Care Transitions for People with Dementia

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Disclosure Information

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Project Funding

- UniHealth Foundation
- Centers for Medicare & Medicaid Services (CMS) Community-Based Care Transitions Program (CCTP) under section 3026 of the Affordable Care Act of 2010
Objectives

- Identify necessary tools for effective care transitions for people with mid-stage dementia and their family caregivers
- Identify components of an effective care transitions training program for care transitions coaches
- Summarize key components of a successful practice-based program
Bringing medicine, patients and community-based services together.
Partners in Care Foundation

• Founded to develop and scale new, evidence-based models of care
• Bring Home and Community-Based Services (HCBS) into medical partnerships
• Address non-medical drivers of health outcomes:
  – Self-management of chronic conditions
  – Environmental factors
  – Social, economic and access issues
  – Medication issues in the home
  – Caregiver issues
The National CCTP Program:

- Community-based Care Transitions Program (CCTP) is a CMS pilot to test a proposed Medicare Benefit; ACA section 3026
- Goal to reduce 30-day FFS Medicare readmissions by 20%
- Funds community based organization (CBOs) to furnish evidence-based transition services to high-risk patients
- Improves patient flow/appropriate bed use
- 3-year funding
- Only 35/150 sites remain – including Partners/UCLA and Partners’ Glendale & Kern sites.
The CCTP requirements

• Clear targeting criteria
• Evidence-based interventions
• Serve FFS Medicare with A & B
• Not hospice eligible
• Identify and visit during hospitalization
• Provide transition services within 24 to 72 hours
Why CBOs

• Health happens at home – system needs eyes & ears in the home

• Discharge home – easy for things to go wrong
  – In-hospital processes like med rec not enough to prepare many patients

• Non-medical issues are vital
  – food
  – transportation
  – safe setting
  – caregivers/adequate support

• Self-management skills crucial
  – observing & reporting changes in condition
  – following up with physician
  – taking medications correctly
  – adherence to diet recommendations
  – physical activity
Ratio of Social to Health Service Expenditures
for Organization for Economic Co-operation and Development (OECD) countries, 2005.

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Focus of Community-based Transition Programs

- Engage chronic patients (&/or caregivers) to activate self-care & behavior change
- Follow post-discharge for in-home med rec and to ensure meds/services received
- Teach/coach regarding medications, self-care, symptom recognition and management
- Remind and encourage patients to keep follow-up physician appointments – ensure transportation
- Alternative non-clinical workforce – Social Workers/Coaches
Coleman Care Transitions Intervention (CTI)

• **Components**
  – Medication Reconciliation & Management
  – Personal Health Record (PHR)
  – Primary care and specialist follow-up
  – Knowledge of red flags re: symptom exacerbation

• **Hospital coach introduces patient/caregiver to program and assesses eligibility**

• **Field coach conducts home visit with patient/caregiver**
  – Introduces and provides Personal Health Record
  – HomeMeds data collection
  – Links patient/caregiver to resources/referrals
  – Assess patient healthcare goals

• **4 Follow-up calls to continue activation**
Bridge Transitions of Care Model

- Bridge (Rush Univ. Medical Center) social work telephone intervention for out-of-area and those who refuse home visit or cannot benefit from coaching (e.g., cognitively impaired)
- Call patient w/in 48 hours of discharge to assess needs
- Connect patient to resources over 30 days
- Ensure patients receive appropriate services at home post-discharge
- Ensure physician follow-up appointments
- Support caregivers to reduce stress and burden
# CCTP Results by Collaborative

