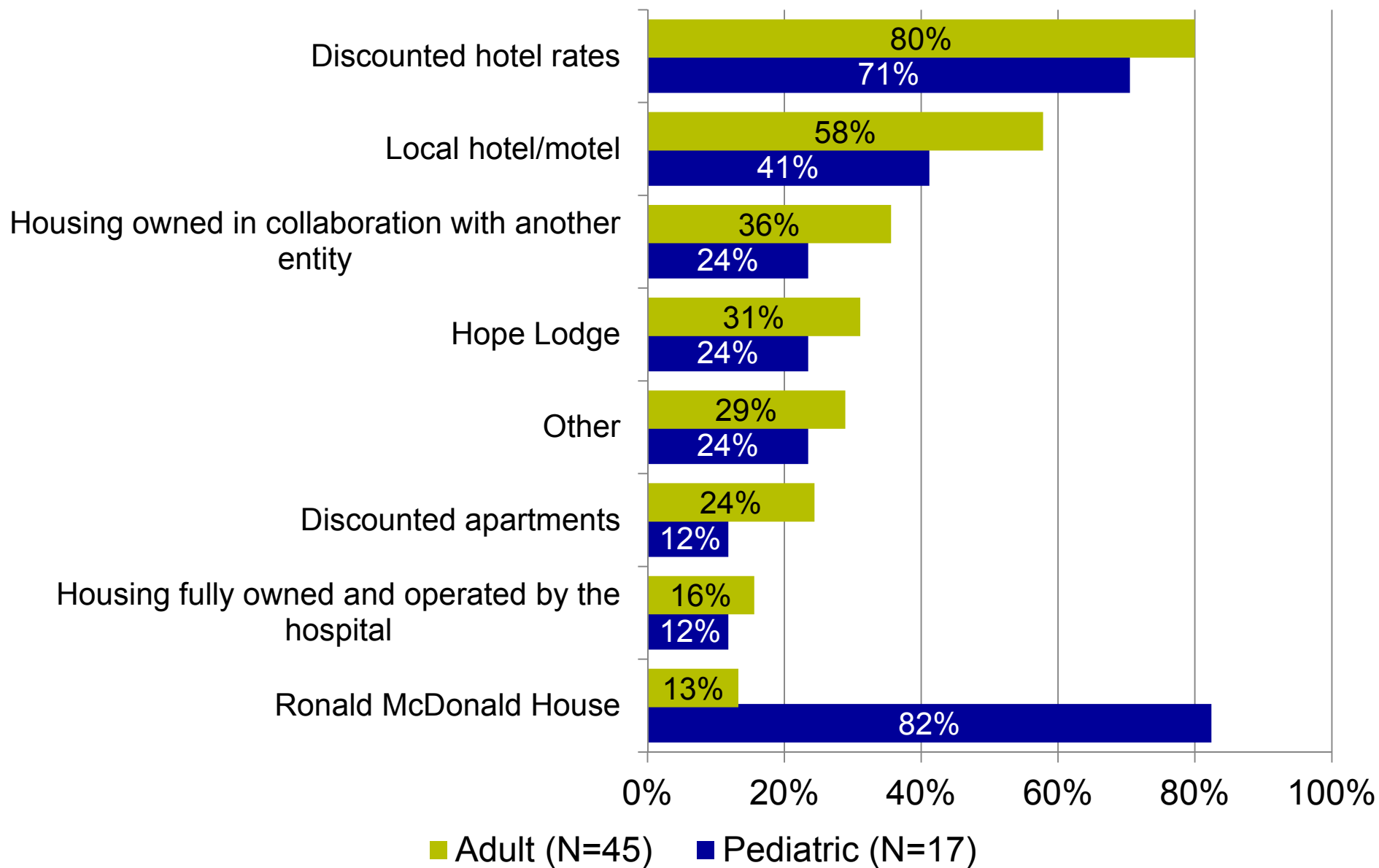
Percent of pediatric patients required to relocate (N=20)

% of patients required to relocate	Number of TCs
0%	2 TCs
1-25%	4 TCs
26-50%	6 TCs
51-75%	2 TCs
76-100%	6 TCs

