Improving Transitional Care by Involving Family Caregivers: The TC-QuIC Collaborative

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United Hospital Fund

- Nonprofit, independent health service research and policy organization in New York City
- Founded in 1879
- Mission: to improve health care for all New Yorkers and the nation
- Key issue areas include innovation, system redesign and chronic care
- Families and Health Care Project started in 1996 to advance partnerships between family caregivers and health care professionals
- Focus on transitions through Next Step in Care campaign
Next Step in Care: Three major activities

1. Transitions in Care-Quality Improvement Collaborative (TC-QuIC) – a collaborative focused on family caregivers in transitions

2. Work with community agencies to train staff to use Next Step in Care materials with family caregivers before a crisis occurs

3. Direct outreach to caregivers through Next Step in Care website – [www.nextstepincare.org](http://www.nextstepincare.org)
Next Step in Care provides easy-to-use guides to help family caregivers and health care providers work closely together to plan and implement safe and smooth transitions for chronically or seriously ill patients. Transitions are moves between care settings, for example, hospital to home or rehab facility, or the start or end of home care agency services. Because transitions

New Guide to Urgent Care

Our newest guide, A Family Caregiver's Guide to Urgent Care Centers, is available now. It answers questions regarding what urgent care centers are, how they can help, and when to go (and when to go to the ER instead).
Next Step in Care website

- 23 family caregiver guides
  - Newest guides: Urgent Care Centers, LGBT Caregiving
  - In preparation: Guide to Hospitalist Care
- All in English, Spanish, Chinese, Russian
- 6 guides for health care providers
- Quality improvement surveys for different settings
- Links and resources
- Guide on how to use website
- Glossary
Use of Next Step in Care Materials

- Website users from 50 states and many countries
- Most often downloaded:
  - Guide to hospice and palliative care
  - Guide to becoming a caregiver
  - Medication management guide and form
  - “What Do I Need as a Family Caregiver?”

Materials – single guides or combinations -- can be used in any transition program across sites and across disciplines
Coordinating Care after A Hospital Stay: Who’s the Patient in “Patient-Focused”?

- Current practice (with notable exceptions) assumes that the about-to-be-discharged hospital patient is well enough, strong enough, alert enough, and savvy enough to manage his or her own care, with a little information from hospital staff and a reminder to follow up with a primary care physician.

- Who is this perfect patient?
6 things to do when you leave the hospital

More than a third of hospital patients fail to get needed follow-up care once they get home, according to research from the Agency for Healthcare Research and Quality. To prevent that from happening to you, take these steps as you prepare for your hospital discharge:

1. **See a discharge planner.** You or your hospital helper should try to do this at least a day before you leave so your family, your doctor, or the hospital can arrange for monitoring or services you'll need at home.

2. **Decide if you're ready to go home.** Hospitals and insurance companies have strong financial incentives to discharge you as soon as possible. And for most patients, the sooner you get home the better. But if you don't feel ready, say so. You shouldn't go home if you feel disoriented, faint, or unsteady; have pain that's not controlled by oral medication; can't go to the bathroom unassisted; can't urinate or move your bowels; or can't keep food or drink down. If your doctor isn't able to extend your stay, appeal to the discharge planner, the hospital's patient advocate or, if available, a state appeals board.
Who Is Missing from The Previous Pictures? The Family Caregiver
Transitions Are Complicated
Why family caregivers are important to transitions

Many transition plans assume a considerable amount of family care. The best-laid transition plans will fall apart if one key partner—the family—cannot fulfill professional expectations.

- If family is not involved in planning, they may not understand what is expected of them.

- They also have no opportunity to refuse, or to have barriers accounted for in the care plan.
Why family caregivers are important to transitions

- “Low cognition at discharge is common among elderly patients without dementia.... and improves one-month post-discharge... Greater reliance on caregivers in discharge and post-discharge planning may help seniors who are identified with low cognition at discharge...” (Lundquist et al., J Gen Intern Med 26(7):765-70)

- To provide care, family caregivers need ongoing training and support.

- No one can absorb all the information and instructions given at discharge without follow-up. *Early preparation* and *post-discharge follow-up* are key.
“We want to include you in this decision without letting you affect it.”
Transitions in Care-Quality Improvement Collaborative (TC-QuIC)

- Round One April 2010-June 2011; Round Two June 2011-June 2012
- 37 teams from hospitals, nursing home rehab programs, home care agencies and hospice working in partnerships across settings
- Use IHI Model for Improvement (Plan-Do-Study-Act rapid cycles of change)
- Next Step in Care tools and other chosen materials
- Online community; 33 biweekly/monthly webinars and 4 all-day Learning Sessions
- Regular coaching and consulting
TC-QuIC Leadership

- **Co-chairs:** David Cohen, MD, Maimonides Medical Center; Audrey Cohen, DSW, Jewish Home LifeCare; Carol Levine, UHF
- **Co-directors:** Deborah Halper and Jennifer Rutberg, UHF
- **Faculty:** Regina Neal, QI consultant; Ann Wyatt, nursing home consultant; Carol Rodat, home care consultant; Amanda Norton, measurement consultant
- **Learning Session speakers:** Mary Naylor, U Penn; Richard Frankel, U Indiana; Anne Myrka, IPRO; family caregivers
- **Evaluation:** Lisa Payne Simon, Boston
- **Funding:** UHF, Altman, Langeloth, Ira de Camp Foundation, New York Community Trust

