Hospital Discharge Following Transplantation: There’s No Place Like Home

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NATCO President

Vanderbilt Transplant Nurse Practitioner Symposium
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Research Funding: Sigma Theta Tau International, Children’s Research Institute and NIH NINR K23
Introduction

- Healthcare providers
  - Safe and quality care to patients and families
- Institute of Medicine
  - Highlight gap between evidence based practice and current health care delivery
  - Poor quality discharge transitions are evidence of this gap
- National Coalition on Care Coordination
  - Enhance the discharge process
- Vulnerable populations
Hospital Discharge and Readmission

- Hospital quality measure at pediatric hospitals
  - Focus on reducing 30-day readmission rate
  - Small percentage of children account for the majority of hospital admission and costs
- Medical complexity
- Research is indicated
  - Determine healthcare team role
    - Discharge transition experience
    - Chronic illness care
- Opportunity to improve transition process and align with national agenda
Discharge Transition

- Discharge Education
  - Clinical process with important outcomes
  - Evolved over time
    - ‘Talked to’ with use of a checklist
    - ‘Talk with’ by using Teach-back
    - Engage families as they continue recovery at home

- Parents who are not prepared for discharge have more difficulty managing their child’s care needs at home

- Parents report feeling:
  - Overwhelmed
  - Underprepared
Research: Pediatric Transplant Recipients

At risk for high readmission rate and can benefit from a better understanding of the discharge transition process
Conceptual Framework

**Discharge Readiness: An Integrative Review Focusing on Discharge Following Pediatric Hospitalization**

Stacey M. Lerret, PhD(c), RN, CPNP

**Purpose:** This review aims to identify factors associated with parental discharge readiness following pediatric hospitalization, with focus applicability to solid organ transplant patients.

**Design and Methods:** Thirty-eight publications, including research and clinical.

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**Quality of Care Coordination**

**Quality of Discharge Teaching**

**Readiness for Hospital Discharge**

- **Parent Coping**
- **Family Impact**
- **Adherence**
- **Utilization of Healthcare Resources**

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**Medical College of Wisconsin**

**Children's Hospital of Wisconsin**
Transition from Hospital to Home

Investigate factors associated with the transition from hospital to home for parents of pediatric solid organ transplant recipients

Funded by Sigma Theta Tau International and Pediatric Nursing Research Consortium
Methods

- Methods
  - √ Quantitative
  - √ Qualitative
- Setting
  - √ 3 pediatric transplant centers
- Participant Selection
  - √ Parent of transplant recipient
  - √ Heart, Kidney or Liver
Methods

Inclusion Criteria

• Parents of children that received a transplant and being discharged to home
• English speaking
• ≥ 18 years of age
• Telephone access

Exclusion Criteria

• Significant communication or cognitive impairment
• History of transition home after transplant
• Extreme co-morbid conditions
Study Procedure

- Two data collection time points
  - 1. Discharge Survey
    - Day of hospital discharge
  - 2. Post-discharge Survey
    - 3 weeks following hospital discharge
    - Telephone interview
- Participant appreciation
- $10 for each time point
Results: Sample

37 parents
(Primary Caregiver)

Hospital A = 18
Hospital B = 18
Hospital C = 1

Heart = 18
Kidney = 10
Liver = 9
# Results: Demographics

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Parent Gender</strong></td>
<td>Female = 27 (73%)&lt;br&gt;Male = 10 (27%)</td>
</tr>
<tr>
<td><strong>Parent Age</strong></td>
<td>Mean 38.9 years (s.d. 9.9)&lt;br&gt;Range 22-55</td>
</tr>
<tr>
<td><strong>Parent and Child Race</strong></td>
<td>White = 25 (67.6%)&lt;br&gt;Black = 7 (18.9%)&lt;br&gt;Did not answer = 3 (8.1%)&lt;br&gt;Asian = 1 (2.7%)&lt;br&gt;Alaskan or American Indian = 1 (2.7%)</td>
</tr>
<tr>
<td><strong>Parent Marital Status</strong></td>
<td>Married = 28 (75.7%)&lt;br&gt;Single = 6 (16.2%)&lt;br&gt;Divorced = 3 (8.1%)</td>
</tr>
<tr>
<td><strong>Child Gender</strong></td>
<td>Male = 21 (56.8%)&lt;br&gt;Female = 16 (43.2%)</td>
</tr>
<tr>
<td><strong>Child Age</strong></td>
<td>Mean 95.2 months or 7.9 years&lt;br&gt;Range 3 months to 18 years</td>
</tr>
</tbody>
</table>
### Results: Hospitalization and Post Discharge