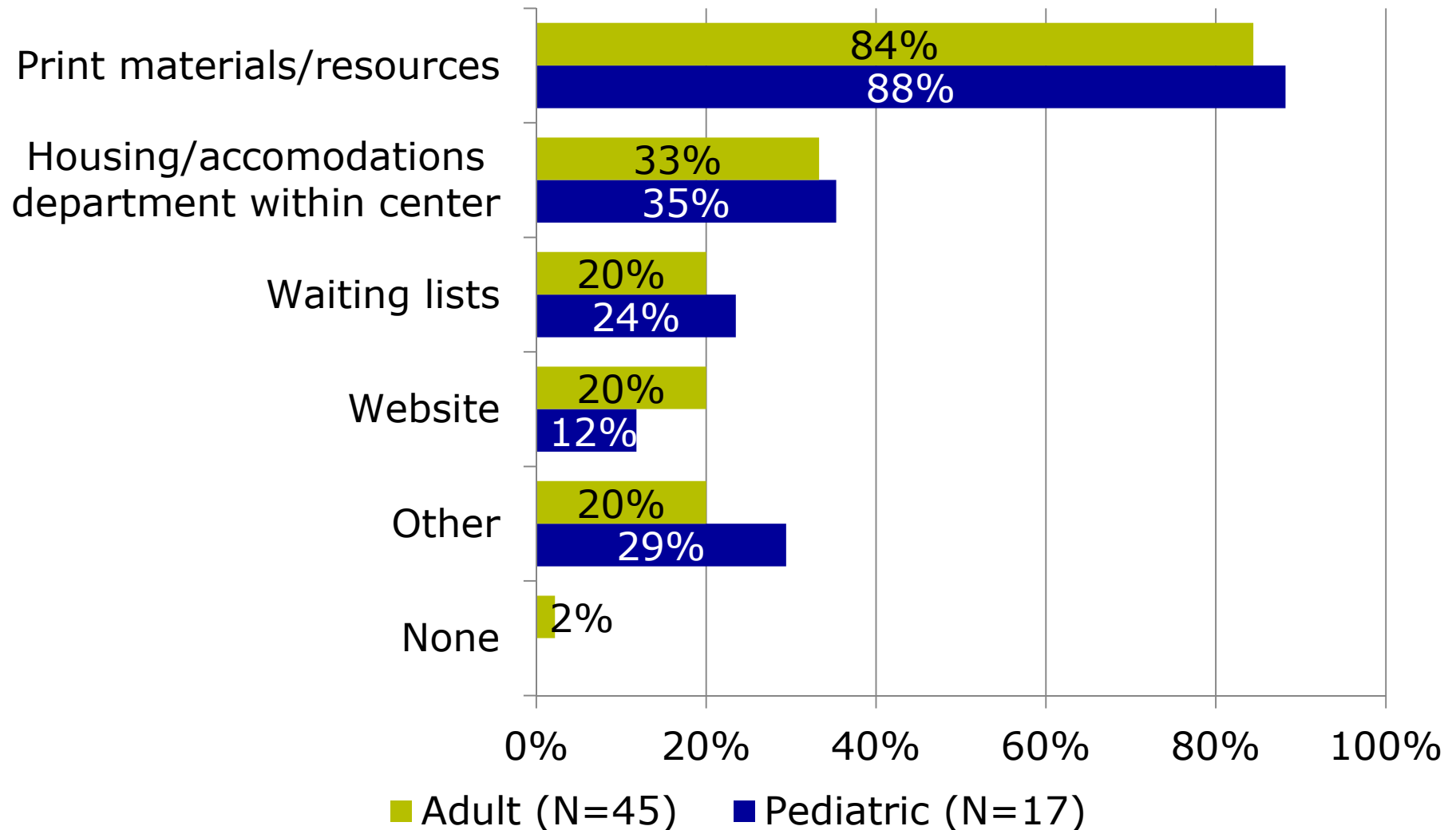
Temporary housing barriers (rank score)