<table>
<thead>
<tr>
<th>CCTP Site</th>
<th>Enrollees</th>
<th>Baseline Readmit Rate</th>
<th>Enrollee readmit rate</th>
<th>% reduction readmit rate</th>
<th># 30-day readmits</th>
<th># Readmits Averted</th>
<th>ROI</th>
<th>Net Savings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Westside</td>
<td>10,139</td>
<td>21.1%</td>
<td>13.0%</td>
<td>38.4%</td>
<td>1,318</td>
<td>821.3</td>
<td>109.3%</td>
<td>$6.6 mil.</td>
</tr>
<tr>
<td>Glendale</td>
<td>6,130</td>
<td>20.7%</td>
<td>13.4%</td>
<td>35.3%</td>
<td>821</td>
<td>447.5</td>
<td>88.6%</td>
<td>$3.3 mil.</td>
</tr>
<tr>
<td>Kern</td>
<td>7,176</td>
<td>20.7%</td>
<td>13.4%</td>
<td>35.3%</td>
<td>962</td>
<td>523.8</td>
<td>88.6%</td>
<td>$3.8 mil.</td>
</tr>
</tbody>
</table>
Why Focus on Alzheimer’s Disease and Related Dementias?
Dementia Prevalence in US (>60 yrs)

- 2001: 3.4 million
- 2020: 5.1 million
- 2040: 9.2 million

Substantial caregiver health and financial burden

Provider frustration
Average Annual Per-Beneficiary Cost of Care

<table>
<thead>
<tr>
<th>Medicare (Medicare)</th>
<th>Medicaid (Medicaid)</th>
</tr>
</thead>
<tbody>
<tr>
<td>$20000 (Medicare)</td>
<td>$10000 (Medicaid)</td>
</tr>
</tbody>
</table>

- **Average Cost of Care for Beneficiaries with Alzheimer's Disease and Other Dementias**
- **Average Cost of Care for Beneficiaries without Alzheimer's Disease and Other Dementias**

**Sources:**
- Alzheimers’s Greater Los Angeles
- UCLA Health System
- Partners in Care Foundation
A Revolving Door: Home to Hospital to Home

Dementia-related risks for hospitalization

- Falls
- Poor management of co-morbidities
- Seizures
- Poorly tolerated behavioral symptoms
- Caregiver burnout
A Revolving Door: Home to Hospital to Home

Dementia-related risks for re-hospitalization

- Poor understanding of discharge instructions
- Limited or no communication with the family/caregiver regarding care
- Mismanagement of medications or medical care
- Poor caregiver understanding of dementia and limitations on capacity
- Caregiver burnout
Most Existing Care Transitions Programs

- Focus on patients *without* dementia
- Patients with mid-stage dementia are *excluded*
- Activate the patient
- Do not focus on interactions with caregiver
- Do not link families to dementia-specific community resources and support services
Cognitive impairment is a major health problem that can complicate hospital stays and lead to readmissions. There is a need for tools and strategies to engage the family/caregiver.
Care Transitions Project With Dementia-Tailored Overlay
Dementia Care Transitions Project Goals

1. Adapt/develop tools and protocols for dementia caregivers, to overlay the Coleman/Bridge Programs to make them applicable to cognitively impaired elders

2. Implement the program among 250 caregivers from diverse cultural backgrounds

3. Conduct an ongoing evaluation and incorporate feedback to refine it

4. Disseminate the tools and protocols
Goal 1: Adapt tools/protocols

- Expand referral criteria to include mid-stage dementia
- Develop strategies for identifying eligible patients, involving the lead coaches (in-hospital)
Goal 1: Adapt tools/protocols

- Focus group with care transitions coaches
- Development of Dementia Care Transitions Notebook; translate into Spanish, Armenian, and Korean*
  - Goal of Notebook: tool for coaches to use in teaching families

*Jewish Family Services participated in the project, short-term, resulting in the development of a Korean language Dementia Care Transitions Notebook and evaluation tool
Goal 1: Develop tools

- Basics of disease
- Cognitive, behavioral, and functional changes
- Impact of disease on self-care
- Disease progression
How Well Can a Person with Alzheimer’s Disease Take Care of Himself/Herself?

In the beginning of the disease, the person with Alzheimer’s can make decisions and take care of himself/herself, but this will change. **Eventually, everyone with Alzheimer’s disease will need a person to help them with day-to-day care.** We call that person a “caregiver.”

In the middle stage of Alzheimer’s, a caregiver may need to help the person with:

- following hospital discharge instructions
- making sure the person with Alzheimer’s is not left home alone
- taking correct medicines
- bathing, dressing, eating, toileting, and other activities
- making doctor’s appointments and following the doctor’s instructions

Using the Hospital Discharge Plan to Understand Care

Look at the hospital discharge plan and write down the main things you, as a caregiver, need to do to help the person with Alzheimer’s. Remember that someone who has middle stage Alzheimer’s will need help with medications and overall care.

