The Transplant Treatment Path

Optimizing patient-centered care for ASCT in multiple myeloma patients

1 — Process Improvement Workshop

2 — Patient Education

3 — Psychosocial Support & Financial Counseling

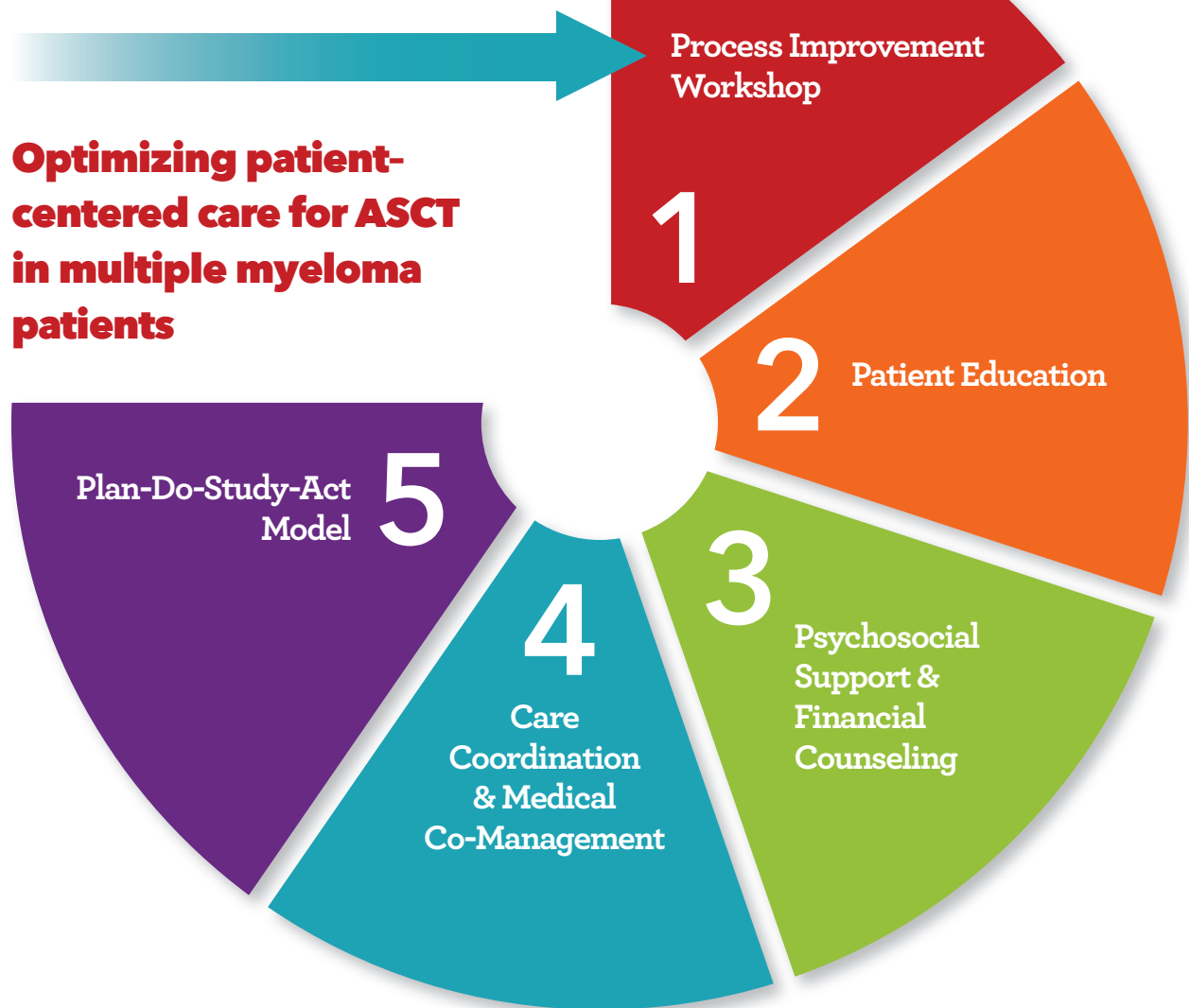4 — Care Coordination & Medical Co-Management

5 — Plan-Do-Study-Act Model

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INTRODUCTION

An ACCC educational initiative, *Transplant Treatment Path: Optimizing Patient-Centered Care for ASCT in Multiple Myeloma,* looked to optimize the treatment of multiple myeloma patients in the community cancer setting, pre- and post-autologous stem cell transplant (ASCT). The project explored ways to improve the treatment journey for patients with multiple myeloma who receive ASCT as part of their therapy. Working closely with several ACCC-member programs with transplant centers, ACCC identified specific strategies to improve communication and clinical workflow processes between referring oncology programs and transplant centers. The Blood & Marrow Transplant Information Network (BMT InfoNet) served as a key partner in this ACCC process improvement initiative; the project was funded by Celgene.

