Survival Skills: Post-transplant education at the bedside

Mara Saunders, RN, NP-BC
Objectives:

1. Outline the primary goals of post-transplant education, and common teaching approaches used in the acute care setting.

2. Describe individual and systems-level challenges to effective post-transplant education.

3. Highlight areas for improvement, and discuss patient-centered approaches to promote knowledge and empowerment after transplant.
**What’s at Stake?**

### National Transplant Statistics

*(OPTN/SRTR data as of 9/14/12)*

#### Annual Transplants (2011) vs. Current Waiting Candidates

<table>
<thead>
<tr>
<th>Organ Type</th>
<th>2011 Transplants</th>
<th>Current Waiting Candidates</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kidney</td>
<td>16,813</td>
<td>93,413</td>
</tr>
<tr>
<td>Liver</td>
<td>6,342</td>
<td>16,010</td>
</tr>
<tr>
<td>Pancreas</td>
<td>287</td>
<td>1,239</td>
</tr>
<tr>
<td>Kidney-Pancreas</td>
<td>795</td>
<td>2,153</td>
</tr>
</tbody>
</table>

#### Average Wait Time (in days, by blood type) (2003-2004)

<table>
<thead>
<tr>
<th>Organ Type</th>
<th>AB (Days)</th>
<th>O (Days)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kidney</td>
<td>855</td>
<td>1,935</td>
</tr>
<tr>
<td>Liver</td>
<td>76</td>
<td>459</td>
</tr>
<tr>
<td>Pancreas</td>
<td>281</td>
<td>686</td>
</tr>
<tr>
<td>Kidney-Pancreas</td>
<td>264</td>
<td>769</td>
</tr>
</tbody>
</table>

#### Percent of Candidates Transplanted (at 2-year point, by blood type) (2003-2004)

<table>
<thead>
<tr>
<th>Organ Type</th>
<th>O</th>
<th>AB</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kidney</td>
<td>19.9%</td>
<td>45.4%</td>
</tr>
<tr>
<td>Liver</td>
<td>54.5%</td>
<td>75.5%</td>
</tr>
<tr>
<td>Pancreas</td>
<td>52.0%</td>
<td>64.9%</td>
</tr>
<tr>
<td>Kidney-Pancreas</td>
<td>48.4%</td>
<td>81.0%</td>
</tr>
</tbody>
</table>
What are Survival Skills?

• **Complex medication management:**
  – Many new medications “green card,” multiple daily or weekly dosing, dosing windows, BP/HR parameters, hold for lab days, no grapefruit…

• **Preventing infection and rejection:**
  – Avoidance of common pathogens, frequent urination, no live vaccines, lab monitoring, daily monitoring of temp/BP/weight, recognizing signs and symptoms, clinic visits, when to call for help…

• **Routine health maintenance:**
  – Cancer prevention & screening, abx for dental work, nutrition, exercise, sunscreen…

• **Recovering from surgery:**
  – Wound care, rest, exercise, driving, working, sex…

• **Bonus points:**
  – JP care, foley care, blood glucose monitoring & insulin dosing…
# What's at Stake?

