EP4 – Nurses create partnerships with patients and families to establish goals and plans for delivery of patient-centered care.

Provide one example, with supporting evidence, of nurses partnering with patients and families to develop an individualized plan of care based on the unique needs of the patient.

AND

Provide one example, with supporting evidence, of nurses partnering with patients and families to improve systems of care at the unit, service line or organization level.

Example 1: Individualized Plan of Care Based on the Unique Needs of the Patient

UVA offers the most advanced care for a multitude of acute and chronic conditions. Coordinating the care of patients with these conditions is complex and involves clear communication by nurses among many specialty services and therapies. Transplant patients are one example of a population with advanced care requirements that is highly reliant on nurses to facilitate their complex needs.

Transplant services include more than just surgery. Transplant patients often have unique medical and psycho-social needs that add to the complexity within their care. They often approach transplant having experienced aggressive medical management that spans years and includes pre-transplant evaluation, time on the transplant list, recovery from the transplant, and follow-up care. When coupled with complex surgical courses, the demands placed on the patient and their family can be overwhelming. It is under these conditions when team communication, coordination and compassion are paramount. Patients that require an organ transplant may have lived with a chronic disease for their entire life. Transplants offer hope and a second chance on life.

Mr. T., a 46-year-old husband and father of two young girls, underwent a liver transplant two years ago due to a history of primary sclerosing cholangitis. Living over three hours away, the commitment to be placed on a transplant list was one encompassing the entire family.

In October of 2012, Mr. T's liver condition began to worsen and he began the pre-transplant screening and evaluation process. His medical condition was complicated by ascites, hyponatremia, moderate malnutrition, weight loss, and jaundice. Due to the severity of the illness, he was placed first on the list for his blood type and he was contacted in April of 2013. Mr. T was brought into the hospital in anticipation of a liver transplant. Unfortunately the donor-liver was declined, and Mr. T. and his family returned home to wait.

Finally, Mr. T underwent a liver transplant in August of 2013. His post-transplant state of health, similar to his pre-transplant state, has been tenuous. He has had an ongoing complicated post-operative course with only brief discharges home and readmissions after two to four days at a time. Needless to say, he and his family have endured multiple readmissions and set-backs.

Mr. T. was most recently readmitted again in December 2014, just before the holidays, with what has proven to be a long and difficult path. As of early March 2015, he remained in the intensive care unit. The staff engaged the family in his care, and have encouraged his involvement in decision making and care.

Mr. T's journey has included multiple procedures and complications. Some of his many issues include

- Ulcerative colitis
- Respiratory failure requiring tracheostomy and chronic ventilator support
- Encephalopathy
- Coagulopathy (with multiple bleeding episodes)
- Deep vein thrombosis
- Cytomegalovirus infection
- Left and Right-sided Heart failure
- Sepsis
- Renal failure
- Subarachnoid hemorrhage

Mr. T.'s wife has been by his side throughout much of his recent hospitalization. Their two daughters are at home staying with family and friends while they attend middle school. Their home is more than three hours from UVA and the course of his care with a chronic and complex condition has been challenging. The condition which directly affects him also has significant impact on his family.

The Surgical/Trauma/Burn ICU cares for patients for whom the complexity can be overwhelming to the most experienced ICU clinicians. To manage this aspect of their patient population, they use a team-based Complex Patient Coordination process (Exhibit EP4.a: Protocol for Complex Patients in STBICU). Every Monday, Wednesday and Friday, the charge nurse screens patients using the complex patient checklist. Patients identified through the screening checklist are included in complex care team meetings. The first team meeting is held within 72 hours of the complex patient designation and subsequent meetings occur weekly on Tuesdays. The team, inclusive of the attending physician, ICU NP, bedside RN, social worker, chaplain, ethicist, and clinical nurse specialist, discuss the unique needs of the patient and family. As appropriate, additional team members are consulted and integrated into the complex care meetings.

An essential element of the team meeting is the identification of the patient, family or surrogate decision maker as liaisons to maintain continuity, consistency of message and targeted goal setting. At each meeting either the social worker or clinical nurse specialist creates a plan of care note entitled Patient Communication.