Types of housing available



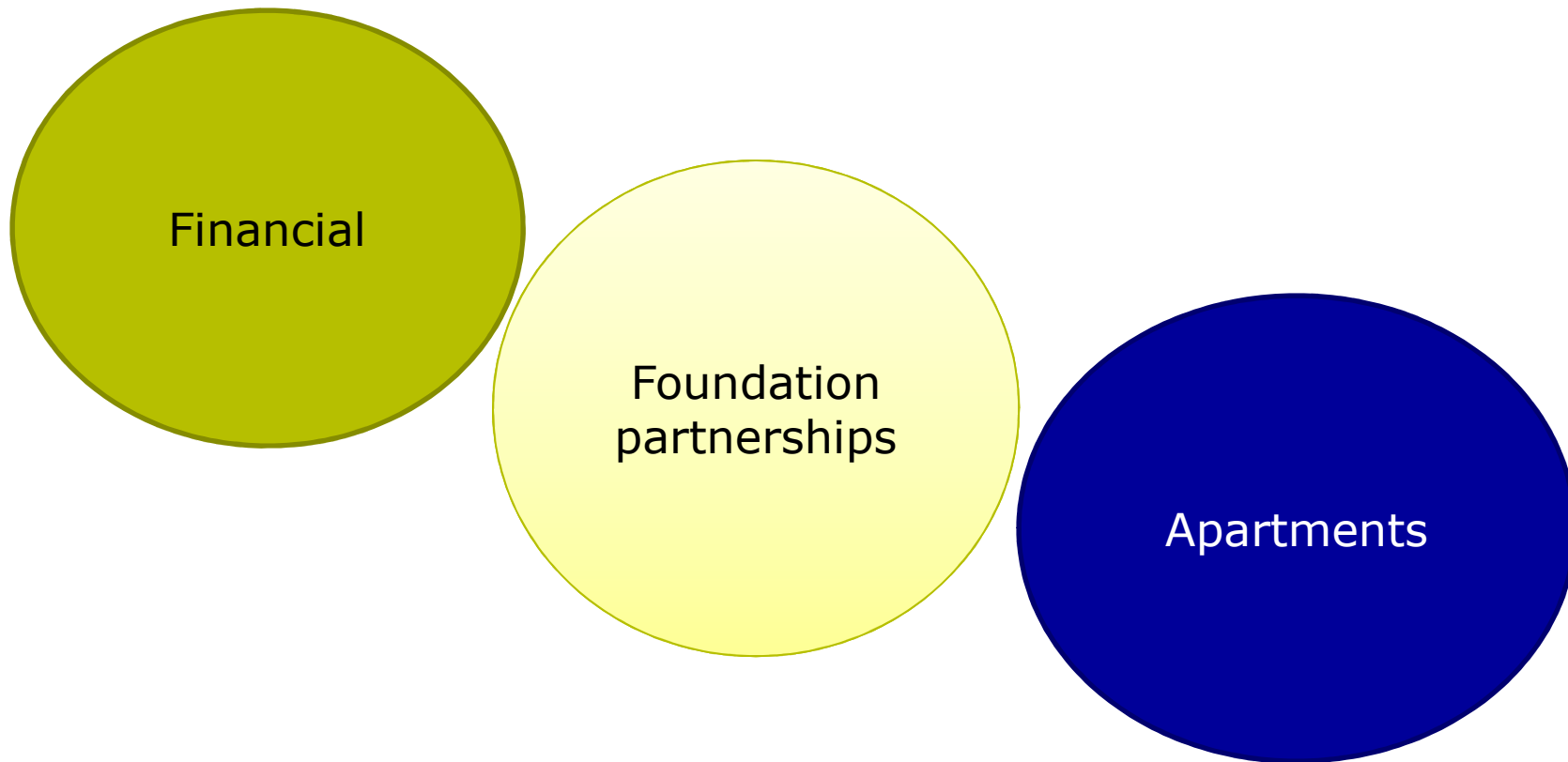
Programs/resources offered to assist patients with finding housing



