



Improving the Quality of Care Delivered to Healthy Related Donors: Implementation of a Related Donor Team

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Bone Marrow and Stem Cell Transplant Program University of North Carolina

- FACT accredited Adult and Pediatric Transplant, Collection and Processing Center
- NMDP Marrow and Apheresis Collection Center
- 16-bed Hepa-filtered unit
- Adult and Pediatric combined inpatient BMTU
- Outpatient (OP) BMT Clinic/Infusion areas
- Pediatric patients seen in OP Peds Hem/Onc clinic

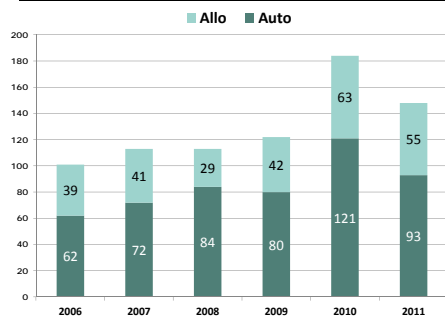
Located on the Campus of UNC-Chapel Hill



North Carolina Cancer Hospital



Yearly Transplants 2006-2011



UNC-CH BMT Program Staffing

- 7 Adult and 2 Pediatric BMT Physicians
- 5 Adult Advanced Practice Professionals (APPs)/ 1 Pediatric APP
- 7 Transplant Nurse Coordinators
- 3 Data Managers
- 1 Financial Coordinator
- 3 Administrative Personnel
- 9 OP Clinic RNs

Transplant Nurse Coordinators

- Each Adult Nurse Coordinator is paired with a specific physician (or physicians)
 - One specific Pediatric BMT Nurse Coordinator
- Coordinates all pre-transplant functions
 - Further therapy as required
 - Pre-admission work-up
 - Clearance/regulatory documentation
- Historically provided coordination of care for their recipient's related donor as well

Related Donor Dilemma - They're a patient, too!

- 2009 – 17 related donors
- 2010 – 28 related donors
- 2011 – 17 related donors*
- Total 2009→ Sept 2011 = 62 related donors audited

* 11 more related donors were collected in the 4th quarter of 2011. Total related donors processed through the program for 2011 = 28

Related Donor Audits

- All related donor charts since 2009 audited for:
 - Completed HHQ (including significant PMH, reviewed by a provider and documented in EMR)
 - Required laboratory studies including IDMs
 - Documentation of potential venous access
 - "Release of Medical Records" form signed/on file
 - Pregnancy assessment(s) as applicable
 - Donor suitability documented in both donor's and recipient's EMR
 - Review of abnormal results w/donor documented
 - f/u recommendations documented as well
 - Follow-up phone call w/donor within 72 hours of donation

Inconsistent Compliance

- IDMs and appropriate lab work – 100%
- Blood Transfusion or other pertinent medical history – 76%
- Signing of Release of Medical Records - 11%
- Donor Consent documentation in EMR – 70%
- Documentation of donor clearance in both recipient's and donor's EMR (41% and 29% respectively)
- Documentation of review of abnormal results with f/u recommendations – 25%

Interventions

- Detailed checklist to help seven (7) Transplant Coordinators (TCs) navigate institutional and regulatory requirements
- Scripted documentation to ascertain compliance in the appropriate EMRs
- One-on-one coaching with each TC
- Scripted coaching with each APP & MD providing donor evaluation/clearance services

Factors Affecting Compliance

- Some improvement - compliance decreased as donor numbers increased
- Inconsistencies from Coordinator to Coordinator
- Inconsistencies from Provider to Provider
- Small number of donor work-ups per Coordinator
- Cryopreservation prior to admission

Interventions

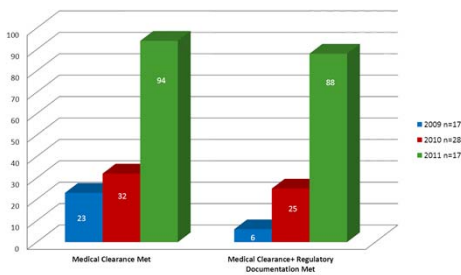
- **Dedicated *Donor Advocacy Model* developed**
 - Implementation January 2011
 - Separate Donor Medical Team
 - Related Donor Nurse Coordinator role established separate from recipient's primary Transplant Coordinator
 - Separate BMT Physician from recipient's primary BMT Physician
- Purpose:**
 - To avoid conflict of interest, provide unbiased care to the donor and provide one dedicated Transplant Nurse Coordinator to care for ALL related donors.

