TRANSPLANT EDUCATION FOR PATIENTS AND FAMILIES: AN ORGANIZATIONAL-WIDE PROCESS

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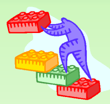
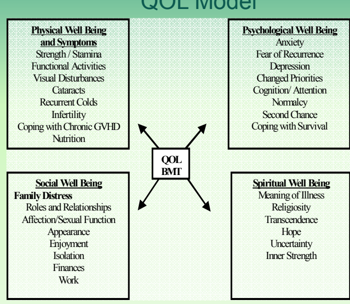
History of COH Discharge Teaching Research

- Quality of Life studies with HCT pts began at City of Hope in 1991 for Tool validation
- Retrospective Chart Review in 2000 of 100 HCT patients looking at readmission patterns. (published 2005 in ONF)
- Pilot study of 10 patients with an educational intervention 2002-2003
- Caregiver research 2003-2005
- **Five Year NCI-Funded Grant (SNIP) for total of 282 patients began in 2005-2010**



Preliminary Studies…

Development of QOL measurement and resulting QOL Model


Physical Well Being and Symptoms
Strength / Stamina
Functional Activities
Visual Disturbances
Cataracts
Recurrent Colds
Infertility
Coping with Chronic GVHD
Nutrition
Psychological Well Being
Anxiety
Fear of Recurrence
Depression
Changed Priorities
Cognition/ Attention
Normalcy
Second Chance
Coping with Survival
QOL BMT
Social Well Being
Family Distress
Roles and Relationships
Affection/Sexual Function
Appearance
Enjoyment
Isolation
Finances
Work
Spiritual Well Being
Meaning of Illness
Religiosity
Transcendence
Hope
Uncertainty
Inner Strength

Grant, et al, 1992; Ferrell et al, 1992; Schmidt, et al, 1993; Grant, 1999

SNIP Design and Study Variables

HCT Patients undergoing allogeneic transplant

- Sociodemographic Characteristics
- Disease and Clinical Factors
- Transplant Factors

Assignment

Group 1 (SNIP)
- Assessment
  -Baseline, 100 Days, 6 Months, 12 Months
- Teaching
  -6 home teaching visits post discharge
  -9 months telephone reinforcements

vs.

Group 2 (Attention Control)
- Assessment
  - Baseline, 100 Days, 6 Months, 12 Months

Outcome Measure
- Quality of Life
- Functional status
- Time to first complication
- Total number of complications
- Unscheduled readmissions
- Treatment response

Additional data for Group 1
1. Post-teaching debriefing information
2. Post-teaching knowledge
3. Referrals/resources provided

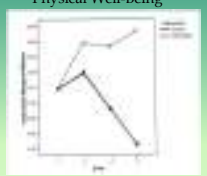
Intervention Highlights

Intervention was **tailored**, included **family** and friends, included in-depth **psychosocial** history/strengths, emphasized patient's and hospitals **resources** for support and referrals, and was **relationship-based** for one year follow-up.

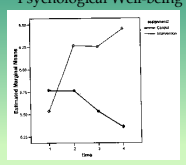
- What were the outcomes?

Quality of Life Dimensions

Physical Well-Being



Psychological Well-being

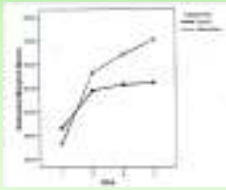


Social Well-Being

Spiritual Well-Being

Continued Results

- High Satisfaction Scores
- Mortality: 16% (intervention) versus 25% (control)
- Higher functional Status
- SF-36 Physical Functioning



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How To Package and Wrap Housewide?

Identification of Five Roles of Nurses Involved in the Trajectory of Care

- Nurse Coordinators
- Advanced Practice Professionals
- Case Managers
- Inpatient Transplant Unit
- Outpatient Transplant Unit

Five Roles of Nurses Involved in the Trajectory of Care to Build Capacity

- Nurse Coordinators
- Advanced Practice Professionals
- Case Managers
- Inpatient Transplant Unit
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Pre-Implementation Nurse Coordinators Role

STABLE ROLE ELEMENTS

- New patient screening and scheduling
- Pre-admission Care Coordination
- Protocol Management

ROLE ELEMENTS NEEDING CHANGE

- Patient and Family Education
  - Varied between nurse
  - Hand-off at the time of admission inconsistent
  - No continued follow-up after admission

Nurse Coordinators Role Change Implementation

1. Established a Baseline level of Knowledge
   - Initiated monthly articles on Hematology
2. Created a Standard Educational template (next slide) as a part of an entire teaching trajectory
3. Initiation of an ongoing class taught by transplant coordinators on "Preparing for Transplant"
   - Taught each day for patients and families
4. Increased the length of relationship with the patient and family
   - Throughout transplant until 100 days
5. Assessed for psychosocial issues
   - Referrals to social work, psychiatry

Nurse Coordinators Role "Topics to Teach"

Pre-Transplant Education	Period of admission planning	Transplant Admission	Post Transplant
• Treatment Plan/work-up schedule including discussion of disease and rational for regimen. • Protocol/ transplant consent with expected side effects • 3. Educational tools provided (Blood and Marrow Stem Cell Transplant Binder) • 4. Teaching on countdown, side effects, engraftment, and discharge criteria.	• Caregiver contract and caregiver education.		• Follow-up Phone call after discharge • Post transplant overview, resources, and long-term follow-up.