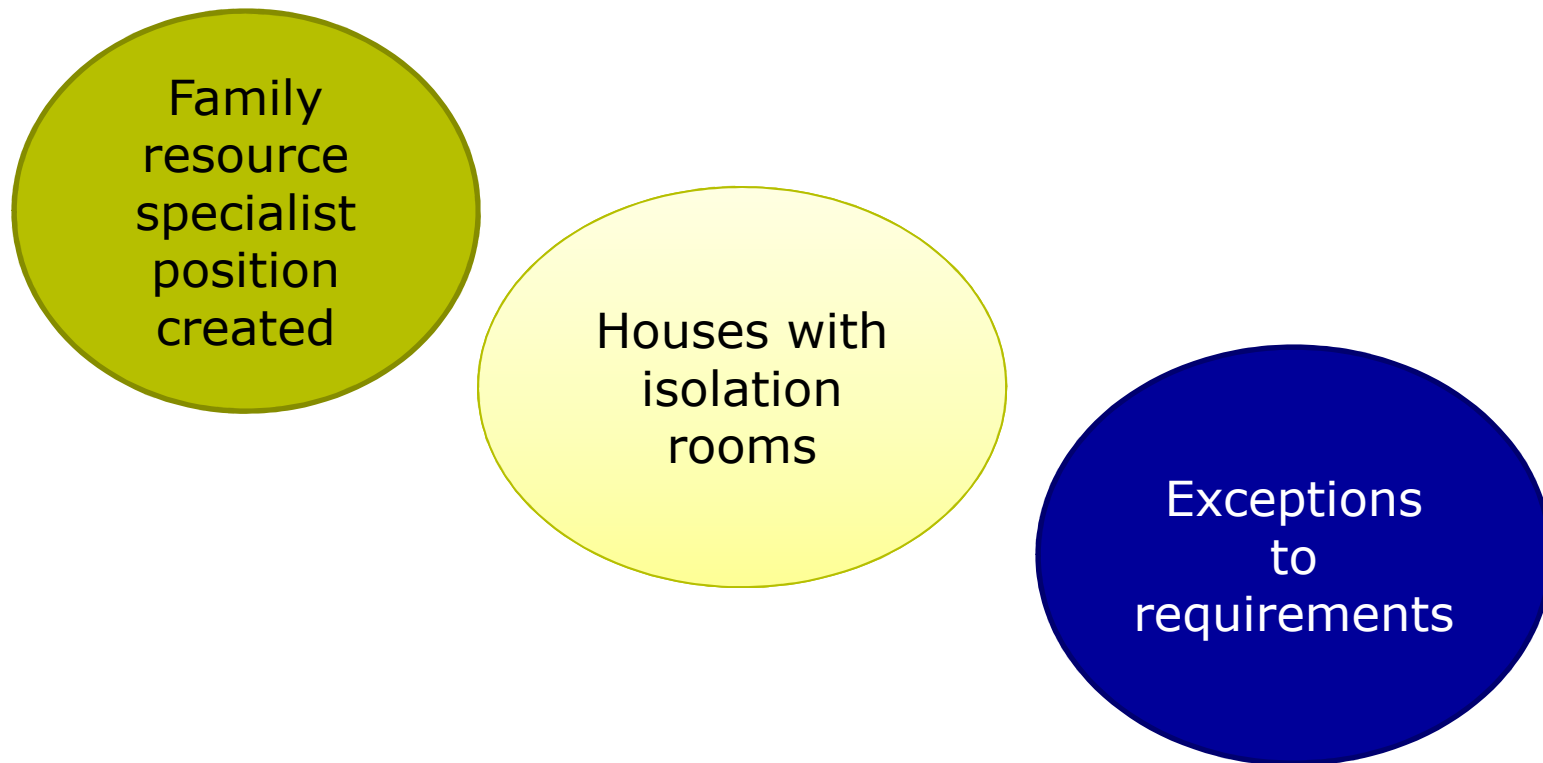
TC housing assistance funds

	Adult (N=45)	Pediatric (N=17)
TC provides housing assistance funds	40% (18)	10% (2)
Types of assistance	<ul style="list-style-type: none"> • Assistance for hotels • Rent for local apartments on a sliding fee scale • Financial assistance program • Grant funding • Donation fund 	<ul style="list-style-type: none"> • Assistance with nightly costs for Ronald McDonald House stay • Connections to a fund that will assist with expenses at home
Requirements to receive housing assistance	<ul style="list-style-type: none"> • Insurance status • Income level • Specific diagnosis 	<ul style="list-style-type: none"> • Nothing specified

Housing solutions in place (Adult)



Housing solutions in place (Pediatric)



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)