Related Donor Coordinator

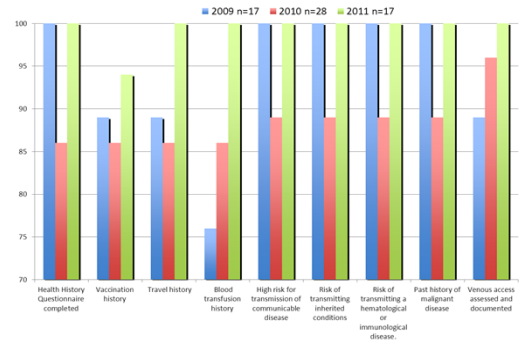
- Registered Nurse / Transplant Coordinator Role
 - Quality Management Nurse Coordinator
 - FACT Nurse Coordinator
 - Safety Coordinator
 - RITN Coordinator



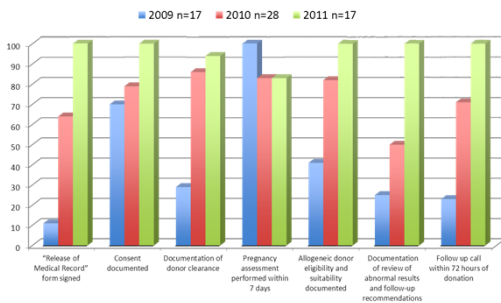
Improvement in Medical and Medical/Regulatory Compliance from 2009 to 2011



Medical Clearance/Compliance



Regulatory and Institutional Compliance

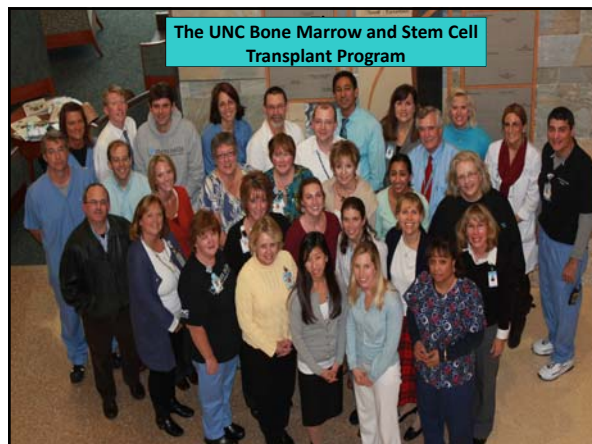


CONCLUSIONS

- The creation of a separate *Related Donor Coordinator* role had a significant impact on compliance improvement in all areas.
- Donor advocacy has risen to a new level.
 - Seen privately without family members present
 - Opportunity provided for one-on-one assessment without additional pressure
 - Separate team focuses solely on donor

Future

- Inclusion of UNC Comprehensive Cancer Support Program in evaluation
 - Clinical Psychologist to be included as part of the donor evaluation process
- Fresh products
- Higher donor awareness
- Donor appreciation



Acknowledgements

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Questions?

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Thank you for your interest!

Using Skin Rounds to Enhance the Care of the Integumentary System in a BMT Population within an Urban Adult Teaching Hospital

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in partnership with the Seattle Cancer Care Alliance



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Objectives

- Understand why skin care is critical in a BMT population
- Obtain knowledge of how the skin rounds program was developed
- Evaluate outcomes from the program and future objectives



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Background

- UWMC is an urban adult teaching hospital
- This unit has 22 BMT acute care beds and 6 oncology ICU beds
 - One of four units that provides inpatient care for the SCCA/FHCRC
 - Only adult ICU unit within the alliance



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Evaluate the Need



- Aggressive skin care in BMT patients is critical
 - Chemotherapy/radiation and graft-versus-host disease change skin integrity
 - Damage to skin integrity can cause increased risk of infection and prolonged care of these patients



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Evaluate the Need

- Lack of awareness and knowledge regarding skin care
 - Two reportable pressure ulcers in last year
 - Misidentification and documentation of skin issues
 - Few standard interventions established
 - Increased anxiety among staff and patients regarding skin care



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Develop a Plan

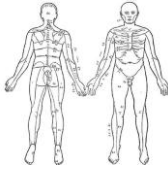
- Skin Assessment Rounds
 - Done once a week by two unit based RNs
 - Perform head to toe skin assessments
 - Discuss findings with RN and help complete necessary tasks
 - Identify skin issues early and establish correct documentation and care



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Develop a Plan

- Collaborate with multidisciplinary team, patients, and family about skin care
- Be a resource to help provide exceptional skin care to all patients
- Provide continuing education to nurses who perform skin rounds



Implementation

- Recruit unit based RN's who are interested in skin care
- Initial training
 - Attend a wound care workshop provided by the hospital
 - Round with Wound Ostomy Resource Nurse and experienced "Skin Rounds" nurses
- Weekly rounds on both day and night shifts performed
 - Prioritize patients based on acuity and Braden Scale