1) __________________________________
2) __________________________________
3) __________________________________

*If you did not get a hospital discharge plan or you lost it, call your doctor to ask for instructions.
Goal 1: Develop tools

- Activating and engaging family caregivers
- Self-management
- “Baseline”/sudden and unusual changes
- Medication administration and management
- Warning signs of pain
Understanding “Baseline”

Baseline is a word that doctors use to describe how a person usually thinks and acts. When someone has Alzheimer’s, his/her thinking and behavior can change, but it is usually a slow change.

What is “USUAL?”

Everyone is different, but you know what the person you are caring for is usually like. When someone has Alzheimer’s, they have some days that are better than others, but overall, they act and think in a certain way.

“My grandpa was usually a happy person. He would sing and dance. He never yelled or got angry. When all of a sudden he started yelling at people and saying mean things, I was concerned. It just wasn’t like him. I called the doctor immediately and it turned out that my grandpa had an infection. Once the infection was treated, my grandpa went back to being his usual nice and happy self.”
- Anonymous caregiver

Knowing When to Call the Doctor: Warning Signs of Health Issues & Common Causes of Delirium

- People with Alzheimer’s disease may not be able to tell you with words or full sentences that something is wrong. They may not be able to say they are not feeling well.
- You should call the doctor if you see that the person has had a sudden and unusual change in the way he/she is acting or thinking, or has a medical condition that is getting worse. These changes can happen over a period of several days.
- Be prepared to tell the doctor what the person is usually like (before he/she had the sudden and unusual change).

Write here what the person is usually like before the sudden and unusual change:

__________________________
__________________________
__________________________
__________________________

- If you think there is a medical emergency, call 911.
What are examples of sudden and unusual behaviors that you should look for?
Here are some examples of things that can happen SUDDENLY:

- major change in memory or mood
- increase in confusion
- not knowing where he or she is, or what time it is
- cannot pay attention
- angry, hitting, and yelling (becoming aggressive or violent)
- going to the bathroom in his/her pants or wetting the bed
- fever
- seizure

If you've seen a sudden and unusual change that concerns you, write it down and contact the doctor:

________________________________________________________________________

________________________________________________________________________

Write down the name and phone number of the doctor:
________________________________________________________________________

Taking Medications

People with Alzheimer's disease will eventually need help taking their medications. Taking too much of a medication, taking too little, or not following the directions can be dangerous.

You cannot rely on the person with Alzheimer's disease to take his/her medications; you will need to make sure the medications are taken correctly.

Also make sure that medications are locked up so they are out of reach.

Why is it important that you assist with medications?

You will help make sure that:

- the right medications are taken
- at the right time
- and the right amount

* When you see the doctor, take all of the medications, vitamins, supplements, and herbs with you.
Goal 1: Develop tools

- Home safety
- Challenging behaviors/IDEA! (Identify, Educate, Adapt)
- Caring for the caregiver/personal goal for caregiver
- Community resources, including Alzheimer’s Greater Los Angeles
Try Using IDEA!

Write down a behavior that has been challenging for you to deal with. Use IDEA! to break it down and figure out some possible solutions.

**Identify the problem**
The challenging behavior is ____________________

**Educate Yourself**

Understand the cause of the behavior
When do you see this behavior happening? ____________________
What are the things that seem to trigger the behavior? ____________________

Understand the meaning of the behavior
What might this behavior tell you about how the person is feeling?

**Adapt**

What can you try doing differently?