#### Hospitalization Characteristics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inpatient number of days</td>
<td>Mean 19.5 (s.d. 15.5)</td>
</tr>
<tr>
<td>Unplanned return to the OR</td>
<td>7 (18.9%)</td>
</tr>
<tr>
<td>Hospitalization infections</td>
<td>7 (18.9%) individual patients</td>
</tr>
<tr>
<td>Hospitalization rejection</td>
<td>5 (13.5%) individual patients</td>
</tr>
</tbody>
</table>

#### Post Discharge Characteristics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of medications at discharge</td>
<td>Mean 11.4 (s.d. 3.3), Range 5-18</td>
</tr>
<tr>
<td>Discharge with enteral tube feeding</td>
<td>12 (32.4%)</td>
</tr>
<tr>
<td>Discharge with wound care</td>
<td>11 (29.7%)</td>
</tr>
<tr>
<td>Discharge with central line care</td>
<td>7 (18.9%)</td>
</tr>
<tr>
<td>Discharge with drainage tube</td>
<td>1 (2.7%)</td>
</tr>
<tr>
<td>Discharge with oxygen</td>
<td>1 (2.7%)</td>
</tr>
</tbody>
</table>
Results

How ready are they? Parents of pediatric solid organ transplant recipients and the transition from hospital to home following transplant


Abstract: Poor discharge transition is evidence of a gap between evi-
Qualitative Findings

What helped or interfered with you feeling confident to care for your child after discharge?
Discharge Teaching

Helped
- Education
- Consistent and knowledgeable staff
- Support
- Nurses and family

Interfered
- Amount of education
- Overwhelming
- Lack of support
- “I feel confident, I just feel they [hospital staff] needs to feel more confident in us.”
Post Discharge Coping

What positively affected your ability to cope in the last three weeks following hospital discharge?

**Community Support**
- Family and friends
- Community
  - Kohl’s house
  - School
- Blogs

**Medical Support**
- Education from entire transplant team
- Nurses always available
- Calling coordinators with questions

**Discharge Teaching**
- Education
- Knowing something bad could happen
- Given tools to be successful

**Being normal**
- Watching child feel better
- Child improving physically
- Child having fun
Qualitative Results

“Going home from the hospital is a big deal, it is life changing.”

“In the first 12 hours I wanted to rush back to the hospital, but then at 24 hours I knew I could do it.”
Next Steps

• Do the significant relationships remain over time?
• What happens with parents who have difficulty coping at 3-weeks after discharge?
• How long do parents have coping difficulty?
• Do things improve with adherence difficulty over time?
Study Purpose

• Parent’s perspective of discharge teaching AND adaptation to chronic illness during the first 6 months following hospital discharge for their child’s transplant
  √ Acute
    › 3 weeks following hospital discharge
  √ Long term
    › 3 and 6 months following hospital discharge

Funded by Children’s Research Institute
Design and Procedure

• Prospective, correlational, longitudinal
• Participant completed questionnaires
  • Day of hospital discharge
  • Telephone interviews following hospital discharge
    • 3-week
    • 3-month
    • 6-month
Methods

Setting

5 Pediatric Transplant Centers

Participant Selection

Parent of transplant recipient

Heart
Kidney
Liver
Lung
Intestine/Liver

Children’s Hospital WI
Lurie Children’s
St. Louis Children’s
Nebraska Medical Center
Levine Children’s
Quality of Care Coordination
Care Transition Measure

Quality of Discharge Teaching
Quality of Discharge Teaching Scale

Readiness for Hospital Discharge
Readiness for Hospital Discharge Scale

Parent Coping
Post Discharge Coping Difficulty Scale

Adherence
Medical Adherence Measure

Utilization of Healthcare Resources
Post Discharge Utilization of Healthcare Services Questionnaire