Implementation

- Continuing Education
 - Quarterly skin team meetings with "Skin Rounds" nurses from all units and Wound CNS
 - Dedicated wound workshops
 - Wound care and "Skin Rounds" binders
- Resource for unit
 - Work with unit based and local practice councils
 - Address issues at education days

Outcomes

- Difficult to initially evaluate program based on incidence of wounds
- Formal survey of staff nurses showed increase in staff satisfaction and skin awareness
- Feedback from patients and family showed decreased stress and increased satisfaction

Outcomes

- Increased accurate identification and documentation of skin issues
- Increased initiation of prevention measures
- Increased awareness of skin care unit wide



Future Steps

- Continue to build skin care team
- Develop tool to identify high risk patients
- Further evaluate effectiveness of skin rounds
- Expand skin rounds to other BMT units in UWMC
- Partner with outpatient BMT clinics to provide continuum of skin care
- Utilize skin team to help implement other interventions that affect skin

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Thank You



Supporting parents during their child's HSCT treatment depends on their parental type



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Psycho-social strain

- ▶ HSCT **interrupts** the parent's and the children's social and professional lives (Foxall et al. 1996, Kronenberg et al. 1998, Vannatta et al. 1998).
- ▶ The parent's **relationship and family function** are placed under **pressure** and the children experience an increasing **dependency** on their parent's, while both have to deal with an **uncertain future** (Clarke et al. 2008, Lesko 1994, Manne et al. 2002).
- ▶ How parent's **cope** with the strain of the child's disease and treatment is related to the parent's **emotional well-being, prior negative life experiences, the home environment, coping strategies and the level of social support** they receive. (Barrera et al. 2008, DuHamel et al. 2007, Manne et al. 2004, Rini et al. 2008, Vrijmoet-Wiersma et al. 2009).
- ▶ Parent's have an **increased level of anxiety and depression.** (Phipps et. al 2005).

Around-the-clock parental care responsibilities during HSCT

- ▶ Master the **isolation requirements**
- ▶ **Primary care** (bath, toilet assistance, food and drink, entertainment)
- ▶ **Complex care tasks** (oral medicine, tube feeding)
- ▶ Assist and **mediate** when nurses performing complex care tasks (tube placement, physical activity training)
- ▶ Emotional **support** to the child

We observed

We observed:

- ▶ Parents have **different approaches to the care** of the child during HSCT

Conflicts definition

- ▶ Conflict: a **disagreement through which the parties (parents, children and/or nurses) involved perceive a threat to their needs, interests or concerns.**
- ▶ **Disagreement** - ...some **level of difference in the positions of the parties involved...**But the **true disagreement** versus the **perceived disagreement** may be quite different from one another.
- ▶ In fact, conflict tends to be accompanied by significant levels of **misunderstanding** that exaggerate the perceived disagreement considerably. If we can **understand the true areas of disagreement**, this **will help us solve the right problems and manage the true needs** of the parties.

(<http://www.ohrd.wisc.edu/onlinetraining/resolution/aboutwhatisit.htm>)

Purpose

- ▶ ...to gain knowledge from a qualitative, interactionistic perspective regarding parents' experiences and reflections of their role as primary caregivers in administering care for a severely ill child treated with HSCT during the inpatient period.

Materials and methods

Inclusion criteria:

- › Parents to children under 18 years of age treated with allo HSCT.
- › Parents who were primary caregivers during the inpatient period.

Exclusion criteria:

- › Parents who did not speak Danish.
- › Parents to terminally ill children.

Data collection period: 2007 – 2009

Data:

25 daily observational studies (childs inpatient isolation period),
21 in-depth interviews with parents at day +100



Theoretic context

Max Weber

4 categories of ideal types of behaviour:

- › **Goal rationale** (best and most efficient way to achieving a specific goal),
- › **Value rationale** (belief in a certain value e.g. ethical, religious),
- › **Emotional rationale** (based on emotions)
- › **Traditional rationale** (based on traditions)



Arlie Hochschild

- › **Positional and personal control system**
- › (Emotion management, surface- and deep acting)



Results

Four different categories of approach:

- › Expertise-mindedness
- › Dialogue-mindedness
- › The approach of the socially challenged
- › The traditionally oriented parents

Expertise-minded parents

- › **Act according to medical, nursing and the HSCT-unit's standards**
- › **Seek expert knowledge** (the staff, internet, second opinions)
- › **Challenge the medical staff's knowledge** and evaluate their answers against their own level of knowledge
- › **Limited acceptance for deviations** (child and staff)
- › **Preserve the medical system**