The education program had several components, including:

1. A needs assessment survey of members
2. Process improvement workshops hosted by four ACCC-member programs
3. This publication, *The Transplant Treatment Path: Optimizing Patient-Centered Care for ASCT in Multiple Myeloma*
4. Three online courses, which will be archived at: accc-cancer.org/multiplemyeloma

RESULTS OF NEEDS ASSESSMENT SURVEY

To assess the current state of patient care in multiple myeloma, ACCC, in collaboration with BMT InfoNet, conducted a needs assessment survey in the early part of 2015 and received responses from 46 cancer programs throughout the country. The majority of survey respondents—57 percent—were academic or NCI-designated comprehensive cancer centers; 22 percent of survey respondents were community cancer programs or outpatient oncology practices. Community-based oncology programs are treating an average of 80 to 100 patients with multiple myeloma and referring approximately 10 to 20 for ASCT annually. Transplant centers are seeing more than 100 patients with multiple myeloma each year; some may be performing over 100 transplants annually in patients with multiple myeloma.

Referring oncology programs and transplant centers were asked to identify their top strengths, their key challenges, and areas that needed improvement (Table 1, right). Some common themes emerged revealing the importance of teamwork to care, access to clinical trials, and expertise in treating myeloma. Survey respondents confirmed that they continue to face challenges as patients with multiple myeloma get referred for transplant and then return to their primary oncologist for disease monitoring and follow-up care. Cancer programs are looking for ways to overcome inefficiencies with communication, transfer of patient records, navigating electronic portals, and care coordination associated with the transitions of care.

TABLE 1.
Top Strengths, Key Challenges & Areas for Improvement

TOP STRENGTHS
REFERRING PROGRAM
- Strong team of physicians and nurses
- Good volume of multiple myeloma patients

TRANSPLANT CENTER
- Multidisciplinary team approach
- Experts in multiple myeloma
- Access to clinical trials and investigational treatments

KEY CHALLENGES
(Same in both settings)
REFERRING PROGRAM & TRANSPLANT CENTER
- Early recognition of treatment toxicities and appropriate management
- Patient compliance with treatment regimens and follow-up appointments
- Patient's logistical, financial, and/or personal barriers

AREAS FOR IMPROVEMENT
REFERRING PROGRAM
- More pre- and post-transplant instructions for patients
- Education on long-term follow-up care
- Better communication with transplant center

TRANSPLANT CENTER
- Better communication and coordination with referring programs

In some cases, patients with multiple myeloma are being referred for ASCT, but then choose not to undergo the procedure. Some of the key barriers or reasons why patients referred for transplant do not undergo ASCT include:

- Insurance coverage or other financial barriers
- Psychosocial reasons, lack of social support
- Patient preference
- Disease progression
- Co-morbidities, functional status

Finally, survey respondents rated some of their top challenges when treating and supporting patients with multiple myeloma. The highest rated issues were:

1. Patient's logistical, financial, and/or personal barriers
2. Lack of psychosocial services/distress management
3. Patient compliance with treatment regimens and follow-up appointments

PROCESS IMPROVEMENT WORKSHOPS

To identify key opportunities for process and communication improvements, ACCC conducted regional process improvement workshops at four transplant centers and invited one to two of their referring programs to participate in the discussion (Table 2, above). The interactive workshops allowed clinicians, transplant coordinators, and administrators to identify ways to improve communication and clinical workflow processes as patients with multiple myeloma undergo ASCT.

Shared Decision Making

The importance of shared decision making was a key topic that emerged in this initiative. Shared decision making is a collaborative process that allows patients and their providers to make healthcare decisions together, taking into account the best scientific evidence available, as well as the patient's values and preferences. Many cancer programs still do not offer formal education or training for their staff on the structured process of shared decision making, which contains six key steps:[1]

1. Invite the patient to participate
2. Present options
3. Provide information on benefits and risks of options
4. Assist patients in evaluating options based on their goals and concerns
5. Facilitate deliberation and decision making
6. Implement shared decision making

Given that cancer care is extremely complex and treatment choices have serious implications for health outcomes and quality of life, it is critical for oncologists and nurses to spend the time explaining how the evidence supporting many clinical decisions may be limited or incomplete. When clinicians understand how patients may differ in how they weigh the trade-offs of different medical choices, they can guide the treatment discussion accordingly. Shared decision making benefits patients because it leads to increased confidence in treatment decisions, greater satisfaction with treatment, and more trust in their healthcare providers. Clinicians need to recognize the value of implementing a structured shared decision making process as they counsel patients with multiple myeloma about ASCT. This can help overcome key barriers that patients may encounter when they are referred for ASCT and offered this treatment option.

During the process improvement workshops, clinicians discussed barriers and concerns associated with the application of shared decision making if staff are not adequately trained and if patients are misinformed. More time may be required to walk a patient through a decision aid and to explain clinical treatment options that continue to remain somewhat controversial or confusing. Furthermore, when family members and other caregivers are in the room, they may have additional questions that may require even more time from the clinician.

Key barriers include:
- Time constraints and high workloads
- Insufficient provider training
- Inadequate clinical information systems

Additional concerns include:
- Patient anxiety
- Misinformation or lack of information
- Unwillingness or inability to participate

Despite the potential barriers and concerns associated with shared decision making, clinicians agree that it remains important to individualize treatment discussions for every patient and to weigh different patient considerations and disease characteristics that may impact clinical outcomes. Oncologists and nurses who are already employing shared decision making agree that the time invested in these discussions helps their patients remain engaged throughout their treatment course.