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**Common Challenging Behaviors and Possible Adaptations (Solutions)**

<table>
<thead>
<tr>
<th>Behavior</th>
<th>Possible Adaptations (Solutions)</th>
</tr>
</thead>
</table>
| Agitation/Combativeness | - Respond in a calm way; use a gentle voice  
- Offer encouragement  
- Use short, simple sentences  
- Make tasks more simple by breaking things down step-by-step  
- Give the person enough time to respond  
- Approach the person slowly and from the front  
- Avoid fighting with the person or correcting them  
- Distract the person with another enjoyable activity  
- Go for a walk  
- Find a quiet place to sit and relax  
- Find a comforting object (like a stuffed animal)  
- Don’t expect the person to do more than he/she can do  
- Keep the home calm, quiet, and clutter free |
| Dressing                | - Give the person extra time  
- Don’t act like you are in a hurry  
- Limit the person’s choices to two outfits; let him/her decide which outfit to wear  
- Lay the person’s clothes out in the order needed to put them on  
- Talk the person through getting dressed using short, simple, one-step instructions  
- If the person loves a certain outfit and refuses to wear anything else, buy several outfits that look the same  
- Use pants with elastic waistbands and pullover tops to make getting dressed easier |

“"My mother would scream every time we tried to bathe her. When I put myself in her shoes, I realized that it was cold in the bathroom and she was uncomfortable getting undressed. As soon as I made the temperature in the bathroom warmer and gave her extra towels to cover up, she stopped yelling. It was important to understand what was causing the yelling so I could make some changes to the environment.”

- Daughter and caregiver
Goal 2: Implement the program

- Five hour training for current CCTP CTI coaches, specific to cognitive impairment
- Lecture, vignettes, videos, activities, “try saying”
- Review of Care Transitions Notebook
Goal 2: Implement the program

- In-home visit and three phone calls in first 30 days after discharge
- For Bridge patient, notebook mailed after first call and then reviewed during subsequent calls
Goal 2: Implement the program

- Ongoing support through monthly group “huddles” with dementia care management expert, to address concerns and enhance skills of the coach

- Coaches discuss challenging cases, learn from experiences of colleagues, brainstorm strategies
Goal 2: Implement the Program

- **Goal**: Enroll 250 caregivers from diverse cultural backgrounds

- **Accomplishments:**
  - 211 caregivers are enrolled in the program for patients discharged from hospital from 11/21/14 through 1/7/16
    - The remaining 39 caregivers will be enrolled by 4/30/16.
  - 11% of the caregivers* identified as African American, 26% as Asian, 23% as Hispanic.
  - Caregivers were enrolled whose primary language was English, Spanish, Armenian or Korean.
  - 12 huddles with the coaches and a Dementia Care Specialist over 18 months.

*Enrolled caregivers who have been surveyed (N=87).
Goal: Conduct ongoing evaluations

Accomplishments:

- 88 caregivers (who received a $25 gift card) have completed a survey:
  - Conducted by telephone, 47 days, on average, after the patient’s discharge date
  - English, Spanish or Armenian
  - Takes 15-20 minutes to complete

Survey content:

- Caregiver and patient demographics.
- Caregiver relationship to patient, living situation and caregiver burden inventory.
- Caregiver’s knowledge and comfort with their caregiving responsibilities and medication management
- Patient behaviors the caregiver experiences as challenging in relation to use of the notebook.
- Patient’s subsequent ER and hospital utilization within 30 days of discharge.
Caregiver & Patient Demographics

**Caregiver**

- **Age** (n=87):
  - Average = 56 years
  - Ranges from 25 to 92 years
- **Education** (n=85):
  - 76% have 1+ years of college

**Patient**

- **Age** (n=88):
  - Average = 85 years
  - Ranges from 41 to 100 years
- **Education** (n=68):
  - 54% have 1+ years of college

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*Includes Native Hawaiian & Other Pacific Islander
**Middle East / North Africa*
62% of caregivers are either related to, or are the spouse/partner of the patient.

Over 60% of caregivers reported they have to watch the patient constantly.

<table>
<thead>
<tr>
<th>Caregiver answered &quot;Quite Frequently&quot; or &quot;Nearly Always&quot;</th>
<th>Caregivers (n=85)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient needs your help to perform many daily tasks.</td>
<td>67%</td>
</tr>
<tr>
<td>Patient is dependent on you.</td>
<td>67%</td>
</tr>
<tr>
<td>You have to watch patient constantly.</td>
<td>64%</td>
</tr>
<tr>
<td>You have to help patient with many basic functions.</td>
<td>48%</td>
</tr>
<tr>
<td>You don’t have a minute’s break from your caregiving chores.</td>
<td>22%</td>
</tr>
</tbody>
</table>
Caregivers’ knowledge and comfort with their caregiving responsibilities

- Caregivers are confident they can identify “red flag” symptoms and behavior and that they will take the appropriate action, such as calling a doctor or taking the patient to the hospital, if necessary.