Mother to a 6-year-old boy

"...You need to know as much as possible about the transplant process. I'm the type of parent who verifies everything that's been said, done or given on the Internet. I need to know everything, and the more I know the calmer I become ...It's very complicated and I think that I have learned an incredible amount about leukemia, ...I can enter into a qualified discussion with the doctors"

Dialogue-minded parents

- › Wish to **include their and the child's values and expectations** into the care.
- › Parents are **carrier of the child's values**
- › Expects the staff **to honor the families values**
- › During **dialogue** with the medical staff, they seek to **concentrate on procedures** that include the child's opinion and that **minimally compromise the child's autonomy**.
- › Try to **twist procedures** according to their values and may reject hospital procedures if they see as irrational or emotionally damaging to their child
- › **Challenge hospital procedures** by questioning their rationale and if they make sense.

Mother to an 11-year-old boy

"...One day I made a deal with my son that if he took one of the three pills orally then the rest could be administered intravenously. I didn't consider the nurses in this deal which resulted in a conflict with the nursing and medical staff, since the procedure prescribed that he should take the medicine orally."

Socially challenged parents

- ▶ Parents with **limited** physical, mental, emotional or social **capacity to take care of their child** when treated with HSCT.
- ▶ When the **child's needs** for care **increases** then it **exceeds the parents capacity** and the child is perceived as a **stress factor**
- ▶ Parents rationality for care are based on **short time management**.
- ▶ **Seek support** from the staff, but **worry** that the staff may find them **inadequate to care of their child**.
- ▶ **Challenge the medical system** by their deficit of resources and their need for support from the staff
- ▶ **Conflicts** arises when the parent are not able to support the child practically or emotionally

Observational study

A divorced, dyslexic mother to a 3-year old girl from an immigrant family who does not speak, read or write Danish is faced with the challenge of administering the daughter's medicine, understanding information and communicating changes in the daughters medical condition.

Traditionally oriented parents

- ▶ Base their rationality for care on **how things are normally done in their family/culture**.
- ▶ Parents are **carrier of the traditional values** and believe they are **transferable to new situations**, and thereby **disregard new information** if they conflict with their traditions.
- ▶ Do **not** enter into **dialogues** with the staff regarding procedures or **challenge** the medical rationality
- ▶ **Challenge the medical system**, by their **disbelief** in the importance of **medical standards**

Mother to a 6-year-old girl

- ▶ "Normally, we brush my daughters teeth twice a day, but during the the HSCT we were asked to do it more frequent. However, if she didn't want to perform the extra oral hygiene -we simply skipped it and put an x on the paper, indicating that we had done it."

Conclusion

- ▶ The parents underlying **rationale are reflected** in how they provide **care** and engage in **interactions** with the child and the staff.
- ▶ **Conflicts arises** when parents **perceive a threat to their needs, interest or concerns** and these conflicts are often exaggerated when **discrepances between true disagreements and perceived disagreements** are involved.
- ▶ Understanding the **parents rationale** may help us to understand the **true discrepancies** and solve the **right problems and true needs of the parents and children**.
- ▶ These four ideal constructions **may assist the staff to understand the parents** underlying rationale for care, **facilitate communication** with the parents and **provide a new perspective** on the complex interaction between parents, children and staff during the child's HSCT.

Thank you



Transition Nursing

The Bridge Between Inpatient and
Outpatient in Bone Marrow
Transplant Patients

Transition Nursing

- Safety of the patient during the initial 24 hours between discharge from the inpatient setting and returning to the outpatient clinic

Purpose of Transition Nursing

- Provide education for patients and caregivers
 - self-care
 - medications administration
 - anticipated side effects, sign and symptoms to monitor and report

Purpose of Transition Nursing continued

- Provide Coordination of services across sites of care
 - outpatient providers
 - insurance case managers

Caregiver Classes Topics

Types/Phases of transplants
Role of the patient and caregivers
Infection control
Symptom management

Discharge Guidelines

- Symptoms of GVHD
- Home care plan and potential home schedule
- Ambulatory clinic routine and expectations
- Infection control at home

Common Discharge Medications

- IV hydration
- IV antibiotics
- IV anti-fungal agent
- Insulin
- Lovenox

Communication with Outpatient Team

- What IV infusions and who is providing them
- Isolation precautions
- Any concerns (i.e. caregiver knowledge, patient anxiety)
- Need for interpreter

Other responsibilities

- Communication with insurance providers
Coordination of discharge to home providers
- Continuing IV infusions
 - Central line care

Outcomes of Transition Program

- Decreased number of days inpatient
Low re-admission rate
Patient satisfaction