13.0 FACILITATING COMMUNICATION BETWEEN HEALTH CARE PROFESSIONALS AND MHP PATIENTS AND THEIR FAMILIES

Neill Adhikari, Joel Aguirre, Denise Evanovitch, Joe Hacket, Amanda McFarlen, Ellen Valleau

13.1 Introduction

The content of this section will address recommendation statement 19: Patients and/or their Substitute Decision Maker for whom the massive hemorrhage protocol was activated should be informed. Actual (e.g., transfusion-associated circulatory overload, hyperkalemia, etc.) and potential adverse effects should be disclosed. Furthermore, patients of childbearing potential should be informed of the risk of red blood cell alloimmunization that may complicate future pregnancies.

The purpose of this section is to supply tips and tools for the MHP healthcare team to share with the patient and their family to keep them informed and advised on what happened during the MHP resuscitation and what complications from transfusion they might expect in the future. A template patient information form has also been included. It is recommended that the TML initiates the process with this form with the number of units transfused during the first 24 hours of treatment, once the initial critical phase has passed and hemostasis has been achieved (e.g., the day after MHP activation).

The tables included in this section of the toolkit model the information to be completed on the MHP Patient Form that will be given to the patient once stabilized. Therefore the tables in the toolkit are provided for a reference only; they are not intended to be completed. The tables provided in the MHP Patient Form will be completed, discussed and given to the patient.

13.2 Initial Patient & Family Contact and Discussion

The healthcare provider tasked with communicating with the family member (or patient once stable) should open the discussion as soon as possible and may want to use the MHP Patient Form as a guide. The person communicating with the patient may be the most responsible physician, another senior physician, or a nurse with expertise in massive hemorrhage. The MHP Patient Form will provide the patient and family with a written resource during a stressful time. Spiritual Care Practitioners are available to address any psychosocial spiritual concerns arising before, during, or after the massive hemorrhage protocol. This includes supporting families through crisis, providing spiritual and emotional support, and addressing values, beliefs, and religious needs of patients and families as they pertain to an MHP. The following items should be communicated with the patient (and patient's family) to describe things that may have occurred during treatment despite or as a consequence of the treatment.

13.3 Problems a massively bleeding patient may experience in the first 24 hours

Check a "Yes" or "No" box for each problem

Yes/No	Problem	How this was controlled or treated	How the patient may feel or appear
☐ Yes ☐ No	Uncontrolled bleeding	Pressure on the wound, balloon devices, endoscopy, surgery	Pressure, anesthesia
☐ Yes ☐ No	Low body temperature	Warm IV fluids, warm blankets where possible	Cold, shivering
☐ Yes ☐ No	Low body pH (acidity)	IV fluids, red blood cell (RBC) transfusion, medication to raise pH	Confusion, rapid shallow breathing

Yes/No	Problem	How this was controlled or treated	How the patient may feel or appear
☐ Yes ☐ No	Not clotting properly	IV calcium, regular laboratory testing, transfusion of plasma, platelets or other blood products, other pro-clotting medications	Wounds not clotting
☐ Yes ☐ No	Anemia and low blood pressure	Red blood cell (RBC) transfusion	Weak, short of breath, dizzy, pale
☐ Yes ☐ No	Electrolyte imbalance	IV medication	Tingling, trouble breathing, chest pain, nausea
☐ Yes ☐ No	Increased fluid in tissues	Diruetics (water reducing medication), reduce IV fluids, chest Xray	Difficulty breathing, general swelling throughout the body
☐ Yes ☐ No	Allergic reactions (including anaphylaxis)	Antihistamine medication	Itchy, hives, puffy eyes, difficulty swallowing and breathing
☐ Yes ☐ No	Fever from the blood products	Tylenol (acetaminophen)	Fever and chills
☐ Yes ☐ No	Lung injury	Oxygen, respiratory support (e.g., with intubation and ventilation), diuretics, chest X-ray for diagnosis	Difficulty breathing, chest pain

13.4 Problems that may affect a massively transfused patient in the future

Problem	How this was controlled or treated	How the patient may feel or appear
Develop red blood cell antibodies that can complicate future transfusions: 1 in 13 patients	It can't be prevented but the transfusion laboratory will ensure they find compatible blood for you if you need another transfusion. You should have a blood test 6 weeks to 6 months after transfusion to see if you have produced any red cell antibodies.	Back pain, weakness, dizziness, and yellow skin/ eyes up to 28 days after transfusion
For female patients with child bearing potential/ capabilities, may cause Hemolytic Disease of the Fetus and Newborn	Will be managed during pregnancy with extra testing, monitoring, and rarely, fetal and neonatal transfusions	Patient's fetus/baby may have anemia. Baby may be jaundiced (yellow).
Blood borne disease: less than 1/1,000,000	Testing and donor screening	No symptoms or disease related (fever, jaundice, etc.)

