Examining Patient & Caregiver Outcome Preferences in Stroke Rehabilitation

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Objectives

• Discuss the importance of Patient-Centered outcomes research in rehabilitation

• Explore the decision making process for transitioning from acute care to rehabilitation following stroke

• Discuss our systematic review of studies examining outcome preferences for stroke rehabilitation.

• Determine which outcomes are important to patients, caregivers in stroke rehabilitation.

• Discuss future plans to examine the effectiveness of stroke rehabilitation using CMS data.
Evidence indicates that individuals receiving IRF rehabilitation experience greater functional improvements compared to those in SNF care (Deutsch et al. 2006, Kane et al. 1998).

Others have suggested that therapy intensity and case mix are associated outcomes, finding that higher intensity SNFs yield better outcomes. (Chen et al. 2002, Wodchis et al. 2005).
Patient-Centered Rehabilitation

• Although rehabilitation teams aspire to be client-centered, researchers have shown that outcome preferences differ between patients and clinicians (Stineman et al. 2008).

• Outcome preferences differ across clinicians by discipline (Stineman et al. 2009, Rist et al. 2008).

• Likewise, patient preferences have been shown to differ across conditions (Steinman et al. 2008).
Outcome Preferences

Assume that you had a severe stroke with varying degrees of limitations in the majority of activities of daily living …

What are the first three areas you would want to see improve?

Rehabilitation & Preferences

Functional gains

- ADL & IADL
- Physical limitation
- Psychological difficulties

Individualized meaning

Structured discourse about functional loss & recovery encourages Patient-Centered decision making

<table>
<thead>
<tr>
<th>Activity</th>
<th>With Help</th>
<th>No Help</th>
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<tbody>
<tr>
<td></td>
<td>Complete Dependence</td>
<td>Some Assistance</td>
</tr>
<tr>
<td>Eating</td>
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<tr>
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<td>Dressing-upper body</td>
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<td>11</td>
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<tr>
<td>Dressing-lower body</td>
<td>Complete dependence</td>
<td>12</td>
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<tr>
<td>Toileting</td>
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<tr>
<td>Bladder management</td>
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<td>13</td>
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<tr>
<td>Bowel management</td>
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<td>14</td>
</tr>
<tr>
<td>Bed, chair, wheelchair transfer</td>
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<td>3</td>
</tr>
<tr>
<td>Toilet transfer</td>
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<td>9</td>
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<tr>
<td>Tub/shower transfer</td>
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<td>15</td>
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<td>Walk/wheelchair</td>
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<td>Comprehension</td>
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<tr>
<td>Memory</td>
<td>Complete dependence</td>
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</tbody>
</table>
Clinicin Preferences

Ethnography: Discharge Planning Meeting
Rehabilitation Decision Process

• The decision about who gets rehabilitation where, is often made by clinical and administrative personnel based on provider opinions about who will benefit most from which setting (Buntin 2010).

• Key determinants for IRF and SNF placement is the severity of illness/needs and the ability to tolerate the intensity of therapy required in IRF settings (Dobkin 2005, Bates 2000).
Participant Observations

Participated in 12 stroke team discharge planning meetings.

- Eligibility (insurance, age, money)
- Medical condition issues (IV antibiotics, hyperbaric, ventilation support)
- Rehabilitative needs (OT, PT, and Speech)
- Family desires
- Patient and Family involvement
  - Often family are not involved
  - Only consistent involvement is with difficult decisions (long history of decline, prior hospitalization, low potential for recovery)
Systematic Review
Systematic Review

3 independent reviewers selected abstracts, articles and extracted information

Medline  n=2,202
PsycINFO  n=236
CINAHL  n=373
Total  n=2,811

Papers for review of title and abstract  n=2,811

Papers excluded: Inclusion criteria not met  n=2,549

Papers for review of full text  n=262

Articles excluded after full text review  n=76

Studies included for patient preferences  n=96

Studies included for caregiver preferences  n=34

Studies included for comparing outcomes in different settings  n=8
Interviews: Stroke Rehabilitation
Interviews

In depth, open ended interviews were conducted.

• 17 patient interviews
• 11 caregiver interviews
• 2 clinician interviews
Interview Topics

- Therapy and services received
- Goals in rehabilitation
- Results from rehabilitation
- What was most important
- Sharing information with others
- What would have been helpful
- What do you wish was done looking back
- Looking forward what is most important
- Information provided about rehabilitation
- Decision making process
Methods and Analysis

Phase 1:
- Interviews are independently transcribed
- Transcription quality is assessed by the primary interviewer
- Interviews were reviewed and independently coded by three members of the research team
- Important outcomes, preferences, and goals were then discussed and confirmed as a group.