For Mr. T. this approach provides multiple focused team planning sessions each week. Mr. T. was readily identified on admission as a complex patient with unique needs. The early team meetings focused not only on his intense medical needs and plans of care but also quickly integrated the needs of his family. During the December 23rd meeting, the team re-iterated the benefits of connecting Mr. T's children with the UVA Child Life Specialist while discussing the benefits of including palliative care principles in his care as they treated infections, adjusted vent settings, and corrected his blood indices. (Exhibit EP4.b: 12/23/2014 Epic Note for Mr. T)

The team meetings and plans developed within served as a guidepost for all clinicians involved in his care. The notes documented the care plan and referenced his unique needs. The care plan was accessible across all shifts for updates and additional inputs. For example, the ventilation weaning plan was adjusted as procedures were required and patient tolerance was noted. Soon after, Mr. T. was also encouraged to develop a list of food preferences and independently utilize a speaking valve with his trach to facilitate communication (Exhibit EP4.c: 2/10/2015 Epic Note for Mr. T). The nurse clinicians used the team meeting note to steer their planning and direct their care.

As time progressed, efforts continued to focus on ventilator weaning, management of Mr. T's medical conditions and solidifying Mr. T's goals of care. Mr. T began to recognize that his optimal state of wellness may be his current condition. The identification of his biventricle heart failure pointed to the decreased likelihood of him overcoming his battle with the complex illnesses that plagued him.

In discussions with team members, Mr. T and his wife began to focus on the need to more formally prepare themselves and their children for the future (Exhibit EP4.d: 2/24/2015 Epic Note for Mr. T). They decided that palliative care services across the institution needed to be tapped. With the adult palliative team working with Mr. T and his wife, the pediatric palliative team was called upon to guide approaches with the daughters. The focus had been on Mr. T and his medical care over the past seven years, a great portion of their young lives. Mr. T and his wife wanted to be sure that the daughters would be prepared for and supported in the loss of their father across all facets of their day. This support included the provision of resources to key individuals in the children's lives at home as well as in the school and local church community (Exhibit EP4.e: 03/10/2015 Epic Note for Mr. T).

The care plan extended beyond Mr. T to the entire family based upon his unique needs and requests. The team continued to address Mr. T's multiple medical needs, and also worked with him as he planned for his children's future without him. A father often

dreams of the day he walks his daughter down the aisle or dances at her wedding. Knowing he would not be there for these precious moments, the team assisted him to write letters to his daughters to be shared at specific milestones in their lives—important milestones, such as a graduation or a wedding, when his physical presence would be forever missed, but his memory and words may add to their special day. This gives Mr. T and his wife some hope that his memory will live strong in the minds of his children, as well as some comfort that their needs are being met and the children are being cared for.

Through the Complex Patient Coordination care planning process, the acute and complicated medical needs of Mr. T are addressed, as well as the intricate psychosocial needs of the entire family.

Participants:

EP4 Table 1. Participants, Care Planning Team for Mr. T

Name	Discipline	Title	Department
Daniel Maluf	Medicine	Surgical Co-director of Liver Transplant	Surgery and Transplantation
Homayoun Pournik	Medicine	Fellow Physician	Surgery and Transplantation
Phyllis Yensen	Social Work	Social Worker	Surgery and Transplantation
Jonathan Bartels	Palliative Nursing	RN Clinician III	3 East Geriatric / Palliative Care
Jacob Peterson	Nursing	RN Clinician II	Medical Emergency Team
Ethan Sturey	Nursing	RN Clinician II	STBICU
Kristi Kimpel	Nursing	Advanced Practice Nurse 2-Clinical Nurse Specialist	STBICU
Yoshi Takahashi	Chaplaincy	Chaplain	Chaplaincy Services & Pastoral Education
Carmele Petralla	Nursing	RN Clinician II	STBICU
Sara Rasmussen	Medicine	Fellow Physician	Surgery and Transplantation
Melinda Bowles	Nursing	Advanced Practice Nurse 1-Nurse Practitioner	STBICU

Gail Bodine	Therapies	Physical Therapist Clinician III	Physical Therapy
Barbara Neel	Therapies	Occupational Therapist Clinician II	Occupational Therapy
Ashley Hurst	BioEthicist	Fellow Bioethicist	Center for Biomedical Ethics
Mary Faith Marshall	BioEthicist	Director, Program in Biomedical Ethics	School of Medicine
Katherine O'Keefe	Student	Bioethicist	School of Medicine
Timothy Short	Medicine	Palliative Care	School of Medicine
Johanna Poston	Nursing	Nurse Practitioner	Transplant
Carol Vincel	Nursing	Nurse Practitioner	Transplant

Example 2: Nurses Partnering with Patients and Families to Improve Systems of Care at the Unit, Service Line or Organization Level — Patient- and Family-Centered Scheduling: Children's Hospital Ambulatory Services

Nurses and interprofessional colleagues engaged in significant planning efforts throughout 2013 for consolidating our Children's Hospital Ambulatory Services into the new Battle Building, then under construction and scheduled to open in July 2014.