Nurse Coordinators Role Change Implementation Measurement

- **Established a Baseline Level of Knowledge**
  - **Online Survey to measure competency in 16 areas : 61% were proficient with 39% beginner**
- **Created a Standard Educational template**
  - **Teaching was Observed and feedback given per Rubric Tool x 4 areas: 88% mean score on performance**
  - **Performance Evaluation includes teaching competent as a measurement**
- **Other aspects of role not affected by increasing teaching capacity**
  - **Transplant Essential data requirements are captured (TED): 100%**

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Pre-Implementation APP Role

STABLE ROLE ELEMENTS

- APP Staff of 20: 4 PAs and 16 NPs with a focus on both Inpt and Outpt Hem/transplant coverage
- Five teams of MDs with approximately
  - 3-4 APPs on each team

ROLE ELEMENTS NEEDING CHANGE

- Patient and Family Education for Discharge
  - varied between APPs
  - with Long Term follow-up information sporadic

APPs Role Change Implementation Measurement

- Established a Baseline Level of Knowledge
  - Two-session "Educational topics" intervention
- Created a Standard of Practice for discharge teaching for all APPs
- Instituted a Yearly test to establish baseline performance for all NPs
- Made long-term follow-up 6mo, 12mo and 2 year printouts easily assessable to staff
- Started a bi-monthly class with social work in the inpatient setting for family and patient about home transition.
  - Done twice a month
- Instituted a "Day 10 Huddle" on the inpatient unit
  - With social work and case management to discuss discharge

Advanced Practice Professional Role "Topics to Teach"

Transplant Admission and first weeks	Seven Days before discharge	72 hours before Discharge	Discharge Day
• Trajectory teaching • Regimen related side effect management • Day 10 huddle with social worker, case manager on barriers to discharge	• Knowledge of line care • Fatigue conservation • Symptoms to report and why • Sexual issues • Depression risk • Caregiver attends psychosocial class	• Infection precautions, • Discharge meds • Pets/home, • clinic routine for follow-up • psychosocial topics • Review	• Medication reconciliation • Review of content • Next follow-up appointment

Advanced Practice Professional Role Change Implementation Measurement

- **Measurement of weekly educational episodes after implementation:**
  - **General teaching < 30 minutes: 8 episodes**
  - **General teaching > 30 minutes: 3 episodes**
  - **Discharge teaching < 30 minutes 7 episodes**
  - **Discharge teaching > 30 minutes 2 episodes**

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Pre-Implementation Case Manager Role

STABLE ROLE ELEMENTS	ROLE ELEMENTS NEEDING CHANGE
Case Management staff with varying transplant knowledge	No follow-up of patients after discharge from hospital by case manager
Role of consisting of pharmacy authorizations equipment coordination securing housing	No discharge teaching done by the case manager
Assignment by MD teams	Little communication with the inpatient service except at time of discharge

Case Management Role Change Implementation

- **Established a Baseline Level of Knowledge**
  - **Two-session "Educational topics" intervention on trajectory expectations for their role**
- **Instituted comprehensive Standard of Practice**
  - **With expected professional behaviors per a timeline reflecting the regulatory guidelines of their role**
- **Discussion of expansion of their nursing role to include**
  - **Early discharge planning assessment,**
  - **With early identification of potential barriers, and educational needs**
  - **Weekly progress notes,**
  - **Family conferences, and**
  - **Follow-up phone calls.**

Case Manager Role "Topics to Teach"

Within 24-48 hours after Admission	Within 72 hours and establishment of weekly notes	Weekly Notes And Mid-point Huddle	Within 24-72 hours of discharge	After Discharge Follow-up Phone call
• Discuss CM role, • initial assessment to barriers, • caregiver plan	• Barrier assessment: identification of physical, psychosocial, insurance-related, transportation, financial, lodging, other	• Weekly Assessment and Progress Note covering condition/complication/ progress, discharge plan, housing, daily communication with CSW and NP, barriers, educational milestones	• Who to call, • How to manage VAD, • Diet, • Exercise • Caregiver has attended class • Review discharge medications	• meds • symptoms, • support at home, • need help with coordination

Care Management Change Implementation Measurement

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Pre-Implementation Inpatient Staff RN Role

STABLE ROLE ELEMENTS

- Staff of 180 for two 36-bed units
  - Autologous
  - Allogeneic
- Mix of both seasoned staff and new grads
- Some variation with discharge teaching
- Not clear distinct roles of discharge care between the case manager, Midlevel, and staff nurse

ROLE ELEMENTS NEEDING CHANGE

- Some variation with discharge teaching
- Not clear distinct roles of discharge care between the case manager, Midlevel, and staff nurse