The reactions experienced and possibility of transfusion reactions in the future should be discussed with the patient or family members once the patient is stabilized. If the patient has child bearing potential and received red blood cells or platelets, the risk of developing Hemolytic Disease of the Fetus and Newborn (HDFN) must be discussed. Where possible, the patient should be tested at 6 weeks to 6 months after transfusion with a group and screen to detect the antibodies (they can be transient and there is a narrow window to detect their presence). Using the MHP Patient Form, list any reactions/events the patient experienced. Explain why they occurred and how they were mitigated when discussing the MHP experience with the patient/family.

13.5 Informing the Patient and Family of all the Blood and Blood Products they Received

Patients want to know the numbers and types of blood components and products they received. Complete this section of the MHP Patient Form and discuss why these transfusions were required. Perform this task with the family members if they wish, even when the patient does not survive.

13.6 Informed Consent

As soon as the patient (or substitute decision maker) is able to make treatment decisions and has the ability to give 'informed' consent, it must be obtained and documented in the patient's chart.

13.7 Explain Who the Patient or Family can Call with Further Questions

Complete this section of the MHP Patient Form with the department name, telephone number of the health care area to answer any further questions the patient or family may have about their MHP treatment. Consider using the same telephone number as included in the routine post transfusion notification letter/notice. Some examples of contact persons include: transfusion safety officer, trauma surgeon, midwife, obstetrician, or any other contact person provided at that particular hospital.

Pediatric

Family presence/inclusion is a core value in pediatric care, and the option to include family members within the resuscitation of a child, while providing designated personnel to support them, has been adopted as a care-standard across pediatric institutions globally. Literature suggests the presence of a family member provides positive psychological benefits for both the child and their guardians while also assisting the clinical team in the assessment and management of an injured child to reduce fear and anxiety, and enhance communication.[99] It is reported that 30% of children suffer from post-traumatic stress disorder (PTSD) after a motor vehicle collision, and in the setting of a critically ill or injured child, evidence thus far demonstrates improved psychosocial outcomes for family, with a greater sense of closure when the resuscitation is unfortunately unsuccessful.[124,174]

for patients and their families

Massive Hemorrhage Protocol
Letter for MHP Patients and their Families

Patient Name: _____ (can apply patient label here)

DOB: _ _ _/_ _ /_ _

Patient #: _____

1. Purpose

The purpose of this letter is to try and answer some of the questions you and your family may have about your transfusion support during your major bleed. The letter can also act as a guide to the discussion with your health care team to ensure you have a chance to hear about your treatment. The health care team members speaking to you could include your primary physician, another physician, a nurse, a social worker or a spiritual care practitioner.

This document provides you with a permanent record of the summary of your transfusion treatments. We have also included a contact at the bottom of the pamphlet, so you can ask any follow up questions you may have at a future date. Please feel free to ask any further questions.

2. How Much Blood was Transfused (so far)?

_____ Red Blood Cells (RBCs)

_____ Platelet Doses

_____ Plasma

_____ Other blood derived products. List _____

3. Problems I experienced during my massive bleed in the first 24 hours

Yes/No	Problem	How this was controlled or treated	How I may feel or appear
☐ Yes ☐ No	Uncontrolled bleeding	Pressure on the wound, balloon devices, endoscopy, surgery	Pressure, anesthesia
☐ Yes ☐ No	Low body temperature	Warm IV fluids, warm blankets where possible	Cold, shivering
☐ Yes ☐ No	Low body pH (acidity)	IV fluids, red blood cell transfusion, medication to raise pH	Confusion, rapid shallow breathing
☐ Yes ☐ No	Not clotting properly	IV calcium, regular laboratory testing, transfusion of plasma, platelets or other blood products, other pro-clotting medications	Wounds not clotting
☐ Yes ☐ No	Anemia and low blood pressure	Red blood cell (RBC) transfusion	Weak, short of breath, dizzy, pale
☐ Yes ☐ No	Electrolyte imbalance	IV medication	Tingling, trouble breathing, chest pain, nausea
☐ Yes ☐ No	Increased fluid in tissues	Diruetics (water reducing medication), reduced IV fluids	Difficulty breathing, general swelling throughout the body
☐ Yes ☐ No	Allergic reactions to blood products (including anaphylaxis)	Antihistamine medication, steroids	Itchy, hives, puffy eyes, difficulty swallowing and breathing
☐ Yes ☐ No	Fever from blood products	Tylenol (acetaminophen)	Fever and chills
☐ Yes ☐ No	Lung injury from blood products	Oxygen, respiratory support (e.g., with intubation and ventilation), diuretics, chext X-ray for diagnosis	Difficulty breathing, chest pain

4. Hospital Contact for any Further Questions

If you think of any further questions, here is someone you can email or speak with by telephone:

Department/Name: _____

Email: _____

Telephone: _____