Phase 2:
- Patient and caregiver perspectives were examined for similarities and differences
- Caregiver perspectives from the systematic review and open-ended interviews were synthesized
Walking

Patient Interview

• “being able to walk again …. Cause they gave me a cane and a walker … I was like I'm not doing this, you know I’m not cripple … I was determined, I was gonna walk … I wish I could walk better … all I want to do is walk … I wish I could walk … … that would be my ability to get around”.

• “always pushing trying to walk… cause I already lost my leg. I mean I wasn’t gonna be bed ridden. There’s no way….Well being able to walk again.”

• “All I want to do is walk, really….”

• “To walk”

Caregiver Interview

• “like walking … To me that seems to be most’.”

Systematic Review

• “…want to get him mobile, … go for a walk.”
Arm & Hand Function

Patient interview

• “to get strong, my shoulder is out of whack … to get back to normal as far as fine motor skills with my hands and stuff…. I don’t want to have to hold my hand you know, it aches all the time … this hand … my left arm … I guess my fine motor skills probably. With my hands cause you knew that I pick something up, it falls right back out”

• “That I could … use my arm, actually my whole left side”

Caregiver Interview

• “The daily tasks things like buttoning the little shirt buttons is important.”

Systematic Review

• “…he has difficulty fastening buttons.”
Patient Interviews

• “Actually I wanted to get my strength back. That’s it. You know just …like I said be able to walk …… yeah walking and strengthening”

• “I couldn’t open a gallon of milk, the plastic top I could not open it I have to give it to [someone to open] … I never was able to open a bottle, water bottle that we all use I can’t open one of those … Grip on it but I don’t have the strength to squeeze down on the lid and then make a turn in the threads”

• “Try to get the strength in my left side. You know, you know probably could accomplish that”

Caregiver Interview

• “the strength thing is very important”

• “…but then that leg too, gets tired fast”
Balance

Patient Interviews

• “I can't balance myself and carry things “.
• “uh i think it was just to be able to walk without any kind of balance problem. that's what i was looking for... the gal showed me a few things, i don't remember exactly what it was. she said, ”you really don't have any balance problems". that was like the third meeting with her. She said you really don't have a balance problem look like to me and i felt a lot better so. I think it was just a matter of time”
• “the only problem i was having was a little bit of balance problem”
• “I fell at home ... he’s nervous about me falling cause he can't get me up”.

Caregiver Interview

• “Balance too me that seems to be most important”
Transferring & Stairs

Caregiver Interview

• “…being able to get himself in and out of bed”

• “Transfers were far more difficult in the home than in rehabilitation…Home is totally different; things are different heights”.

• “I mean he's got a staircase he's got to climb just to get into the house.” I always tell him, "Take two, three steps, stop."

• “Just getting him up and down the stairs”
Patient Interview

• “Well, worse problem I have is with my eyes ... and yes it could be a special type of glasses but I wish I would have pushed harder on my primary care doctor to look into the eye problem”

• “My eyes ... they don’t focus together ... would take care of my vision. I guess I’m wishing something can be done about my eyesight ... I wish and hope something can be done about my eyesight ... my depth perception is real off. I would go to set my glass on the table and I would miss the table and things like that”

• “Yes and my vision”

Caregiver Interview

• “...his eyes are jumping around and the idea of his eye not staying shut is one big thing.”
Speech & Communication

Patient Interviews
- “it was talking because I was just mumbling you know, it was aggravating but I can talk … work on the most important first, that would be talking … my speech was a little like I said … a little bit clumsy for a while”

Caregiver Interviews
- “..the biggest thing is her communication…I just want her to get to the place where she can come out and say them.’, My goals was for her to speak as well’
- “I will get completely pissed off by the non communication…”
- “Because I would feel like if she couldn’t talk she couldn’t communicate with us and she would feel even worse”
- “My goals was for her to …speak as well”
Caregiver Interview

- But for him just to keep reminding him, to tell him, "Did you take that pill?"
- If he forgets his pills, then well. You write it down, you look later and, "Oh, yeah. I forgot that pill." But I'm making him do it like a routine. Write it down, write it down.
- "there was things that I would like for him to do, like a daily reminder. This is what I've got to do in the morning. ...I've got that down, it's just I have to constantly be behind him all the time to do things like that"
Positive Attitude