> When clinicians understand how patients may differ in how they weigh the trade-offs of different medical choices, they can guide the treatment discussion accordingly.

Patient Education Resources

There are numerous educational resources about ASCT developed by national organizations, but use of these brochures and booklets varies highly across cancer programs. Furthermore, a wealth of both good and bad information may be found on the Internet as patients research to learn more about their disease and treatment options. Since some of the public information may be outdated or erroneous, it becomes critical for members of the transplant team to guide and educate patients properly.

Many transplant centers develop and provide their own patient education resources to patients who are preparing for ASCT. Seattle Cancer Care Alliance (SCCA) has an Autologous Transplant Resource Manual and makes it a point to emphasize social media, video libraries, and weekly online classes to educate and engage patients in an interactive environment. Emory University Bone Marrow and Stem Cell Transplant, Winship Cancer Institute, offers patient education books on both autologous and allogeneic stem cell transplants.

BMT InfoNet offers a resource titled, *Autologous Stem Cell Transplants: A Handbook for Patients*. This book walks the patient through what to expect before, during, and after transplant by providing perspectives of patients and caregivers. Some transplant centers have incorporated resources like this into their routine evaluation process for patients interested in exploring ASCT as a treatment option for their multiple myeloma. Book chapters include:

- History of Transplantation
- Nuts and Bolts of a Transplant
- Choosing a Transplant Center
- Insurance and Fundraising
- Emotional Challenges
- When Your Child Needs a Transplant
- Preparative Regimen
- Infection
- Liver Complications

- Nutrition
- Relieving Pain
- Caregiving
- Sexuality After Transplant
- Family Planning
- Planning for Survivorship
- About Blood Cells
- Understanding Blood Tests

Learn more at: bmtinfonet.org.

At Ohio State University (OSU), patients who are preparing for ASCT undergo an educational course where they are evaluated by OSU staff and provided with detailed instructions on what to expect. A key resource that is used is an autologous transplant patient education binder that includes tips, checklists, images, and other important information. In the binder, patients will find a "Blood and Bone Marrow Question and Answer Sheet" that encourages them to write down questions, track answers, and make further notes. This is especially critical when patients are having discussions with family members and caregivers about their preparation plans for transplant.

During the process improvement workshops, transplant centers and referring programs agreed that it would be valuable to use the same patient educational resources and decision aids at referring locations so that patients are presented with the same information when they are referred for ASCT consultation and when they arrive at the transplant center. Based on this insight, several of the transplant centers agreed to develop and distribute a one-page patient resource about ASCT to the surrounding referring oncology programs. This way, when patients with multiple myeloma are referred to a transplant center for an ASCT consultation, the primary oncologist has the opportunity to give the patient a resource developed by that same transplant center.

Following the process improvement workshop at OSU, their team developed a concise Bone Marrow Transplant brochure with the intent of sending this out to referring programs that could use this as a common patient education tool. View this brochure online at: **accc-cancer.org/multiplemyeloma**.

PATIENT PREPARATION FOR ASCT

When patients with multiple myeloma are referred for ASCT, many are not adequately prepared for the conversation that will occur when they arrive at the transplant center for their initial consultation. Hence, the preparation process should start early by including a discussion about the medical reasons for considering ASCT, but it must also include an assessment of psychosocial support and financial considerations so that the transplant team can be best equipped to guide the patient through an effective discussion. Although the majority of autologous stem cell transplants occur in the inpatient setting, some perform ASCT in the outpatient setting, so these centers wanted to ensure that patients would be prepared for that option.

Seattle Cancer Care Alliance's Autologous Transplant Resource Manual lists and defines seven specific steps through transplant so that patients can have a better understanding of the journey (see Table 3, page 8). SCCA also provides manuals on practical issues such as housing, transportation, and parking since these have been identified as key issues and concerns for patients not familiar with the Seattle facilities or area.

SCCA is further exploring ways to improve patient readiness for transplant by collecting and analyzing information when patients present for a transplant consultation. Teams are filling out questionnaire cards to identify trends and patterns that will provide more insight into why some patients may not be prepared for transplant, such as:

- Lack of a solid caregiver plan
- Psychiatric or social issues
- Medical problems (other than primary diagnosis)
- Housing (or other funding) issues
- Insurance issues
- Substance abuse
- Dental issues
- Donor issues

Importance of a Caregiver

A key factor to help patients prepare for ASCT is to have them identify a caregiver or a group of caregivers early in the process. Ideally, the caregiver is identified before patients go to their transplant consultation appointment, and should accompany patients to this visit, so that they may learn what to expect when patients complete ASCT and return home. Some transplant centers make it a point to spend adequate time on educating and preparing patients and their caregivers by having them undergo a series of educational sessions, workshops, and meetings so that they are counseled about smoking cessation, learn how to manage their central venous access line or port, and receive proper instructions on diet and nutrition. By providing this education and training to both patients and caregivers, the transplant team can ensure that there will be greater adherence and accountability to key self-management instructions that will impact patient outcomes and experience.

> A key factor to help patients prepare for ASCT is to have them identify a caregiver or a group of caregivers early in the process.

SCCA's Autologous Transplant Resource Manual specifically outlines typical caregiver responsibilities, including making arrangements, giving emotional support, providing physical care, maintaining the home environment, and patient advocacy (see Table 4, page 9).