Karin League, MSN, RN, NEA-BC, Associate Chief of Children's Hospital and Women's Services, and Rebecca Lewis, MSN, RN, NE-BC, Administrator for Clinical Logistics and Planning, served as nurse leaders on the Battle Building Steering Committee. This planned consolidation of pediatric care provided an opportunity to improve patient- and family-centered appointment scheduling as well. As a regional academic medical center serving medically complex pediatric patients, appointment scheduling had been primarily provider-centric and was recognized as an area for improvement. As nursing leaders, Karin and Becky saw the overall Battle Building transition as a golden opportunity to also facilitate the work needed to improve the scheduling process and all the associated logistics involved.

Karin League, MSN, RN, NEA-BC, Associate Chief of Children's Hospital and Women's Services served as one of the nurse leaders on the Battle Building Steering Committee.

In June-July 2013, small groups of leaders from the Battle Building Steering Committee team visited several peer children's hospitals to learn from their efforts to improve this process in their ambulatory operations. Milwaukee Children's, Texas Children's and Pittsburgh Children's all had experienced significant gains in patient / family satisfaction through the implementation of coordinated centralized scheduling. Jan Allaire, Director of Ambulatory Children's Hospital and Women's Services, one of the UVA project leads, conducted these site visits and brought findings back to the committee.

In November 2013, the Patient- and Family-Centered Scheduling (PFCS) Oversight Committee was formed. Led by Jan and Steve Borowitz, MD, Professor of Pediatrics in Pediatric Gastroenterology, this team led the process of implementing a system to achieve the primary objective: provide a patient-centered scheduling process with one-call capability for scheduling multiple appointments in a single visit. Achieving this would improve access and customer service, as well as reduce no-show rates. Clinic efficiency would improve by collecting all the information needed in a single phone call, and families' and referring provider offices' time and frustrations would be reduced.

Standardizing scheduling policies and procedures would ensure consistency and accuracy in scheduling complex appointments and support organizational targets for access and availability. These include monitoring the amount of time it takes for patients to get an appointment and time it takes to confirm preauthorization.
Exhibit EP4.f shows an overview of the goals, objectives and team members. (Exhibit EP4.f: Patient- and Family-Centered Scheduling Overview)

UVA Health System parent feedback on surveys, during clinic visits and in community meetings demonstrated the many challenges our system posed for parents and their children, such as:

- Leaving an appointment knowing that follow-up appointments were needed and having to call back to arrange them;
- Making multiple calls to different clinics to obtain appointments, when telephone access can be challenging for many families;
- Inability to coordinate appointments between clinics to facilitate one trip to Charlottesville and / or to facilitate the sequence of care steps needed – obtaining transportation, especially long distance;
- Time and resource consumption involved in travel not being maximized; and
- Logistics of moving children with many needs during multiple trips, which can be a physical and emotional drain on the patient and entire family.

As plans were underway to address the appointment scheduling changes, Penny H., parent of a longstanding UVA pediatric patient and the family advocate on several of our Children's Hospital Committees, took on a lead role in eliciting and representing family feedback to shape the program for patient- and family- centered scheduling. Penny serves in a formalized and sanctioned role with the Children's Hospital as family liaison. She collaborates with a network of 25 core Children's Hospital parents who regularly give and receive feedback to improve our systems.
Penny sits on the Centralized Scheduling Committee for this project as well as attending weekly meetings of the Communications Subcommittee, totaling four hours of meeting time commitment per week on a consistent basis. Parents' feedback clearly and cohesively informed the committee that parents did not want a fully automated system. They wanted a live person to help them coordinate and plan appointments. In November 2013-March 2014, Penny was part of the formalized focus group of interviews of various stakeholders in the process, and gave detailed feedback about her own experience with her now 16-year-old child with cerebral palsy. (Exhibit EP4.g: Patient- and Family-Centered Scheduling Interview Guide) The team heard this feedback and modified its original plan via the work of the Centralized Scheduling Oversight Committee and its subcommittees. Penny's feedback was central to the revisions of the communication plan to parents affected by the changes to the scheduling system made in April 2014. (Exhibit EP4.h: 042914 PFCS Communication Meeting Minutes)