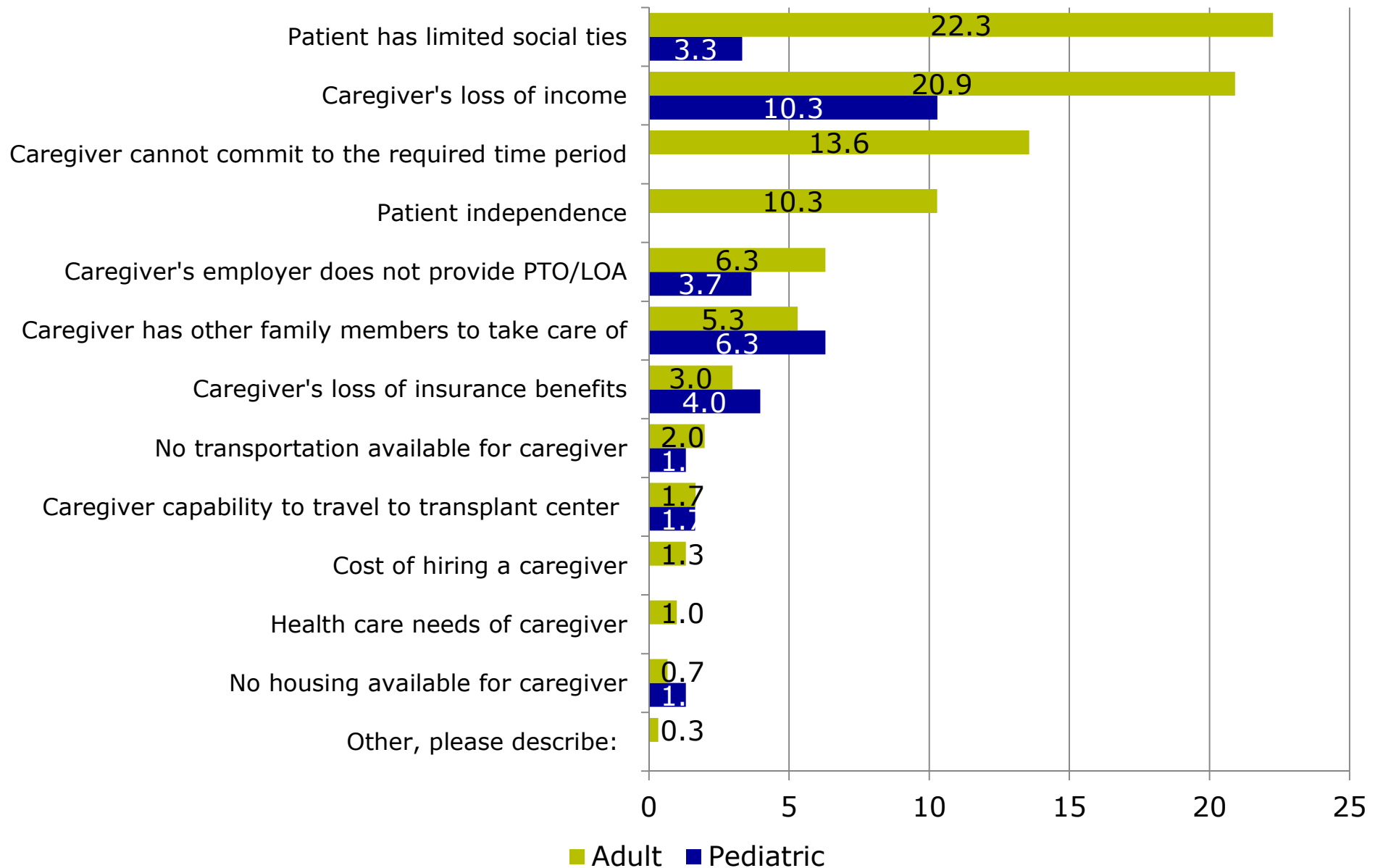
- Autologous:
 - Requirements range from 10 days to up to 50 days post-HCT
 - Limited occasions no caregiver- but requires patient to remain inpatient
- Allogeneic:
 - Requirements range from a couple weeks to 100 days post-HCT

“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)



Does your TC use a caregiver contract?

