



*Photos by Dr Donald Donovan (ENT surgeon with Baylor College of Medicine)  
and Carolyn Waddington, RN, MSN, CNOR*

# Treating the Epidermolysis Bullosa Patient

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Epidermolysis bullosa (EB) is the name given to a group of congenital genetic disorders resulting in the defect of proteins that promote adhesion of the epidermal cells to each other and to the basement membrane. This results in three effects: the first is weakness of the epidermal layer - which is prone to shearing or separation from the basement membrane; the second is bullae or blister formations; and the third is scarring during healing after minor trauma.<sup>6</sup>

There have been more than 20 types of EB identified; however, they are typically categorized into three groups: EB simplex, dystrophic EB and junction EB.<sup>1</sup> EB occurs roughly 1 in every 20,000 births, with 92% of these cases presenting as EB simplex, 5% as dystrophic EB and 1% as junctional EB.<sup>7</sup> The remaining 2% are unclassified.

The main parts of the body affected by EB are the airway, oral cavity, gastrointestinal system, extremities and skin. All types of EB can present with scarring of the soft and mucosal tissue, which may result in strictures of the airway or failure of oral feeding. This is a particular concern for all surgical patients with EB as their airway may be difficult to maintain. Another common defect associated with EB is pseudosyndactyly, or mitten hand deformity. Finally, patients with epidermolysis bullosa are highly susceptible to various forms of skin cancer, especially squamous cell carcinoma.<sup>2</sup>

While there is no cure for EB, there are several surgical treatments that can help reduce the crippling effects of the disease as well as

## LEARNING OBJECTIVES

- ▲ Learn about the extreme care needed when dealing with EB patients
- ▲ Identify the various ailments that are commonly associated with this disease
- ▲ Review the protocols for room set up and patient prep when preparing for an EB case
- ▲ List the considerations mentioned for induction and intubation
- ▲ Recall the procedures for maintaining an airway in EB patients

increase the quality of life. In this article, a brief presentation of surgical procedures performed to treat the side effects of EB and increase the patient's quality of life will be explored.

### GENERAL CONSIDERATIONS WHEN PREPARING THE SURGICAL PATIENT

Since EB is a rare condition it is rarely encountered in a surgical setting. Nevertheless, the surgical technologist must have a basic understanding of the condition and the major concerns regarding the patient with EB, namely shearing and new bullae formation since these can lead to chronic wound infection, loss of airway and the inability to maintain proper nutrition. By following some basic guidelines of patient prep, patient positioning and case set up, the surgical technologist will help reduce the possibility of these injuries.

Several factors need to be considered when setting up the room and gathering supplies and equipment. The surgical technologist will need to focus on how to reduce any sort of shearing, bruising or blistering of the skin of an EB patient. They will also need to secure and maintain the airway of the patient during induction and intubation. Since patients with EB are more likely to suffer injury, the surgical team will need to take extra precautions to ensure that communication is clear, and that members of the OR team understand the plan before bringing the patient into the room as to avoid mistakes and injury to the patient.