Family Management
PedsQL Family Impact Module

Completed on Day of Hospital Discharge

Completed at 3 weeks, 3 months and 6 months post discharge
## Results: Sample

<table>
<thead>
<tr>
<th>Participants</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Liver</td>
<td>19 (37)</td>
</tr>
<tr>
<td>Heart</td>
<td>16 (31)</td>
</tr>
<tr>
<td>Kidney</td>
<td>10 (20)</td>
</tr>
<tr>
<td>Intestine or</td>
<td>5 (10)</td>
</tr>
<tr>
<td>Intestine/Liver</td>
<td>1 (2)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Organ Type</th>
<th>N (%)</th>
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</thead>
<tbody>
<tr>
<td>Liver</td>
<td>19 (37)</td>
</tr>
<tr>
<td>Heart</td>
<td>16 (31)</td>
</tr>
<tr>
<td>Kidney</td>
<td>10 (20)</td>
</tr>
<tr>
<td>Intestine or</td>
<td>5 (10)</td>
</tr>
<tr>
<td>Intestine/Liver</td>
<td>1 (2)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Hospital</th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>18 (35)</td>
<td>13 (25)</td>
<td>12 (24)</td>
<td>5 (10)</td>
<td>3 (6)</td>
</tr>
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</table>
## Results: Demographics

<table>
<thead>
<tr>
<th></th>
<th>N evaluated</th>
<th>N (%)</th>
</tr>
</thead>
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<tr>
<td><strong>Parent Gender</strong></td>
<td>51</td>
<td></td>
</tr>
<tr>
<td>• Female</td>
<td></td>
<td>44 (86)</td>
</tr>
<tr>
<td>• Male</td>
<td></td>
<td>7 (14)</td>
</tr>
<tr>
<td><strong>Parent Age (Years)</strong></td>
<td>46</td>
<td></td>
</tr>
<tr>
<td>• Median</td>
<td></td>
<td>34.5</td>
</tr>
<tr>
<td>• Range</td>
<td></td>
<td>19-55</td>
</tr>
<tr>
<td><strong>Parent and Child Race</strong></td>
<td>51</td>
<td></td>
</tr>
<tr>
<td>• White</td>
<td></td>
<td>41 (81)</td>
</tr>
<tr>
<td>• Black</td>
<td></td>
<td>8 (16)</td>
</tr>
<tr>
<td>• Alaskan or American Indian</td>
<td></td>
<td>2 (4)</td>
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<tr>
<td><strong>Parent Marital Status</strong></td>
<td>50</td>
<td></td>
</tr>
<tr>
<td>• Married</td>
<td></td>
<td>36 (72)</td>
</tr>
<tr>
<td>• Single</td>
<td></td>
<td>12 (24)</td>
</tr>
<tr>
<td>• Divorced</td>
<td></td>
<td>1 (2)</td>
</tr>
<tr>
<td>• Widowed</td>
<td></td>
<td>1 (2)</td>
</tr>
<tr>
<td><strong>Child Gender</strong></td>
<td>51</td>
<td></td>
</tr>
<tr>
<td>• Male</td>
<td></td>
<td>26 (51)</td>
</tr>
<tr>
<td>• Female</td>
<td></td>
<td>25 (49)</td>
</tr>
<tr>
<td><strong>Child Age</strong></td>
<td>51</td>
<td></td>
</tr>
<tr>
<td>• Median</td>
<td></td>
<td>3.2 years</td>
</tr>
<tr>
<td>• Range</td>
<td></td>
<td>3 weeks to 17.5 years</td>
</tr>
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</table>
## Results: Patient Characteristics

### Hospitalization Characteristics

<table>
<thead>
<tr>
<th>Description</th>
<th>Median</th>
<th>Range</th>
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</thead>
<tbody>
<tr>
<td>Inpatient number of days</td>
<td>13</td>
<td>4-89</td>
</tr>
<tr>
<td>Unplanned return to OR (%)</td>
<td>4 (8)</td>
<td>3 (6)</td>
</tr>
<tr>
<td></td>
<td>3 (6)</td>
<td></td>
</tr>
<tr>
<td>Hospitalization (%)</td>
<td>7 (14)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>4 (8)</td>
<td></td>
</tr>
</tbody>
</table>

### Post Discharge Characteristics

<table>
<thead>
<tr>
<th>Description</th>
<th>Median</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medications (%)</td>
<td>10</td>
<td>5-21</td>
</tr>
<tr>
<td>Additional medical needs (%)</td>
<td>19 (37)</td>
<td>17 (33)</td>
</tr>
<tr>
<td></td>
<td>15 (30)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3 (6)</td>
<td></td>
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Results