Patient Interview

• “Probably that depression because that, I mean that’s a major thing you know …drop down into that depression”

• “I think that’s the most important thing cause if you Keep a good positive attitude … And I’ve had that attitude since the get go”

• “I was really, to be honest with you I was really pissed off bout the stroke thing … I was really ticked about it and that was part of my depression … I think I’m good with that now. I got some medication so…I’m pretty good

• “just remember feeling really down all the time. …”

Caregiver Interview

• “I'm just going to sit here and just die," and I'm like, "Stop talking like that.‘… He talks about it all the time. "I should've gone before you mother." Stop talking like that. I don't want to hear that no more”
Bathing & self-care

Patient Interviews

• “To not be dependent on people … never wanted to be dependent … To make them independent as fast as possible. Like being able to take a shower on your own. You know, to get the dignity back …

• “I’m widowed now so I didn’t want to be dependent on my daughters and all this so you know…my main deal was being able to take care of myself … not being dependent cause I never wanna be dependent on my daughters”

Caregiver Interviews

• “He can do most of it. Showering or whatever, usually I help him in the bathroom and then he'll sit down and disrobe and then take his own shower. But the rest of it pretty much me.”
Other self-care skills

Patient Interview
• “I dust you know, I try to do dishes, I get yelled at. I try to wash clothes I get yelled at. I try to cook, I get yelled at…. So he takes something out of the freezer, you can use the microwave …”
• “I have projects around the house that I would be able to do …. But it takes forever to accomplish something”.

Caregiver Interview
• “he could barely dress himself to get out of the hospital’, ‘…he has difficulty fastening buttons,”
• “Her going to the bathroom is important’, ‘I guess, physical independence…meaning you know bathroom … my goal was you know be more independent for his personal stuff”.
• “Just like every day needs that she did for herself prior to the stroke like bathing, cooking”
• “Taking care of herself needs too”

Systematic Review
• “be independent with most ADLs and IADLs… and be able to be alone at least for short periods of time.”
Social Activities

Patient Interview

- “I’d go out on dates and stuff … “
- “more social stuff … “
- “get more active out … “
- “to get away from the house more”.
Patient Interviews

• “My only goal was really start researching the blood pressure and make sure everything was alright on that because the doctor told me, you need to... it took quite a few adjustments to get it right”

• “You can’t really call this my goal but not to have another stroke would be my goal. What are the things that I need to do to insure or that I can do to help me achieve that goal”
Communication with the team

Patient Interview

• “what sorts of medicines should be taken in order to preclude or minimize the possibility of a second stroke occurring … what kind of recovery is expected”

Caregiver Interview

• “I would share to just to stay informed, stay focused and stay alert about all her changes because the process, the process being what’s going on. I had to be, I had to sometimes ask what happens here. What happened there? In case they didn’t because I would miss them or something of that sort. Just to be alert … Stay informed, talk to the doctors and things of that nature. Have a lot of communication between the treatment, doctors and clinicians … A lot of communication”

• “I was unable to meet with … wanted to talk to her, it didn’t work… by the end of the day when she was supposed to be “dismissed” from the hospital, I really had no choice …I never got to chose and we wound up at the rehab center at the hospital just because there was no other choice”

Systematic Review

• “I wasn’t physically shown the best way to support him … it was all trial and error”
Summary

• The Interviews and systematic review revealed some common, as well as, independent outcome preferences across stakeholders.

Shared preferences
• Important outcome preferences identified by patients and caregivers included: walking, arm & hand function, strength, balance, vision, speech & communication, positive attitude, bathing and self-care, communication with the healthcare team.

Unique Preferences
• Caregivers additionally identified memory, transfers and stairs
• Social activities were identified as important to patients
Medicare Study: Secondary Data Analysis
CMS Datasets

We will be linking 4 CMS data files to allow us to explore stakeholder identified outcomes for those who receive IRF and SNF stroke Rehabilitation.