At Emory University, the social worker completes a BMT Evaluation Form and specifically asks the following questions regarding a caregiver:

- Who is in the patient's support system?
- Who will be the patient's caregiver?
- Can caregivers provide transportation?
- Does the caregiver have a history of psychiatric treatment or substance abuse? If yes, please explain.
- If caregivers work, what is the plan for them to be out from work?

Table 5, page 9, identifies opportunities to improve patient preparation for ASCT, including strategies for making improvement.

TABLE 3.
SCCA's 7 Transplant Steps

STEP 1. PLANNING AHEAD
- Assess financial coverage and other financial resources; consider fundraising
- Select caregiver(s)
- Make decisions about childcare and schooling
- Complete advance directives *(This can be done at SCCA)*
- Decide on arrival date at SCCA
- Contact volunteer office for airport pick-up
- Decide if special preparations are needed (e.g., dental, nutrition, fertility)
- For allogeneic transplant, donor selection

STEP 2. PREPARATION
- Arrive at SCCA. Receive your "color" team name. Meet your team: physician, physician's assistant, and nurse
- Meet with other members of your team: nutritionist, social worker, oral medicine, chaplaincy, pharmacist, and psychology or psychiatry, if appropriate
- Get a medical evaluation
- Attend conference; read and sign consent forms and protocols
- Attend teaching session with your team nurse
- Ask questions; talk with staff about any concerns
- Make a plan on how to cope with transplant
- Attend classes for patients and caregivers
- Keep active; walking or other exercise of choice
- For autologous transplant, collection and storage of stem cells

STEP 3. CONDITIONING
- Receive conditioning therapy
- Take medication to prevent and relieve symptoms
- Let staff know how you are doing and what you need
- Balance rest and activity

STEP 4. TRANSPLANT
- Receive infusion of cells through your central line
- Celebrate!

STEP 5. WAITING FOR ENGRAFTMENT
- Monitor your counts
- Receive transfusions of blood cells or platelets, if needed
- Staff will monitor you closely for side effects or complications of treatment and signs of infection; you will be admitted to the hospital or seen in the clinic almost every day
- Take advantage of support services, such as chaplaincy and social workers
- Keep as active as possible

STEP 6. RECOVERY AFTER ENGRAFTMENT
- Your caregiver helps you with recovery, giving medications and monitoring your symptoms
- Go back to eating regular meals
- Attend support groups
- Gradually increase activities
- Rest periods for recovery
- Take things "day by day" and keep track of daily goals to see progress
- Get out and do something fun!

STEP 7. LONG-TERM RECOVERY
- Return to the care of your referring physician
- Report any new symptoms to your physician promptly
- Contact the long-term follow-up staff if questions arise

TABLE 4.
Typical Caregiver Responsibilities

STEP 1.
MAKING ARRANGEMENTS
- Transportation
- Financial
- Tracking appointments

STEP 2.
GIVING EMOTIONAL SUPPORT
- Being physically present
- Giving encouragement

STEP 3.
PROVIDING PHYSICAL CARE
- Identifying changes in patient's condition
- Reporting patient's symptoms to healthcare staff
- Obtaining medical care, if needed
- Monitoring patient compliance in self administration of oral medication
- Recording medications taken and/or administered
- Acquiring and maintaining medical supplies
- Performing tasks, such as central line care
- Administering fluids and medications using an intravenous pump

STEP 4.
MAINTAINING THE HOME ENVIRONMENT
- Cleaning
- Food preparation
- Shopping

STEP 5.
ADVOCATING FOR THE PATIENT
- Gathering information and ensuring that patient information is given to medical staff
- Helping with decision making

STEP 6.
PROVIDING ASSISTANCE & SUPPORT TO OTHERS
- Serving as a communication link with other family members and friends
- Imparting information to children
- Providing childcare

TABLE 5.
Patient Preparation: Process Improvement Table

OPPORTUNITIES FOR IMPROVEMENT	EFFECTIVE CHANGES
• Clinicians may not be in the habit of regularly incorporating shared decision making (SDM) into their discussions with patients.	• Modify the electronic health record (EHR) template so that it prompts clinicians to review and utilize a structured SDM decision aid or tool. • Provide formal training on shared decision making for all staff on a routine basis.
• Different patient education resources and tools are used by referring programs and transplant centers.	• The transplant center develops a consolidated educational resource and distributes these to referring programs so that patients are introduced to some key concepts before they arrive at the transplant center.
• Patients who may benefit from transplant do not feel prepared and may refuse treatment.	• Identify key issues and trends in your patient community that may directly impact patient readiness for transplant. • Create resources and tools to proactively address those concerns or questions before patients arrive for a transplant consultation (e.g., housing options, lack of a caregiver, etc.).
• Patients may not recognize the importance of having a caregiver or they have difficulty finding a caregiver.	• Introduce the importance of identifying a caregiver (or a group of caregivers) when patients are being referred for a transplant consultation. This will allow patients to have more time to think about this issue and identify potential caregivers. This will also help patients be more prepared for the initial transplant consultation, especially if caregivers accompany patients.