<table>
<thead>
<tr>
<th>Independent Variable</th>
<th>Dependent Variable</th>
<th>Model Statistics</th>
<th>B</th>
<th>SE</th>
<th>Standardized β</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care Transition Measure</td>
<td>RHDS</td>
<td>F(1,49) = 4.85, p = .03, R² = .09</td>
<td>.61</td>
<td>.28</td>
<td>.30</td>
<td>2.20</td>
<td>.03</td>
</tr>
<tr>
<td>Quality Discharge Teaching Scale</td>
<td>RHDS</td>
<td>F(1,49) = 14.29, p = .00, R² = .23</td>
<td>.41</td>
<td>.11</td>
<td>.48</td>
<td>3.78</td>
<td>&lt;.001</td>
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</table>
### Readiness for Hospital Discharge (RHDS) and Its Impact on Various Outcomes

<table>
<thead>
<tr>
<th>Independent Variable</th>
<th>Dependent Variable</th>
<th>Model Statistics</th>
<th>B</th>
<th>SE</th>
<th>Standardized β</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>RHDS 3 weeks</td>
<td>Parent Coping</td>
<td>F(1,47) = 6.87, p = .01, R² = .13</td>
<td>-.23</td>
<td>.09</td>
<td>-.36</td>
<td>-2.62</td>
<td>.01</td>
</tr>
<tr>
<td>3 months</td>
<td>Parent Coping</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6 months</td>
<td>Parent Coping</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>RHDS 3 weeks</td>
<td>Parent and Family Adjustment</td>
<td>F(1,47) = 6.58, p = .01, R² = .10</td>
<td>.24</td>
<td>.10</td>
<td>.35</td>
<td>2.56</td>
<td>.01</td>
</tr>
<tr>
<td>3 months</td>
<td>Parent and Family Adjustment</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>6 months</td>
<td>Parent and Family Adjustment</td>
<td></td>
<td></td>
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### RHDS and Medication Adherence

<table>
<thead>
<tr>
<th></th>
<th>N eval</th>
<th>Do Not Miss Medication</th>
<th>N eval</th>
<th>Miss Medication</th>
<th>p value</th>
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<tbody>
<tr>
<td>3 week</td>
<td>46</td>
<td>250 (203-288)</td>
<td>3</td>
<td>243 (227-257)</td>
<td>.62</td>
</tr>
<tr>
<td>3 month</td>
<td>37</td>
<td>251 (203-278)</td>
<td>10</td>
<td>228 (208-267)</td>
<td>.03</td>
</tr>
<tr>
<td>6 month</td>
<td>39</td>
<td>247 (208-278)</td>
<td>8</td>
<td>259 (203-273)</td>
<td>.38</td>
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</tbody>
</table>

### RHDS and Utilization of Healthcare Resources

<table>
<thead>
<tr>
<th></th>
<th>N eval</th>
<th>Urgent Care or ED</th>
<th>N eval</th>
<th>No Urgent Care or ED</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>3 week</td>
<td>9</td>
<td>243 (203-288)</td>
<td>40</td>
<td>250 (208-278)</td>
<td>.75</td>
</tr>
<tr>
<td>3 month</td>
<td>12</td>
<td>257 (220-274)</td>
<td>35</td>
<td>247 (220-274)</td>
<td>.45</td>
</tr>
<tr>
<td>6 month</td>
<td>11</td>
<td>234 (203-278)</td>
<td>36</td>
<td>250 (203-278)</td>
<td>.39</td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Readmission</strong></td>
<td></td>
<td><strong>No Readmission</strong></td>
<td></td>
</tr>
<tr>
<td>3 week</td>
<td>14</td>
<td>238 (209-274)</td>
<td>35</td>
<td>251 (203-288)</td>
<td>.34</td>
</tr>
<tr>
<td>3 month</td>
<td>15</td>
<td>249 (209-274)</td>
<td>32</td>
<td>249 (203-278)</td>
<td>.81</td>
</tr>
<tr>
<td>6 month</td>
<td>13</td>
<td>228 (209-274)</td>
<td>34</td>
<td>251 (203-278)</td>
<td>.07</td>
</tr>
</tbody>
</table>
Results Summary

• Readiness for hospital discharge is influenced by:
  • Care team process
  • Quality of discharge teaching
• Readiness for hospital discharge is associated with subsequent post-discharge outcomes:
  • Post-discharge coping difficulty
  • Impact on family
  • Adherence
  • Readmission?
Transition from Hospital to Home: Next Steps

- Extension of our prior research enhanced by:
  1. Family self-management
     - The Individual and Family Self-Management Model
     - Depicts the variables related to self-management behaviors
  2. mHealth
     - Mobile technology
     - mHealth improves patient and provider communication applicable to complex care populations
Why use mHealth?