### ROOM SET UP AND PATIENT POSITIONING

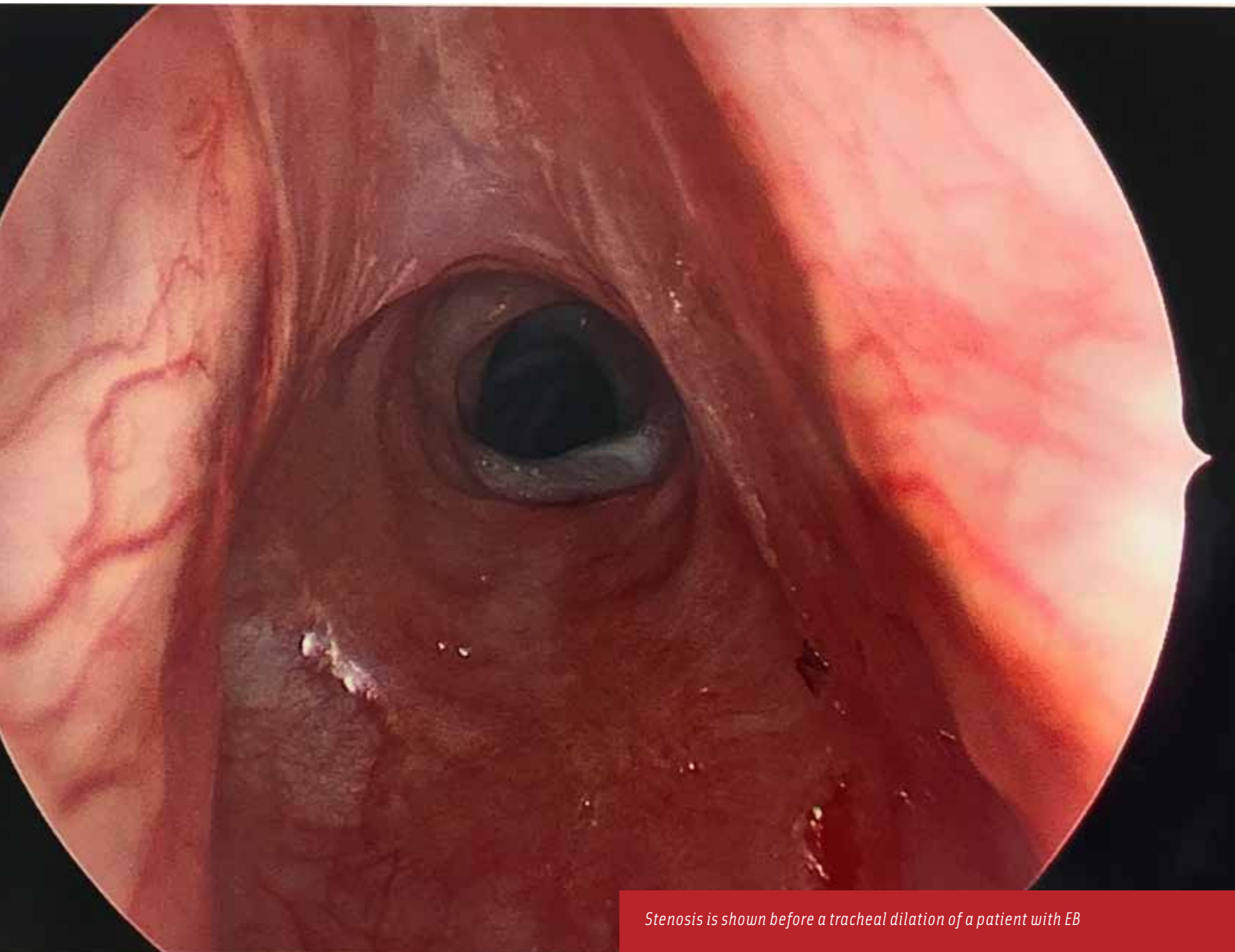
When setting up the room, the circulator and surgical technologist will need to make a clear path to move the stretcher into the room without rolling over any cords or tubing. The room will need to be set up so that there is as little movement as possible. In some cases, leaving the patient on the stretcher may be the best option. If at all possible, allowing the patient to remain in his or her own clothes during the procedure may help reduce any damage that might be caused by changing clothes.<sup>6</sup> Often the patient has acquired seamless clothing, which can reduce friction and shearing.<sup>3</sup>

Once the patient is in the room, moving and positioning will need to be as slow and coordinated as possible so that the skin does not tear or blister. The most effective way is to lift the patient using a draw sheet and at least four people; however, a using a patient transfer needs to be

used with extreme caution. The suggested guideline for pediatric patients is to use sheepskin. It may be placed underneath the child for padding, as well as used for moving the patient to help avoid injuring the skin.<sup>6</sup> While healthier surgical patients often can move themselves from the stretcher to the OR bed before the surgery, it is not recommended for patients with EB, as lateral movement from one bed to another may create accidental shearing.<sup>6</sup>

Padding used will need to be generous and well positioned over pressure points. Using soft cotton dressings will be needed to wrap pressure points. Gel positioning and pressure relief products will need to be used as they are less likely to slip than foam and provide a better barrier between the patient and the surgical equipment. Any sort of adhesive tape will need to be avoided, if at all possible, as nearly all EB patients are extremely sensitive to the tape, which can cause damage to the epidermal layers. Instead, cotton dressings will need to be used to help secure the patient or safety straps and offer a layer of protection between the straps and the patient's skin. While sequential compression devices are recommended for most patients, it is typically contraindicated in patients with EB, as the constant compression can damage the patient's skin on their legs.<sup>1</sup> If at all possible, monopolar electro-cautery should not be used as the patient will be more prone to peripheral tissue damage, and the grounding pad for monopolar cautery also may cause damage to the tissue. Currently, there is no consensus on what to do if monopolar cautery is needed for these cases. If it is necessary, finding an area of skin for the grounding pad with little or no bullae formation may be used.