PSYCHOSOCIAL SUPPORT & FINANCIAL COUNSELING

Patient Evaluation & Referral

In the needs assessment survey, the number one rated challenge associated with the treatment and support of patients with multiple myeloma was: "the patient's logistical, financial, and/or personal barriers." Clearly, cancer programs must be prepared to discuss and address practical issues of psychosocial support, insurance coverage, and total cost of treatment. When patients with multiple myeloma are referred from their primary oncologist for an ASCT consultation, there is a key opportunity to conduct a psychosocial assessment that includes financial counseling. The treatment costs associated with ASCT may be significant and many patients may have difficulty understanding their health insurance benefits and even basic health insurance terminology.

Support Groups for Patients & Families

GW Medical Faculty Associates holds a monthly multiple myeloma support group for patients and family members. They invite speakers to provide education and offer support as the group discusses common issues and concerns. Patients at all stages of diagnosis and treatment attend these meetings on a regular basis—both to offer and receive support. A social worker facilitates the discussion and gathers information on patients to provide follow-up on an ongoing basis. Support group discussions can also alert members of the care team about patient factors that may need to be addressed proactively before they cause significant distress.

Covering the Basics of Health Insurance

The Centers for Medicare & Medicaid Services (CMS) has a series of valuable resources that are freely available to educate patients about basic health insurance terminology. One of the top resources is a "Glossary of Health Coverage and Medical Terms."[2] This resource includes useful graphics that effectively illustrate key terms, such as deductible, co-insurance, co-payment, and out-of-pocket limit.

The ACCC Financial Advocacy Network (FAN)

The ACCC Financial Advocacy Network offers a full range of tools and resources for cancer care providers who deal directly with patients on complex financial issues surrounding their cancer diagnosis and treatment, including skill-based educational materials for program staff currently providing financial counseling, as well as those new to financial advocacy. Furthermore, as part of the ACCC MyNetwork online members-only community, the FAN Forum offers members the chance to have informative discussions and share their knowledge of financial assistance issues in real-time with peers who are dealing with similar concerns. Examples of recent discussions include questions on what staff members are providing financial counseling services, financial advocate job descriptions, challenges and solutions to finding assistance programs and resources for patients, and more. ACCC also produces an annual Patient Assistance and Reimbursement Guide that includes information about pharmaceutical and non-pharmaceutical patient assistance and co-pay programs.

> **Identifying the job titles and functions can also be important to improve communication between the referring oncology program and the transplant center.**

Fundraising

Even if insurance covers most of the treatment costs, patients may need additional funds to help pay for transportation, housing, food, and childcare. Fundraising options may include institutional events, such as charity running races, or may include individual online crowd-funding websites, such as GoFundMe. SCCA's "Preparing for Transplant" resource has a special section specifically on fundraising ideas that lists some practical suggestions on how and why to raise funds to cover treatment costs.

At Emory University, the social worker provides fundraising information to patients and discusses possible options. The social worker also provides a list of organizations that provide financial assistance along with a Bone Marrow Foundation financial assistance application.

Role of Transplant Team Members

Patients are often confused about the role of different healthcare team members. This can be especially true when patients visit an academic medical center that has medical and nursing students, resident physicians, visiting clinicians, and large teams of people making bedside rounds.

The OSU transplant patient education handbook outlines the titles and job functions of key members of the transplant team (Table 6, page 12). Every transplant center may use slightly different titles for certain jobs and functions, so it is important to ensure that patients are properly informed about who to contact when specific questions arise.

Identifying the job titles and functions can also be important to improve communication between the referring oncology program and the transplant center. Referring programs may not have staff transplant coordinators, financial counselors, or nurse navigators. However, referring programs need to maintain strong communication with the transplant center before, during, and after the patient undergoes ASCT. Administrative, financial, or psychosocial issues that are identified should be co-managed and jointly coordinated between the referring program and transplant center to ensure the smoothest transitions of care before and after ASCT.

To foster ongoing communication with referring oncology programs, the transplant team at Emory updates their list of key contacts on a regular basis. The list includes physicians, transplant nurse coordinators, and transplant nurse navigators.

At smaller centers like GW Medical Faculty Associates, the oncologists in the community may have developed close relationships with the faculty at GW because some of them did their residency or fellowship training at GW and remained in the area to practice. In those situations, frequent phone calls and direct communication about patient care lead to better co-management of patients before, during, and after the active transplant process.

Table 7, page 13, identifies opportunities to improve psychosocial support and financial counseling for patients undergoing ASCT, including strategies for making improvement.

TABLE 6.
OSU Blood and Marrow Transplant Team

PROGRAM DIRECTOR
- Physician who oversees all activities in the BMT program

ATTENDING PHYSICIAN
- Directs patient treatment and coordinates patient care with other healthcare team members; this physician will rotate every two weeks

FELLOW
- A physician who is training to be a specialist in hematology/oncology or BMT

NURSE PRACTITIONER (NP)
- A nurse with advanced training that works with the physician; the NP may do procedures and prescribe medicine

REGISTERED NURSE (RN)
- Plans, coordinates, and directs nursing care to meet the specific needs of patients; patients have an RN assigned to them 24 hours a day

CLINICAL NURSE SPECIALIST (CNS)
- An RN who is a resource person for patients and the nursing staff about patient treatment