<table>
<thead>
<tr>
<th>Organ Type</th>
<th>Follow-Up Period</th>
<th>3 Months</th>
<th>1 Year</th>
<th>3 Years</th>
<th>5 Years</th>
<th>10 Years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kidney: Deceased Donor</td>
<td>graft survival</td>
<td>96%</td>
<td>91%</td>
<td>81%</td>
<td>70%</td>
<td>44%</td>
</tr>
<tr>
<td></td>
<td>patient survival</td>
<td>93%</td>
<td>96%</td>
<td>90%</td>
<td>82%</td>
<td>62%</td>
</tr>
<tr>
<td>Kidney: Living Donor</td>
<td>graft survival</td>
<td>98%</td>
<td>95%</td>
<td>90%</td>
<td>82%</td>
<td>61%</td>
</tr>
<tr>
<td></td>
<td>patient survival</td>
<td>95%</td>
<td>98%</td>
<td>95%</td>
<td>91%</td>
<td>71%</td>
</tr>
<tr>
<td>Pancreas Alone</td>
<td>graft survival</td>
<td>85%</td>
<td>74%</td>
<td>62%</td>
<td>52%</td>
<td>35%</td>
</tr>
<tr>
<td></td>
<td>patient survival</td>
<td>97%</td>
<td>96%</td>
<td>90%</td>
<td>89%</td>
<td>77%</td>
</tr>
<tr>
<td>Pancreas After Kidney</td>
<td>graft survival</td>
<td>85%</td>
<td>90%</td>
<td>66%</td>
<td>53%</td>
<td>36%</td>
</tr>
<tr>
<td></td>
<td>patient survival</td>
<td>92%</td>
<td>98%</td>
<td>94%</td>
<td>89%</td>
<td>68%</td>
</tr>
<tr>
<td>Kidney-Pancreas</td>
<td>kidney graft survival</td>
<td>98%</td>
<td>92%</td>
<td>87%</td>
<td>79%</td>
<td>60%</td>
</tr>
<tr>
<td></td>
<td>pancreas graft survival</td>
<td>89%</td>
<td>86%</td>
<td>79%</td>
<td>72%</td>
<td>56%</td>
</tr>
<tr>
<td>Liver: Deceased Donor</td>
<td>graft survival</td>
<td>91%</td>
<td>82%</td>
<td>71%</td>
<td>68%</td>
<td>54%</td>
</tr>
<tr>
<td></td>
<td>patient survival</td>
<td>94%</td>
<td>89%</td>
<td>79%</td>
<td>73%</td>
<td>60%</td>
</tr>
<tr>
<td>Liver Living Donor</td>
<td>graft survival</td>
<td>91%</td>
<td>82%</td>
<td>80%</td>
<td>74%</td>
<td>59%</td>
</tr>
<tr>
<td></td>
<td>patient survival</td>
<td>94%</td>
<td>90%</td>
<td>84%</td>
<td>80%</td>
<td>67%</td>
</tr>
</tbody>
</table>
What’s at Stake?

• High rates of non-adherence to medications and clinic visits (kidney), and relapse to drugs/etoh/cigarettes (liver)
  – Leading causes of late morbidity & mortality (graft rejection, cancer)
  – Increased health care costs ($33K), decreased quality of life
  – Increased risk of mortality (78%) with return to HD after transplant
  – Non-adherent behaviors may prevent patient from being re-listed

• First 6 months is predictive of long-term outcomes
  – Opportunity to interact with a variety of HC professionals in one setting
  – Patterning behaviors, overcoming barriers
  – Future opportunities for education and support may be limited
  – “Captive audience” while in the hospital
Common Approaches

• **Pre-transplant preview**
  – Orientation class pre- or post-listing, pre-transplant binder or packet mailed to home

• **Face-time with team members post-transplant**
  – Nurses, coordinators, MDs, pharmacists, dieticians, diabetes specialists…
  – Education integrated with daily RN care, 1-2hr class with coordinator
  – Post-transplant checklist to standardize approach

• **Involving support systems**
  – Caregivers attend pre- and post-transplant education sessions
  – Support groups in the hospital with caregivers, past patients

• **Homework**
  – Post-transplant binder/handbook, med card
  – Handouts on drain care, foley care, diabetes care…
  – References to websites
Barriers to Education

ANNA Transplant Special Interest Group Topic (2008)

- Inadequate literacy/health literacy
- Compressed time due to mandate for decreased length of stay
- Sedating effect of pain medication
- Distractions (pain, fatigue, anxiety)
- Language barriers
- Information overload
- Cultural differences
- Lack of repetition of concepts
- Low participation of patients in their own care
- Depression
- Failure of caregivers to attend education sessions
# Barriers to Education