Nurse representation within the PFCS and subcommittees for this effort has been instrumental in shaping a realistic and effective system centered on patient needs. The design team organizational structure is shown in Exhibit EP4.i. (Exhibit EP4.h: PFCS Scheduling Design Team Structure) Nurses lead three of the six committees working on this project, and others serve as members. This significant representation is needed, as the scheduling system change will change how all the clinics function. With all patient scheduling being centralized in the new system, clinic staff that had been performing

this function will transition it to the central process. This will allow nurses who had been a part of the scheduling process to have more time for patient and family education and care coordination. Within the centralized scheduling, RNs will continue to have a vital role in triaging and coordinating clinical elements of scheduling with the numerous access support staff, who will drive process logistics.
Lisa Letzkus, MSN, RN, CPNP-AC, CCRN, Advanced Practice Nurse 2-NP, has been instrumental in educating medical staff and others in the Children's Hospital clinics about the rationale for the change and proposed change elements that will affect their practice. Lisa sits as RN representative on the Communication Subcommittee of the project, and interfaces regularly with Penny. Lisa has used Penny's in-depth feedback as part of this group to further shape the process and the communication with families. Together, they effectively advocated for change in provider-centric processes to move us to patient- and family-centered processes based on these expressed needs.

As a result, the new patient- and family-centered process is delivering the key elements that Penny had articulated as representative of the parent and family perspective:

- Families call one phone number; there is no waiting and they speak to a live person to assist them.
- RN coordination of care to assure the smooth and logical flow of appointments is part of the scheduling system, outside of the clinic itself.

  Follow-up appointments are made immediately following the clinic visit prior to patient departure for the day. Families leave with their follow-up schedule ready to go.

Deficient Example (Not Accepted by ANCC): Individualized Plan of Care Based on the Unique Needs of the Patient

Links are not active in example below.

This case reviews the nursing partnership with the interprofessional team and community resources in caring for a 46-year-old gentleman with chronic sigmoid volvulus needing partial colectomy in January 2013, and a 62-day postoperative stay due to complex social history and complications. The 5 Central nursing staff, CNS and Case Managers were involved in significant tailoring of the inpatient plan of care to meet the patient's needs, build his capabilities back to his baseline and work on appropriate placement to meet his ongoing needs. The patient had no family support system and was unable to advocate for himself.

Mr. X was a middle-aged man with a history of developmental delay and low intelligence quotient, seizures, chronic pseudo-obstructions and sigmoid volvulus. He had presented to UVA Health System from a group home where he had been living with supervision

and support, and subsequently required a surgical repair of his sigmoid volvulus to address his acute needs.

Upon arrival at 5 Central, the patient was agitated, restrained and nonverbal. The night shift RN working with him requested CNS consultation of Kathleen Rea, MSN, RN, CNL, PCCN, ACNS-BC, to assess his respiratory status and was overall concerned. The assessment diagnosed pain control needs, aspiration risk with his significant abdominal distension, and altered mental status with risk for self-injury and inadvertent nasogastric tube removal, central line or indwelling urinary catheter removal. The nurses quickly synthesized vital information and developed a comprehensive set of interventions. They administered pain medication, adjusted oxygen delivery and evaluated lines and drains while repositioning and assessing the need for restraints and safety precautions. The off-going and on-coming nurse and CNS discussed a plan of care for the next shift and identified priorities.

Collaborating with his surgical team, the nurses established plan-of-care priorities and ensured that consults with nutrition, physical therapy, occupational therapy and social work were in place. They ensured that criteria for removing his restraints were clear, and this was identified as a priority. Assessment of his home medications revealed several were missing, which could have been contributing to his agitation. Nurses, the clinical pharmacist and the resident worked together to determine intravenous medications that could substitute and thus reduce his symptoms. This intervention improved his agitation.

The nursing staff and patient care assistant team were challenged in the care of this man with limited ability to express his needs. Providing pain management and creating a calm environment were essential to his safe care. He would quickly become agitated when being repositioned. They evaluated and implemented several different communication strategies to engage him in his care and surroundings. Mr. X responded well to warm washcloths on his face and hands to gain his attention. He quickly became overstimulated, so one voice directing care interventions was important. Rest time between activities and music when he was awake brought him to a more alert level. It was not clear what all of his needs were at that point, but the staff began a routine, which was communicated consistently to all care providers, and he began to more consistently rest.