- mHealth
  - Mobile device applications intended to improve health outcomes, delivery of health care services, communication, or enable health research
- Smartphones are ideal for self-management
  - Socially acceptable
  - All SES and minority groups are users
  - Can transmit data and feedback remotely in real time
- Strengths
  - Potential to overcome time and access limitations
  - Monitor data that far exceeds what can be measured in a brief clinical encounter
- Focused and frequent contact via mHealth improves health outcomes
  - Medically complex adults (Devito-Dabbs, 2015)
mHealth Family Self-management Intervention for Parents of Pediatric Transplant Recipients

Supported by the National Institute of Health
National Institute of Nursing Research under Award Number K23NR017652
We propose use of a family self-management intervention that employs a mHealth approach as a strategy for improving the discharge transition process.
Individual and Family Self-Management Theory Applied to Pediatric Transplant

Context
Risk and Protective Factors
- Condition-Specific Factors
  - Transplant Type
  - Transplant Complication(s)
- Individual & Family Factors
  - Family members and Child Demographics

Process
The Self-Management Process
- Knowledge & Beliefs
  - Family Coping
    - Post Discharge Coping
    - Difficulty Scale

Proximal Outcomes
Individual & Family Self-Management Behaviors
- myFAMI app
  - Difficulty managing medications and medical follow-up regimen
  - Child transplant symptoms and family member response
- Use of Healthcare Resources
  - Emergency Department visit, Readmission and Unplanned Clinic Visits

Distal Outcomes
Health Status and Quality of Life
- PedsQL Family Impact Module™

Intervention: myFAMI app
Frequency of use by family member, number of trigger alerts generated by app, and Transplant Nurse response to family member within 2 hours of trigger alert (Self-management Science Center, P2O1R015339)

Ryan and Sawin, 2009
Study Aims

Determine feasibility of family use of *myFAMI*.

Determine feasibility of nurse response to trigger alerts identified by *myFAMI*.

Determine the efficacy of *myFAMI*:
- Improve family coping, quality of life, family self-management for medications, follow-up and symptoms
- Decrease use of healthcare resources
Design

• Randomized controlled trial
• Enroll at three pediatric transplant centers

• Inclusion
  • English speaking
  • Family members
    • 18 years of age or older
  • Pediatric transplant recipient
    • <18 years old
    • Received a heart, kidney or liver transplant
    • Discharged home from the hospital

• Exclusion
  • Communication or cognitive impairment
  • Child is a previous transplant recipient

Figure 2. Study Enrollment Description

40 family units of transplant recipients

myFAMI
n = 20 family units

Control
n = 20 family units

n = 40 total family units
(80 family members)

Family unit = 1 primary family member plus 1 secondary family member
Intervention: *myFAMI*

- Evaluate the efficacy of a family self-management intervention
  - √ mHealth approach as a strategy for improving the discharge transition process
- Implement intervention via a Smartphone application (app)
  - √ **Family Self-Management Intervention**
    - *myFAMI*
- The *myFAMI* app promotes daily communication
  - √ Initiated by an in-app notification
  - √ Completed by the family member for 30 days following discharge

Family caregiver response on smartphone
Intervention: myFAMI

- Family member daily questions
  - √ Coping
  - √ Family self-management behaviors of complex care at home
    - Difficulty with medication administration
    - Difficulty managing the medical follow-up regimen
  - √ Management of the child’s transplant symptoms
    - Fever, pain, vomiting, diarrhea, other illness
- Pre-identified critical responses will trigger an alert to the research team
  - √ Subsequent Zoom (face-to-face) response from the study team nurse