	Adult	Pediatric
Signed contract	32%	6%
Guidelines on roles/responsibilities but not a signed contract	15%	25%
No contract	53%	69%

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)

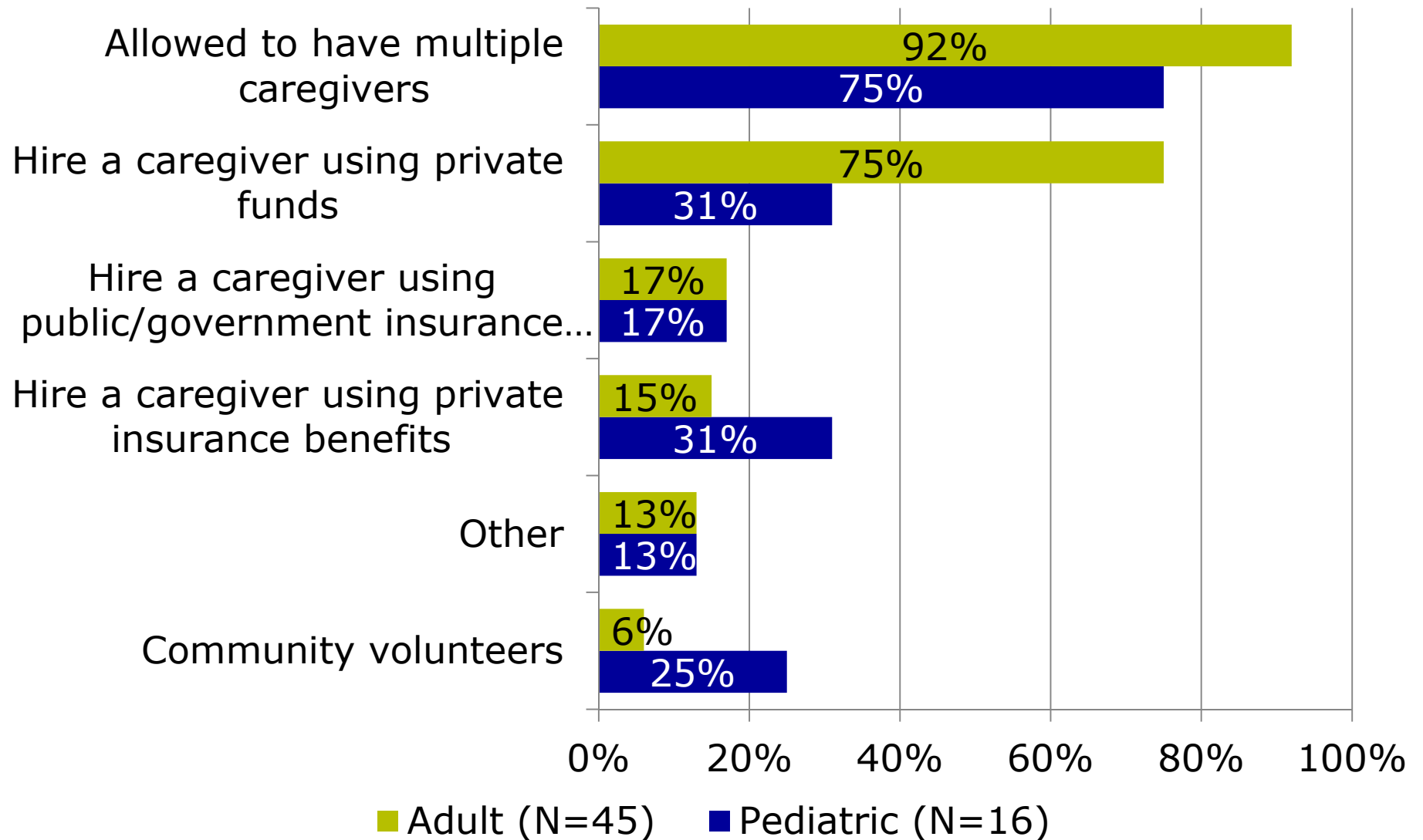
What happens if a caregiver plan falls through after the patient has received a transplant? (Pediatric)



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



Caregiver Availability Solutions (Adult)

Multiple caregivers

Parking cost assistance

Lifeline/Medalert buttons



Allison, caregiver to her husband Sean

Help with FMLA

Employment board at local nursing school

Assisted living partnership

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

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