NURSE MANAGER
- RN who oversees the nursing care of the unit

ASSISTANT NURSE MANAGER
- RN who oversees the daily nursing activities

PATIENT CARE ASSOCIATE STUDENT NURSE
- Trained in certain nursing care procedures; works with the RN to take care of patients

PATIENT SERVICE ASSOCIATE
- Stocks supplies on the unit and helps take patients to tests and procedures

REGISTERED DIETITIAN
- Provides education about nutrition and food choices

PHARMACIST
- Oversees how patient medicines are prepared and provided to patients

SOCIAL WORKER
- Provides counseling and helps patients and families find resources to meet their needs

PATIENT CARE RESOURCE MANAGER
- Case manager who helps coordinate care for patients when they leave the hospital

CHAPLAIN/PRIEST
- Available to talk with patients and families about their spiritual needs

RESPIRATORY THERAPIST
- Takes care of oxygen equipment, if necessary

PHYSICAL THERAPIST, OCCUPATIONAL THERAPIST & SPEECH THERAPIST
- Help patients with walking, self-care, and speech problems to improve their independence after an injury or illness

HEALTHCARE PROFESSIONAL STUDENTS
- Students training in various medical roles

TABLE 7.
Patient Preparation: Process Improvement Table

OPPORTUNITIES FOR IMPROVEMENT	EFFECTIVE CHANGES
• Patients and family members who lack psychosocial support may feel isolated and discouraged.	• Monthly support groups led by social workers can bring together patients and family members to openly discuss common concerns and issues. These meetings may also alert the care team about patient factors that may need to be addressed proactively.
• Patients who face significant financial barriers may not be aware of the resources and options that may be available for them.	• Use the resources available through the ACCC Financial Advocacy Network (accc-cancer.org/FAN). • Use public resources like the CMS Glossary of Health Coverage and Medical Terms to educate patients about the basics of health insurance. • Assign and train dedicated financial advocates or counselors who can guide the patient through the complex process of financial navigation.
• Referring programs may not have the staffing resources to perform psychosocial and financial assessments and evaluations.	• The transplant center may coordinate monthly or quarterly conference calls to provide education and guidance for referring staff members on key psychosocial and financial considerations and point them to common, shared resources and tools that may assist patients who are being referred for transplant.
• Key members of the cancer care team may have different titles at the referring program vs. the transplant center.	• Coordinate communication between equivalent members of the cancer care team between the referring program and the transplant center. This ensures stronger communication between these groups on clinical, administrative, financial, and psychosocial issues. • Provide an ongoing updated list of key contacts along with their contact information to referring programs.

CARE COORDINATION & MEDICAL CO-MANAGEMENT

Managing Patient Records

Although most oncology programs and transplant centers use EHRs, these systems are often disparate and fragmented. Many states have developed health information exchanges (HIEs) to facilitate communication and transmission of patient records across different health systems and hospitals, but HIEs still remain largely under-developed and poorly utilized. Even today, many oncology programs and transplant centers are relying on fax machines and mail package delivery services to transmit patient records.

Some transplant centers offer referring oncology programs access to secure online portals to send and retrieve patient records. At SCCA, several referring oncology programs within their network have access to U-Link, a secure online portal for referring clinicians. U-Link provides access to the records of patients at UW Medical Center, Harborview Medical Center, and SCCA.[3] U-Link offers the following benefits:

- Patient records are available as soon as they are dictated, transcribed, and uploaded, usually within 48 hours. This saves time in requesting and receiving faxed or mailed records. (Conversely, printed records are not mailed or faxed until they are authenticated by the attending physicians, which can take up to two weeks to be received by mail or fax.)
- Referring physicians have access to the same records to which transplant centers and medical staff have access. This includes: lab results, dictated notes and transcripts, medication lists, and radiology reports and images.

To facilitate the management of patient records, Emory University asks referring oncology programs to fill out a "Myeloma/Amyloid Consult Checklist" to ensure that key relevant patient information is provided when the patient arrives for the initial consultation. This checklist ensures that specific tests have been performed and that results are available for the transplant team to review (Table 8, right).

Digital Faxing Solutions

Given that patient records are still primarily faxed back and forth between referring oncology programs and transplant centers, the adoption of digital fax solutions has made the process more efficient. However, many cancer programs still use a traditional fax machine and run into delays and inefficiencies when they have to retrieve and resend patient records. Electronic faxing or e-faxing solutions that are secure and encrypted provide an efficient means for communication, especially when they integrate directly with the EHR system. E-faxing allows hospitals to efficiently route messages to the correct departments and may also eliminate the need to have multiple fax numbers for the transplant department. Cloud-based e-faxing solutions also provide ways for providers to log in and access old sent and received faxes online.

FIGURE 1.

Transplant Center: Short-Term & Long-Term Follow-Up

SHORT-TERM FOLLOW-UP (30 TO 60 DAYS POST-TRANSPLANT)
- Follow-up visits
- Lab tests
- Treatments

LONG-TERM FOLLOW-UP (3, 6, 9, 12+ MONTHS)
- Follow-up visits
- Lab tests
- Treatments

Primary Oncologist: Long-Term Follow-Up

ONGOING CARE AND FOLLOW-UP
- Disease monitoring
- Lab tests
- Treatments

Coordination & communication of test results & treatment plans are shared between the transplant center & referring program.