When monitoring the patient, the same attention to care needs to be taken. The soft cotton dressings will need to be applied to the extremity where the blood cuff will be placed. To help reduce risk of epidermal damage, the cycling of the blood pressure cuff can be reduced so that it moni-

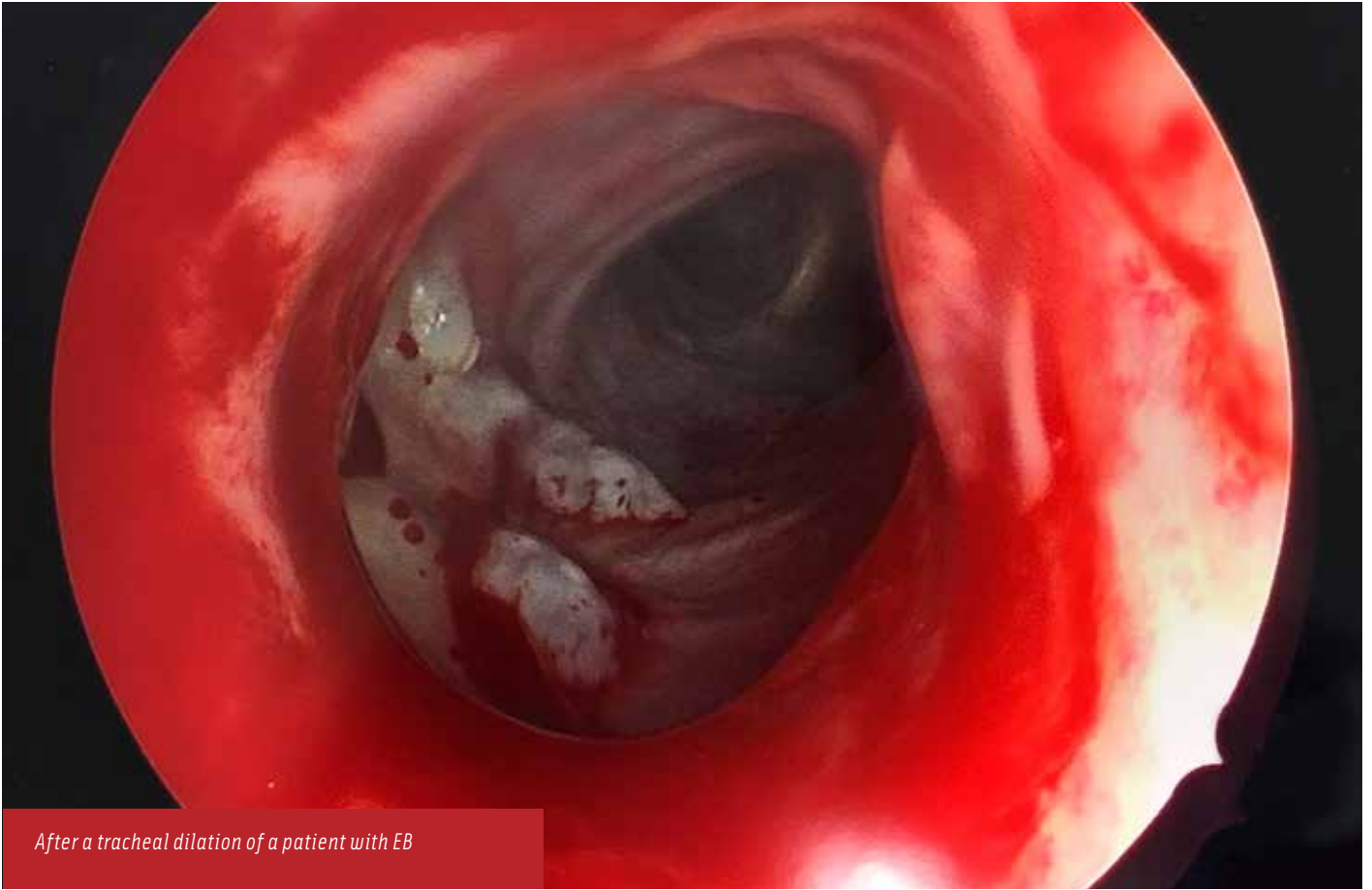


*Stenosis is shown before a tracheal dilation of a patient with EB*

tors the patient's blood pressure in less frequent intervals as long as anesthesia deems it is safe to do so. If the case is going to be a prolonged one, the anesthesia care provider may suggest using intra-arterial monitoring of the blood pressure to avoid potential trauma of repeated inflation of the cuff.<sup>6</sup> Oximetry will be monitored by either by covering the sticky side of a wrap-around pulse oximetry probe, placing it around the digit and securing it with an elastic self-adherent wrap, or by using a clip-on probe if the patient can tolerate it. A well-lubricated axillary temperature probe will be used to monitor the patient's temperature. In order

to regulate their temperature, a forced air-warming device may be used. However, a layer – such as a sheet or blanket – will need to be placed between the forced air-warming blanket or gown and the patient to prevent burning of the patient's skin.<sup>6</sup>