Face-to-face response by study team nurse
<table>
<thead>
<tr>
<th>Family Member Question</th>
<th>Family Member Response</th>
<th>Trigger</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Does your child have a fever of 100.4 °F or greater?</td>
<td>Yes/No/Don’t Know or NA</td>
<td>Yes/Don’t Know</td>
</tr>
<tr>
<td>2. Is your child having emesis or throwing up?</td>
<td>Yes/No/Don’t Know or NA</td>
<td>Yes/Don’t Know</td>
</tr>
<tr>
<td>3. Is your child experiencing diarrhea or loose stools?</td>
<td>Yes/No/Don’t Know or NA</td>
<td>Yes/Don’t Know</td>
</tr>
<tr>
<td>4. Is your child experiencing any pain?</td>
<td>Yes/No/Don’t Know or NA</td>
<td>Yes/Don’t Know</td>
</tr>
<tr>
<td>5. Is your child having any illness symptoms (such as cough/runny nose)?</td>
<td>Yes/No/Don’t Know or NA</td>
<td>Yes/Don’t Know</td>
</tr>
<tr>
<td>6. On a scale of zero to ten, how much difficulty are you having coping at home?</td>
<td>0 = no difficulty</td>
<td>≥3</td>
</tr>
<tr>
<td></td>
<td>10 = great deal of difficulty</td>
<td></td>
</tr>
<tr>
<td>7. On a scale of zero to ten, how much difficulty are you having giving the medications at home?</td>
<td>0 = no difficulty</td>
<td>≥3</td>
</tr>
<tr>
<td></td>
<td>10 = great deal of difficulty</td>
<td></td>
</tr>
<tr>
<td>8. On a scale of zero to ten, how much difficulty are you having with attending lab and clinic appointments?</td>
<td>0 = no difficulty</td>
<td>≥3</td>
</tr>
<tr>
<td></td>
<td>10 = great deal of difficulty</td>
<td></td>
</tr>
<tr>
<td>9. If answer yes to questions 1-5 (a pre-identified trigger), then family member will be asked the following: “Please provide additional information regarding (fever, emesis, etc)”.</td>
<td>I have: 1) not done anything different, 2) administered a medication, 3) changed the diet, 4) done something else</td>
<td>NA</td>
</tr>
</tbody>
</table>
## Preliminary Results

### Enrollment and Feasibility Data

<table>
<thead>
<tr>
<th>Intervention Group</th>
<th>Goal</th>
<th>Data for n=8 family members</th>
</tr>
</thead>
<tbody>
<tr>
<td>myFAMI participants complete daily questions for 30 days following discharge</td>
<td>80% 24/30 days</td>
<td>1 of 8 had response rate less than 80%</td>
</tr>
<tr>
<td>Study nurse response to participant trigger within 2 hours</td>
<td>100%</td>
<td>33/34 (97%) total triggers replied within 2 hours</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Control and Intervention Group</th>
<th>Goal</th>
<th>Data for n=16 family members</th>
</tr>
</thead>
<tbody>
<tr>
<td>Control and myFAMI participants complete the 30-day post-discharge telephone interview</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>
Preliminary Results

• Enrollment
  • 12 transplant family units (24 family members)
  • 4 in the intervention group and 8 in the control group

• Family member
  • “I know the transplant team is just a phone call away, but I love that there is someone else watching over her (patient) because of this app”
  • “The app was easy to use, took less than 2 minutes”
Conclusions

Aim 1. Determine feasibility of family use of myFAMI.

Preliminary evidence for the feasibility of family member use

Aim 2. Determine feasibility of nurse response to trigger alerts identified by myFAMI.

Preliminary evidence for the feasibility nurse response

Aim 3. Determine the efficacy of myFAMI.

Efficacy analysis will be done when data collection is complete
Future Directions

• This *innovative* research addresses a gap in knowledge
  ✔ Evaluation of the impact of an individualized family-centered mHealth application to enhance daily post-discharge communication following pediatric transplant

• Early identification of transplant symptoms and difficulty coping
  ✔ Allows the medical team to offer additional support and preventive management strategies

• Results will lay the foundation
  ✔ Future research with *myFAMI*
  ✔ Build the science from which to consider post-discharge monitoring and decrease cost of care in other pediatric chronic illness populations
• Gastroenterology and Hepatology
  ✓ Grzegorz Telega, MD
  ✓ Bernadette Vitola, MD
  ✓ Manu Sood, MD
  ✓ Johnny Hong, MD

• Marquette University
  ✓ Dr. Marianne Weiss, DNSc, RN

• Mentors
  ✓ Rachel Schiffman, PhD, RN
  ✓ Rosemary White-Traut, PhD, RN
  ✓ Barbara Medoff-Cooper, PhD, RN
  ✓ Dr. Pippa Simpson, PhD
  ✓ Dr. Ahamed Sheikh, PhD

• Team
  ✓ Rachel Unteutsch
  ✓ Adrianne Mueller
  ✓ Heart Transplant
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    › Alyssa Pollow, CPNP, RN
    › Steven Kindel, MD
  ✓ Kidney Transplant
    › Shelley Chapman, DNP, RN
    › Cynthia Pan, MD
  ✓ Children’s TRU
  ✓ Ann & Robert H. Lurie Children’s Hospital, Chicago
    › Estella Alonso, MD
    › Katie Neighbors, MA
  ✓ Duke Children’s Hospital
    › Alisha Mavis, MD

thank YOU SO MUCH
Teamwork

...has its sweet rewards!