<table>
<thead>
<tr>
<th>Individual-Level</th>
<th>Systems-Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inadequate literacy/health literacy</td>
<td>Heavy reliance on printed material</td>
</tr>
<tr>
<td>Sedating effect of pain medication</td>
<td><em>Mandate for decreased length of stay</em></td>
</tr>
<tr>
<td>Distractions (pain, fatigue, anxiety)</td>
<td>Lack of repetition of concepts</td>
</tr>
<tr>
<td>Cultural differences</td>
<td><em>Standardized approach to education</em></td>
</tr>
<tr>
<td>Language barriers</td>
<td>Translated materials &amp; interpreters N/A</td>
</tr>
<tr>
<td>Information overload</td>
<td>Lack of designated RN time for education</td>
</tr>
<tr>
<td>Low participation of patients</td>
<td><em>Regulations limit teaching tools</em></td>
</tr>
<tr>
<td>Depression, Anxiety, <em>PTSD</em></td>
<td>Limited resources to address MH issues</td>
</tr>
<tr>
<td><em>Avoidant behaviors</em>, Poor coping mechanisms</td>
<td>No RN training around MH barriers</td>
</tr>
<tr>
<td>Lack of family/community support</td>
<td>Lack of support for caregivers</td>
</tr>
<tr>
<td><strong>Failure of caregivers to attend</strong></td>
<td>Provider-centric model</td>
</tr>
<tr>
<td><em>Caregiver burnout</em></td>
<td>Limited outreach, telecommunication use</td>
</tr>
<tr>
<td></td>
<td><em>Poor/inconsistent quality of info online</em></td>
</tr>
</tbody>
</table>
Avenues for Change

• Early and continued outreach and education
  – More use of pre-transplant teaching tools (e.g. videos/handouts at HD centers)
  – Consistent education throughout evaluation and waiting phase
  – More home visits and community-based outreach post-transplant
  – Leverage internet and cell technology (develop organization/reminder apps, text communication, internet portals)
  – More follow up for patients at greater risk (due to MH, substance abuse, etc.)

• Increased support for caregivers and family
  – Caregiver-specific classes pre-transplant offering anticipatory guidance
  – Support groups or regular check-ins with caregivers post-transplant
  – More emphasis on participatory/empowering approach for caregivers
  – “Widen the net” identify other caregivers/resources within the community (e.g. peer advocates, community health workers)
Avenues for Change

• **Prioritize education, and customize to meet patient’s needs**
  – Designate discrete “themed” teaching sessions to avoid information overload and allow for repetition
  – Train nurses around teaching/learning styles, working through barriers
  – Pre-screen patients for MH/behavioral barriers, learning style, risk factors
  – Develop a comprehensive teaching curriculum that is shared between providers
  – Schedule interpreters for discrete teaching sessions
  – Greater emphasis on patient involvement and empowerment (“teach back” method vs. didactic, developing organization, routine, problem-solving skills)

• **Improve quality of online and printed materials**
  – Review websites and offer list of “vetted” resources
  – Develop more institutionally-sponsored websites
  – Translate written materials into more languages
  – Develop more non-written education materials (e.g. videos, pictorial handouts)
Promising Approaches

- **Ruppar et. al (2009) Qualities of “successful” kidney recipients**
  - Qualitative study of 19 kidney recipients with grafts lasting >25 years
  - 4 common themes identified: reminder methods, obtaining medications, maintaining routines, problem-solving strategies

- **Tong et. al (2008) Caregiver support intervention**
  - Systematic review of 3 interventions directed at caregivers of patients with CKD (pre and post-transplant)
  - Caregiver training reduces cost and burden, and improves long-term psychosocial outcomes for caregiver and patient
  - Participatory and empowerment approaches are most effective

- **Russell et. al (2011) TIMELink Study**
  - RCT of a continuous self-improvement intervention involving 30 adult kidney transplant recipients
  - Continuous self-improvement approach shows promise in increasing medication adherence, and could be delivered in inpatient setting
  - Focus on working actively with patients, identifying individual challenges, resources, and solutions, and providing continuous feedback
Promising Approaches

Suggestions???

Thank You!
References


UCSF Data Center Transplant Summary CY2012

M. Lalonde, UCSF Inpatient Liver Transplant Coordinator, Email correspondence: 9 September 2012

L. Wedge, Beth Israel Deaconess Med Ctr Liver Transplant Coordinator, Email correspondence: 12 September 2012

A. Phelps, UCLA Inpatient Kidney/Pancreas Transplant Coordinator, Email correspondence: 29 August 2012