Inpatient Change Implementation

- **Established a baseline expectation of teaching**
  - Discussed at several staff meetings about the comprehensive approach to discharge teaching
  - Created 4 teaching videos for staff to access outlining the expected time from admission to discharge and covering both content and expected behaviors
- **Created an interdisciplinary carepath as a poster of the trajectory of teaching behaviors displayed in the conference rooms**
  - Outlined roles of all health care professionals who see inpatients in the inpatient transplant admission
  - Created accompanying flow sheets for charting the teaching behaviors

Inpatient RN Role "Topics to Teach"

First week of stay	Within 7 days of discharge	72 hours Prior to discharge	Discharge
•Orientation to transplant schedule •Orientation to transplant activities (calendar of activities) •Orientation to support personnel (CSW, chaplain, rehab, dietician) •Transplant Education focused on inpatient needs (admission to discharge prep) •Trajectory of transplant •Regimen discussion and expected side effects: •Common Medications •Expected transplant-related symptoms: rash, GVHD, immune issues •Assess for psychosocial distress (use distress thermometer and refer to appropriate support personnel	• Diabetic teaching • Begin diet teaching • Home preparation • Fatigue conservation • Begin teaching on discharge medications • VAD care • Teaching on symptoms management at home and what symptoms to report to • Discuss psychosocial topics of sexuality, depression, caregiver fatigue, role and family disruption, and assess for refers if needed Staff RN	• VAD care* • Neutropenia and infection precautions • Fatigue conservation • Reportable symptoms • Psychosocial topics of depression, sexuality, caregiver fatigue, role changes, family disruption, help for children • Pets • Clinic routine	• Discharge medications • Formal discharge instructions • Follow-up appointment through TSR • Medication/DME authorization Case Management • Village coordination • Medication reconciliation, finalize the prescriptions Nurse Practitioners • Long-term survivorship teaching*

Inpatient Change Implementation Measurement

- None= EMR has arrived

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Pre-Implementation Outpatient Transplant Staff RN Role

STABLE ROLE ELEMENTS

Outpatient Day Hospital
- 10 beds
- New staff

ROLE ELEMENTS NEEDING CHANGE

Multidisciplinary Team to break down tasks of needed information for patients
1. Research/Quality protocol
2. Nurse Education
3. Policy and Procedure support
4. Day Hospital Forms
5. Patient and Caregiver Education

Outpatient Transplant Staff Change Implementation

- **Quality Data on**
  - Clinical, operational, quality
- **Communication with MDs**
  - Inclusion and discharge criteria
- **Nurse Education**
  - Both clinical and educational competency
- **Supportive Documentation**
  - Forms including algorithms and flowsheets
- **Patient and Family Education**
  - Off hours problems solving
  - Flowsheet for caregiver for symptom management

Outpatient RN Role "Topics to Teach"

First week of stay	Within 7 days of discharge	72 hours Prior to discharge	Discharge
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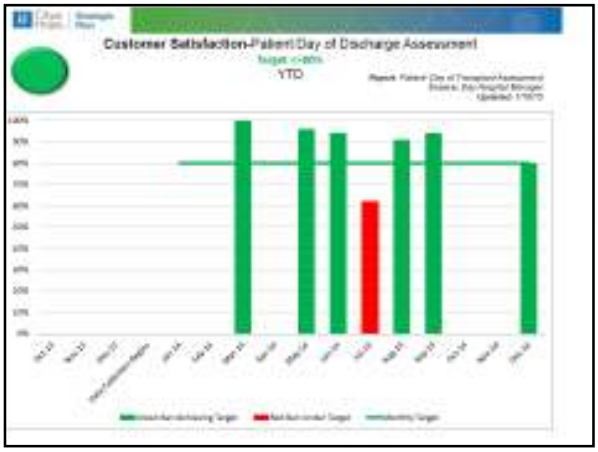
Outpatient Requirement for Daily Discharge

Symptoms	Yes	No
Afebrile		
Pain score less that "4"		
Alert, and orientated x 3		
BP, HR and RR WNL		
Clear lungs		
Heart rate regular rate and rhythm		
Able to drink without vomiting		
WHO Mucositis Grading Score less than 3		
Less than 3 episodes of diarrhea in 24 hours		
Last check of chem-7 Electrolytes WNL or treated		
Urine output within the last 3 hours		
PU Caregiver able to verbalize symptoms since last visit		

Outpatient Change Implementation Measurement

- 30-day and 100 day treatment-related mortality,
- Infections, incidence and severity
- GI-related complications and symptoms
- Admissions within 100 days
- Length of stay in the day hospital
- Engraftment data
- Evidence of DVT
- Readmissions within 100 days
- Reasons for readmissions
- Evidence of charted patient and family education,
- Patient and caregiver preparedness, and
- Number of ETC visits
- Patient satisfaction with financial support, lodging, transportation, quality of life, obtaining medications and the outpatient experience.



Summary

- Change is challenging for an organizational system
- A Consistent approach is best
- Needs CNO backing
- Build in sustainers of change
  - Managers
  - Educators
- Clear role expectations
- Measure success to support change
- Be flexible to accommodate how change needs to occur in various settings.