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Next Step in Care™
Family Caregivers & Health Care Professionals
Working Together
TC-QuIC Features

- Focus on family caregivers as “key learners” in transitions (Institute for Healthcare Improvement)
- Partnerships between facilities/agencies that share patients regularly
- Include transitions beyond hospital to home
- Involve regular staff (nurses, social workers, case managers, QI specialists, pharmacists, physicians)
- Based on belief that transitional care is every professional’s responsibility, even if there is a designated coach or navigator to support patient and family
Collaborative-Wide Results
December 2010-May 2011

- 1,086 family caregivers identified; only a third had needs assessed
- Participation of family caregivers in medication reconciliation increased from 53% to 84%
- Average of 3 medication discrepancies identified
- Medication reconciliation took place one full day earlier
- 95% of caregivers had questions about medications
- Training and education took place earlier in care episode (day BEFORE discharge in hospital; week before discharge in SNF)
- Caregivers reported better prepared; staff reported fewer post-discharge “fires to put out”
Individual Teams and Partnerships

- Teams that measured readmissions reported decrease – Maimonides and First to Care Home Care found only 4% readmission in CHF patients; Metropolitan and HHC Home Care reduced readmissions from 22% to 14%
- NYU Langone Medical Center and VNSNY created “Patient and Caregiver Dyad Assessment Tool” for patients with CHF
- Cobble Hill Nursing Home – simple change (increasing spaces between lines for medication instructions) made big difference in legibility, understanding
- Beth Israel Medical Center – used Chinese translation of Next Step in Care needs self-assessment
Evaluation

- Lisa Payne Simon engaged to conduct evaluation; semi-structured interviews of team participants, senior leaders, faculty; roundtable at Learning Session 4
- Faculty and staff had all-day retreat
- Consensus on positive aspects: TC-QuIC had firmly established importance of family caregivers in transitions; many providers described it as “eye-opening” and “rewarding”
- Consensus also on aspects that didn’t work as well: partnerships varied, data collection and analysis difficult for some teams, resistance from other staff; uncovering system flaws that affect transitions
Results of TC-QuIC Round One (con’t)

- Team building takes time
- Some partnerships work very well; others not so much
- Difficulty in data collection and analysis
- Culture change is difficult even when change is an improvement for staff
Changes for TC-QuIC Round Two

- 22 teams, several from Round One but with different participants
- Longer and more structured preparatory work
- Initial focus on internal processes; partnerships to come later
- More structured and intensive coaching
- Collaborative-wide measures introduced at outset; to include readmission data
- Four “Aims” redefined as six “Strategies” with more advice about how to test change
TC-QuIC Round Two: Goal, Foundation, and Method

**Goal**: To improve transition process and outcomes by including family caregivers of seriously and chronically ill patients in decision making and providing focused information, preparation, and training.

**Foundation**: Early identification of family caregivers and self-assessment of needs for training and support

**Method**: The Institute for Healthcare Improvement Model for Improvement (Rapid Cycle Tests of Change)
Foundation: Identifying Family Caregivers

- Not done systematically in hospitals or nursing home rehab programs or home care
- Assumptions may be wrong
- Even if correct family caregiver is identified, information may not be added to patient’s chart
- Need to ask patient, “Who helps you with your medications?”
- May be more than one family caregiver
- Find out who does what; important for coaching
TC-QuIC Round Two: Strategies

1. Inclusion of family caregiver in medication reconciliation
2. Identification of post-discharge patient needs and discussion of discharge options with the family caregiver
3. Discharge preparedness (training, expectations of the day of discharge)
4. Well-orchestrated day of discharge
5. Closing the loop (communication of post-discharge outcome with family caregiver and receiving agency)
Results from Preparatory Work

- Longer prep time allowed teams to map processes, review charts, and survey family caregivers
- Differences among staff about what process actually is and who is responsible for what
- Longer time needed to prepare for data collection and analysis
Lessons Learned

- Reducing readmissions may compete with reducing LOS
- Primary focus on reducing costs may overshadow goal of improving quality
- Need more than technical changes or better forms -- changing culture (behavior and attitudes)
- Improvements have to work across shifts and settings
- Cross-institution collaboration (care coordination) requires more than a corporate structure
- Staff who work on coordinating care have to be motivated and willing to work with partners and to accommodate different requirements
Future Challenges

- Cooperation among patients, family caregivers, hospitalists, and PCPs in rapidly changing environment
- Education of patients and family caregivers about hospitalists’ role
- Better understanding of what care coordination entails and who is best suited to do what aspects
- Collaboration with community agencies; closing the gap between medical and “social” care
- Communication involving listening not just talking
Policy Implications

- If family involvement in transitional care is really valued, then it must be:
  - Recognized in specific actions
  - Measured in meaningful ways
  - Paid for appropriately
  - Monitored for accountability
Works in Progress

- **National survey of family caregivers** to determine what medical/nursing tasks they perform, who (if anyone) trained them, and what impact that performing this type work has on their lives (e.g. health, relationships, mood, quality of life, finances)

- **Broader dissemination of Next Step in Care through community service providers** to prevent crises and hospitalizations

- **Bringing TC-QuIC materials to the website** so that other providers can use them
Improvements don’t just happen.

Our thanks to our fellow employees for their hard work. And solid results.
Thank you!

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