The nurses assumed responsibility for driving his mobility and return to a baseline level of self-care. They collaborated with the 5 Central RN case manager to discuss his previous functioning with his group home. As the staff and CNS began to plan and discuss his longer-term needs with the case manager, different stories came to light. The nurse from his group home was circumspect about his abilities. The group home manager felt he should be placed in a skilled nursing facility. They were elusive in response to questions about Mr. X and his activities of daily living. The case manager heard vastly different descriptions of the care possibilities for Mr. X from his community

case worker. The social worker was receiving inconsistent information from the adult protective services agency and the group home.

The first issue in this emerging ethical dilemma was a lack of open and honest communication between our healthcare team, on behalf of the patient, and his group home. Nursing insisted on an in-person meeting. Our team had a responsibility to this patient to not allow the progress he had made in the community to evaporate. The team came to learn that he had moved from long-term placement in an institution to successfully living in a community setting only three years earlier. Meetings with the patient's appointed case worker, staff from the previous group home and our multidisciplinary team were facilitated. With the advocacy of nursing as expressed by the CNS, the team was able to identify shared goals and incompatible needs. It was apparent that Mr. X was in a situation where there were conflicts of interest. These initial meetings were not successful in generating a morally appropriate plan. The multidisciplinary care team believed that placement in a skilled nursing facility, as desired by the case worker, was not necessary and would condemn Mr. X to spending the rest of his life in an institution. (Exhibit EP4.a: 022013 Kelly Wesson Progress Note) The CNS assisted in identifying the moral distress of the team and outlined goals to move thing forward. Ethical deliberation involves analyzing and dealing with differing and opposing demands. The team established goals for a safe, timely discharge to a facility that would support Mr. X at his baseline level of function or would provide a milieu of rehabilitation and social services support for transition to a group home in the future.

To achieve these goals, nursing staff needed to provide a rehabilitation environment for the patient within the acute care setting. This would allow the care team to clearly present the case for return to previous level of function. Nurses worked together to return Mr. X to as close to baseline independence as possible through a variety of approaches, including an investment from therapy colleagues to achieve a rehabilitation level of care that is not the standard for inpatients. Nursing partnered with patient care assistants to establish Mr. X's consistent participation in his care and toileting. It took more time to support his independence, and coaching staff to invest that time was a priority. The CNS collaborated with pediatrics to obtain developmentally appropriate toys, coloring books and crayons. Mr. X began to dress himself, feed himself and use the bathroom appropriately. Achieving continence was a team success! (Exhibit EP4.b: 022713 Kathleen Rea Progress Note)

The multidisciplinary team sought guidance from the legal department, senior nurse administrators and social work administration to guide the discharge plan for Mr. X. The team finalized a plan that clearly stated the original home or a skilled nursing home were not options for this patient. Due to her persistence and creativity, the RN case manager located a group home that would consider taking Mr. X. There was great hesitation on their part. The 5 Central team provided care team meetings with them to outline his progress and needs. Several interactions were needed to resolve their

concerns and develop a plan for his safe transition. Ultimately, he was discharged close to his baseline level of function to a nearby group home. The integrated nursing team of 5 Central had done all it could to maximize its commitment to Mr. X's long-term welfare. (Exhibit EP4.c: 022713 Kelly Wesson Progress Note)

Participants:

EP4 Table 1.: Participants, Care Planning Team for Mr. X.

Name	Discipline	Title	Department
Kathleen Rea	Nursing	Advanced Practice Nurse 2-Clinical Nurse Specialist	5 Central
Kelly Wesson	Nursing	Inpatient Case Manager	Case Management
Nicole Schulz	Social Work	Clinical Social Worker	Social Work
Daniel Gilsdorf	Resident Physician	Surgical Resident	Surgery
E. Tad Hardee	Physical Therapy	Physical Therapist Clinician 3	Physical Therapy
Caroline McDaniel	Nursing	Infection Preventionist RN	Hospital Epidemiology
RNs of 5 Central	Nursing	Names in record	5 Central

This patient required a tremendous amount of team coordination. The team's commitment to ensure that his needs were met on many levels was demonstrated by his successful transition to a facility that would support his unique needs.