<table>
<thead>
<tr>
<th>Caregiver answered &quot;Agree&quot; or &quot;Strongly Agree&quot; to the statement:</th>
<th>Caregivers (n=54)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel confident identifying red flags and calling the doctor if I see a sudden and unusual change in my family member or friend with Alzheimer’s disease.</td>
<td>90%</td>
</tr>
<tr>
<td>I can identify possible warning signs of pain in my family member or friend with Alzheimer’s disease.</td>
<td>90%</td>
</tr>
<tr>
<td>I can identify red flag behavior changes that indicate risk for hospitalization and readmission.</td>
<td>80%</td>
</tr>
<tr>
<td>I can name several resources for caregivers available through the Alzheimer’s GLA.</td>
<td>70%</td>
</tr>
<tr>
<td>I have made changes to my family member or friend’s home since his or her discharge from the hospital, to make it more safe.</td>
<td>40%</td>
</tr>
<tr>
<td>I have contacted Alzheimer’s GLA since my family member or friend was discharged from the hospital.</td>
<td>20%</td>
</tr>
</tbody>
</table>

**Note:**
1. These survey questions were asked only of caregivers who stated the patient had a diagnosis of Alzheimer’s, Dementia or Memory Loss.
Caregivers’ knowledge to assist with medication administration and management

- The three key concepts communicated to caregivers via the Notebook, regarding medication administration and management are:

  - Right Medication
  - Right Time
  - Right Amount

- As part of the survey, caregivers are asked:
  
  “Can you say what are the 3 things that are most important for someone like you to assist your family member or friends in taking their medications?”

<table>
<thead>
<tr>
<th>Included in the caregiver’s response to the above question:</th>
<th>Caregivers (n=83)</th>
</tr>
</thead>
<tbody>
<tr>
<td>All three key concepts</td>
<td>25%</td>
</tr>
<tr>
<td>Two of the three key concepts</td>
<td>30%</td>
</tr>
<tr>
<td>One of the three key concepts</td>
<td>6%</td>
</tr>
<tr>
<td>None of the three key concepts</td>
<td>39%</td>
</tr>
</tbody>
</table>

- Caregivers were most likely to remember the “right time” key concept.

Notes:
1. The question is open ended i.e. answers to the question are recorded verbatim and each answer, if relevant, is categorized into one of the three key concepts.
2. The question excluded caregivers who indicated that someone else has responsibility for the administration of medication.
Caregivers’ experience of the patients’ behavior

- Patient behaviors most frequently identified by caregivers as challenging are:
  - Arguing, irritable and/or complaining
  - Trouble remembering recent events
  - Waking up the caregiver or other family members during the night
  - Asking the same question over and over

- 70% of caregivers reported referring to the Notebook:
  - A caregiver is more likely \((\text{Chi-Square } p\text{-value } = 0.03)\) to refer to the Notebook if they experienced the patient’s behavior as challenging.

Note:
1. Twelve caregivers did not answer at least one of the two questions used to categorize a caregiver as having referred to the Notebook or not.
Self-reported ER and hospital utilization

Survey/phone interview questions of caregivers regarding Emergency Room (ER) visits and hospitalizations within 30 days of discharge:

- ER visits (one or more within 30 days of discharge) = 15%
- Hospitalization (one or more within 30 days of discharge) = 5%

among those caregivers who completed the phone interview.
Summary

- The program was successfully implemented with a culturally diverse population.

- Barriers to completing phone surveys were addressed and improved over time.

- Huddles with the coaches and a dementia care specialist were leveraged to make changes to the program to better emphasize and reinforce key concepts.

- Caregivers who needed the most help, used the materials/notebook provided.

- Overall, ER and hospitalization rates within 30 days of hospital discharge (based on self-report) were lower than historical reports.
Project Team

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