Beneficiary Summary file

- Individual level demographic data

MedPAR file

- Inpatient hospital record
- Includes IRF and SNF stays within a given year
- Data include admitting diagnosis and other codes
- Days of care
Rehabilitation Files

IRF-PAI files: contains items for the inpatient rehabilitation facilities

MDS 3.0: contains Items for skilled nursing facilities

- Impairment categories or groups
- Clinical factors
- Functional variables
MDS – 3.0

SNF: Resident Assessment Instrument

Functional Status Items

G0110. Activities of Daily Living (ADL) Assistance
Refer to the ADL flow chart in the RAI manual to facilitate accurate coding

Instructions for Rule of 3
- When an activity occurs three times at any one given level, code that level.
- When an activity occurs three times at multiple levels, code the most dependent, exceptions are total dependence (4), activity must require full assist every time, and activity did not occur (8), activity must not have occurred at all. Example, three times extensive assistance (3) and three times limited assistance (2), code extensive assistance (3).
- When an activity occurs at various levels, but not three times at any given level, apply the following:
  - When there is a combination of full staff performance, and extensive assistance, code extensive assistance.
  - When there is a combination of full staff performance, weight bearing assistance and/or non-weight bearing assistance code limited assistance (2). If none of the above are met, code supervision.

1. ADL Self-Performance
   Code for resident’s performance over all shifts - not including setup. If the ADL activity occurred 3 or more times at various levels of assistance, code the most dependent - except for total dependence, which requires full staff performance every time
   Coding:
   - Independent - no help or staff oversight at any time
   - Supervision - oversight, encouragement or cueing
   - Limited assistance - resident highly involved in activity; staff provide guided maneuvering of limbs or other non-weight-bearing assistance
   - Extensive assistance - resident involved in activity, staff provide weight-bearing support
   - Total dependence - full staff performance every time during entire 7-day period

7. Activity occurred only once or twice - activity did occur but only once or twice

<table>
<thead>
<tr>
<th>Item</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>A.</td>
<td>Bed mobility - how resident moves to and from lying position, turns side to side, and positions body while in bed or alternate sleep furniture</td>
</tr>
<tr>
<td>B.</td>
<td>Transfer - how resident moves between surfaces including to or from: bed, chair, wheelchair, standing position (excludes to/from bath/toilet)</td>
</tr>
<tr>
<td>C.</td>
<td>Walk in room - how resident walks between locations in his/her room</td>
</tr>
<tr>
<td>D.</td>
<td>Walk in corridor - how resident walks in corridor on unit</td>
</tr>
<tr>
<td>E.</td>
<td>Locomotion off unit - how resident moves to and returns from off-unit locations (e.g., areas set aside for dining, activities or treatments). If facility has only one floor, how resident moves to and from distant areas on the floor. If in wheelchair, self-sufficiency once in chair</td>
</tr>
<tr>
<td>F.</td>
<td>Dressing - how resident puts on, fastens and takes off all items of clothing, including donning/removing a prosthesis or TED hose. Dressing includes putting on and changing pajamas and housedresses</td>
</tr>
<tr>
<td>G.</td>
<td>Eating - how resident eats and drinks, regardless of skill. Do not include eating/drinking during medication pass. Includes intake of nourishment by other means (e.g., tube feeding, total parenteral nutrition, IV fluids administered for nutrition or hydration)</td>
</tr>
<tr>
<td>H.</td>
<td>Toilet use - how resident uses the toilet room, commode, bedpan, or urinal; transfers on/off toilet; cleanses self after elimination; changes pad; manages ostomy or catheter; and adjusts clothes. Do not include emptying of bedpan, urinal, bedside commode, catheter bag or ostomy bag</td>
</tr>
<tr>
<td>J.</td>
<td>Personal hygiene - how resident maintains personal hygiene, including combing hair, brushing teeth, shaving, applying makeup, washing/drying face and hands (excludes baths and showers)</td>
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</tbody>
</table>
**IRF: Inpatient Rehabilitation Facility Patient Assessment Instrument**

**Functional Status Items**

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<tr>
<th>Item</th>
<th>Description</th>
<th>ADMISSION</th>
<th>DISCHARGE</th>
<th>GOAL</th>
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<td>37.</td>
<td>Walk</td>
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<td>38.</td>
<td>Wheelchair</td>
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*The FIM data set, measurement scale and impairment codes incorporated or referenced herein are the property of U B Foundation Activities, Inc. ©1993, 2001 U B Foundation*
Ongoing Research Activity

Continue with interviews expanding to clinicians (e.g. physicians, nurses, therapist, social workers, etc.) as well as facility administrators.

Develop an electronic survey using the identified outcomes that will allow stakeholders from outside the geographic region to rate and rank the importance of rehabilitation outcomes.

Conduct comparative effectiveness analyses beginning with walking and communication outcomes for IRF and SNF rehabilitation.
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Thoughts & Feedback?

Comments & Questions?

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