Improving Patient Navigation & Care Coordination

When patients are discharged from transplant, they enter a period of short-term follow-up where most of the care coordination is handled by the transplant center. Many patients also schedule an appointment with their primary oncologist during this short-term follow-up period. Eventually, patients transition to a long-term follow-up period, and this is where it becomes critical for the primary oncologist to help coordinate the follow-up visits and share treatment and test results with the transplant center (Figure 1, left).

Care Coordination after ASCT Transplant

At SCCA, a copy of a Post-Transplant Monitoring Calendar is sent to patients and the referring oncology programs so that the scheduling of labs and tests can be coordinated effectively between SCCA and the primary oncologists. This tool also allows patients and caregivers to create calendar reminders and notes and to understand where and when appropriate follow-up visits will need to occur.

TABLE 8.
Emory Winship Cancer Institute Myeloma/Amyloid Consult Checklist

DESCRIPTION	CHECK ITEM
• Office Notes: History and physical (specifically at the time of diagnosis and most current). If patient referred from another physician, includes notes from original hematologist.	✓
• Diagnostic work up (all lab reports) and most recent labs.	✓
• All serum protein electrophoresis and immunofixation results (SPEP).	✓
• All urine protein electrophoresis and immunofixation results (UPEP).	✓
• All beta 2 macroglobulin, CRP, LDH results.	✓
• All quantitative immunoglobulin results (i.e., IgG, IgA, IgM, free light chain).	✓
• Bone marrow biopsy reports (all).	✓
• Cytogenetics, flow cytometry and FISH reports (all).	✓
• All skeletal bone survey/bone scan results.	✓
• Treatment regimen chemo flowsheets to include all chemotherapy cycles.	✓
• Radiation treatment and radiation oncology notes.	✓
• HLA typing of patients (obtain confirmatory typing if already typed by a different facility).	✓
• Obtain diagnosis slides and sent to Emory for review by pathology.	✓
• Confirm request for path slides received.	✓
• Path slides received and logged in.	date
• Notified patient of NPV and emailed/mailed NPV schedule.	
• Confirmed patient's NPV, 24 to 48 hours prior to consult date.	
• Chart completed by:	date
• Chart reviewed by:	date

Clinical Trials

In the community, oncologists may not always have up-to-date information about the ongoing clinical trials in their region. Some may receive regular communication from major cancer centers and this information may help their team identify patients who may be eligible for clinical trials. For example, Emory sends a monthly "Winship Clinical Trials eNewsletter," which lists current clinical trials, the principal investigator, the trial sponsors, and a brief description about the study. Every month, the Winship Cancer Institute Clinical Trials Office, in collaboration with each research group, compiles open clinical trials available at Winship Cancer Institute into a Winship Clinical Trials Protocol Card that is viewable online.

Table 9, right, identifies opportunities to improve care coordination and medical co-management for patients undergoing ASCT, including strategies for making improvement.

TABLE 9.
Care Coordination & Medical Co-Management: Process Improvement Table

OPPORTUNITIES FOR IMPROVEMENT	EFFECTIVE CHANGES
• There are opportunities to improve the coordination of short-term and long-term follow-up when the patient is discharged.	• Using a common shared discharge calendar that specifically lists dates, visits, tests, and procedures can help ensure that the patient, the transplant center, and the primary oncologists are in alignment with all the necessary follow-up steps. • Clearly define the roles and responsibilities between the transplant center and referring program during the short-term and long-term follow-up period.
• Faxes may get lost or may need to be resent.	• Use of a digital, cloud-based e-faxing solution may alleviate some of the inefficiencies and redundancies associated with sending and retrieving patient records by fax. • E-faxing solutions that integrate directly with the EHR can save additional time and further streamline efficiencies.
• Referring oncology programs may not be aware of the latest clinical trial opportunities for their patients.	• The transplant center can send a weekly or monthly electronic newsletter that lists new and open clinical trials as an ongoing form of communication.

PROCESS IMPROVEMENT RESOURCES

Process Improvement Team

Leadership and physician involvement from all key departments are essential when establishing a core team that will lead process improvement efforts focused around the management of patients with multiple myeloma undergoing ASCT. The interdisciplinary nature of this team strengthens the ability of physicians, nurses, and administrators to work collaboratively to identify opportunities to make workflow improvements and establish changes that will improve productivity and patient outcomes. An effective interdisciplinary team structure would contain members representing the following areas:

- Physician champion. A medical hematologist/oncologist at the transplant center who will lead the process improvement initiative.
- Hematology/Oncology clinicians. Physicians, NPs, PAs, and nurses representing the transplant center and referring oncology programs.
- Transplant coordinators and nurse navigators. These clinicians provide input regarding current workflow processes, communication, and coordination with the patient and referring programs.
- Social workers and financial advocates. These clinicians provide input regarding psychosocial assessments, logistical challenges, and financial navigation.
- Process improvement professionals. A representative from the Quality and/or Safety Department and/or an external consultant or resource to assist and guide the team through process improvement methodologies.
- Administrative leadership. Cancer program director, service line leader, or department chair who will provide support and accountability.

Self-Assessment: Baseline Testing Rates & Workflow Processes

The first step in process improvement is to review baseline clinical workflow processes and communication behaviors. This step may also be referred to as the "current state," since changes will need to be identified and implemented so they will lead to meaningful improvements. Measuring the baseline performance may include a combination of the following:

- Surveys of clinicians and staff members about the current workflow processes and the effectiveness of communication techniques. Input should be collected from both the transplant center and the referring oncology programs.
- Open discussions and dialogues between the transplant center and referring oncology programs to better understand problem areas and opportunities for improvement. This may be done most effectively through a series of focus groups or an ongoing working group.

Establishing Goals & Objectives

Some process improvement goals are more measurable than others, so the team must choose and prioritize which goals they will track and measure during the course of an improvement initiative. Some quantifiable goals for improvement may include:

- Average number of days a multiple myeloma patient needs to wait prior to initial ASCT consultation.
- Average number of days it takes a referring program to receive a discharge summary from the transplant center.

Other goals may be measured through subjective surveys, interviews, and focus groups:

- Ease of obtaining complete patient records when the transplant center requests them from the referring program.
- Patient assessment of shared decision making discussions with the physician
- Quality of psychosocial patient assessment prior to the initial transplant consultation.
- Patient satisfaction regarding the quality and level of education prior to transplant.

Plan-Do-Study-Act

After reviewing baseline workflow processes, the team may identify possible opportunities for improvement and use the structured Plan-Do-Study-Act (PDSA) cycle for improvement (Figure 2, right). The physician champion will play a key role in working with the rest of the team members to assess and prioritize the ideas that would lead to the greatest improvements. The PDSA Worksheet (Figure 3, right) is a useful tool when implementing a process improvement initiative. The PDSA cycle is a structured way to evaluate the impact of a change by developing a plan to test the change (Plan), carrying out the test (Do), observing and learning from the consequences (Study), and determining what modifications should be made to the test (Act).[4] The PDSA Worksheet has been used by numerous healthcare organizations and forms the basis for the Institute for Healthcare Improvement (IHI) Model for Improvement.[4]

The team should identify two to three process changes that may lead to improvements in clinical workflow or communication and complete a PDSA Worksheet for each of those changes. It is critical to establish clear goals for improvement and to assign specific members of the team to provide follow-up to the larger group in three to six weeks.

FIGURE 2.
Plan-Do-Study-Act Cycle for Improvement

WHAT ARE WE TRYING TO ACCOMPLISH?

HOW WILL WE KNOW THAT A CHANGE IS AN IMPROVEMENT?

WHAT CHANGES CAN WE MAKE THAT WILL RESULT IN IMPROVEMENT?

FIGURE 3.
PDSA Worksheet for Testing Change

AIM
(Overall goal the team wants to achieve)
Every goal will require multiple smaller tests of change

Describe your first or next set change.
- Person responsible:
- When to be done:
- Where to be done:

PLAN
List the tasks needed to set up this test of change.
- Person responsible:
- When to be done:
- Where to be done:

Predict what will happen when the test is carried out.
- Measures to determine if prediction succeeds

DO
Describe what actually happened when you ran the test.

STUDY
Describe the measured results and how they compared to the predictions.

ACT
Describe what modifications to the plan will be made for the next cycle based on what you learned.

SUMMARY

Transplant Treatment Path: Optimizing Patient-Centered Care for ASCT in Multiple Myeloma provided a unique opportunity for transplant centers and referring oncology programs to work together and identify key opportunities for process improvement. The management of multiple myeloma remains clinically complex, but effective changes can be made to improve how patients receive care that is co-managed between the primary oncologists in the community and the transplant center. There will always be opportunities to improve communication between referring oncology programs and transplant centers. As technology evolves, both groups should be evaluating how they use EHRs, digital portals, and newer faxing solutions to improve communication and clinical workflow efficiency. Transplant centers can also proactively take the lead to ensure that they are routinely sharing common tools and resources that can be used by oncology programs in the community that may refer patients. They can also devote time and resources to provide ongoing education and training about psychosocial, financial, and clinical management issues for oncology programs that may have fewer resources in these areas.

The process improvement ideas that were identified and implemented in this educational initiative may also benefit the management of other hematologic malignancies where ASCT is a treatment option. Cancer programs that successfully adopt a culture of continuous process improvement will always identify ways to make improvements, and ACCC will continue to share those findings and facilitate new opportunities for collaborative process improvements designed to enhance patient care.

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> **The management of multiple myeloma remains clinically complex, but effective changes can be made to improve how patients receive care that is co-managed between the primary oncologists in the community and the transplant center.**

ABOUT THE ASSOCIATION OF COMMUNITY CANCER CENTERS

The Association of Community Cancer Centers (ACCC) is the leading advocacy and education organization for the multidisciplinary cancer care team. Approximately 20,000 cancer care professionals from 2,000 hospitals and practices nationwide are affiliated with ACCC. Providing a national forum for addressing issues that affect community cancer programs, ACCC is recognized as the premier provider of resources for the entire oncology care team. Our members include medical and radiation oncologists, surgeons, cancer program administrators and medical directors, senior hospital executives, practice managers, pharmacists, oncology nurses, radiation therapists, social workers, and cancer program data managers.

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