And, above all else, it is critical to discuss the exact care plan with the patient. Often times in such cases, EB patients have received prior surgical treatments and can assist in explaining what has worked for them as far as positioning, maintaining their airway and securing of leads.<sup>3</sup>



*After a tracheal dilation of a patient with EB*

### **CONSIDERATIONS DURING INDUCTION AND INTUBATION**

Once the patient is placed on the OR bed and prepared for anesthesia, the surgical team will need to be aware of the standard suggested precautions for EB patients. Severity of the patient's EB, how easy it is to maintain his airway and the type of procedure will affect the precautions taken. With regards to EB patients and anesthesia, most teams feel that less is more.

Starting an IV in the majority of EB patients is typically easy as the veins are easy to visualize and cannulate using a small bore cannula. When establishing an IV, the elastic tourniquet should not be used and excessive rubbing needs to be avoided.<sup>8</sup> When IV access is gained, the nursing staff will need to help protect the patient's IV site by providing a buffer between the hub of the IV cannula and the patient. This will be done by wrapping the hub with petroleum jelly-coated gauze and a light crepe bandage. The IV will then be secured to the patient using cotton dressings and the light crepe bandage.<sup>1</sup>

While IV induction is preferred, inhalation induction is also not contraindicated if the facial skin is fairly intact. A

well-lubricated and inflated mask may be used; however, the staff needs to be careful not to place too much pressure on the face when securing the mask, as this can risk traumatizing the skin around the mouth and over the mandible.<sup>6</sup> If IV access cannot be established and inhalation induction is contraindicated, intramuscular induction with a dissociative anesthetic may be possible, though this is seen as a last resort.

Once the patient is under anesthesia, moistened eye pads will be placed over the patient's eyes in place of tape or transparent film dressings. In order to maintain the airway, the use of a face mask loosely placed on the face is the preferred method as it avoids the risk of trauma to the mouth or airway. However, some cases require intubation. If endotracheal or nasal intubation is required, fiberoptic intubation has been found to be the most successful in reducing trauma to the airway. Using a small, well-lubricated tube will also help reduce trauma.<sup>1</sup> Some surgeons may request a cuffless tube, especially during tracheal or esophageal procedures. The tube will be secured using an endotracheal tube fastener placed beneath the patient's neck instead of on the patient's

face with minimal applied pressure, and the pads placed on the mandible.<sup>8</sup> Although there is not much literature about laryngeal mask airways, many anesthesiologists recommend against it as there is a high risk of bullae formation in the oral cavity as a result.<sup>6</sup>

### **SURGICAL SITE PREPARATION**

Before a surgical procedure, patients with EB are encouraged to bathe with chlorhexidine soap or wipes like any other surgical patient. A 0.9% saline can be mixed with chlorhexidine soap to reduce the stinging. If the patient cannot tolerate chlorhexidine, an antimicrobial soap can be used instead.<sup>8</sup>

Chlorhexidine is the recommended surgical site prep solution, primarily for its lasting antimicrobial effect, reducing the chances of surgical site infections, especially for patients who are more susceptible because their epidermal layer has been compromised. When applying the prep, the common repetitive motion should not be used due to the friction applied to the skin. Instead, a dabbing or blotting motion should be applied. The circulator or surgical technologist prepping the surgical site will need to take extra care to prevent pooling when using any alcohol-based prep solution because it may cause burning of the skin.<sup>8</sup>

### **COMMON SURGICAL TREATMENTS FOR EB PATIENTS**

#### **General Considerations**

For every surgical procedure, the main concern is the formation of new bullae and shearing of the epidermis. In order to reduce the chance of bullae formation and shearing, the surgical technologist should take into account basic considerations for EB patients. The scrub will need to ensure that no instrumentation, equipment or supplies are placed on the patient. The tech will need to ensure all sharps are sharp at all times, which may mean more frequent changes of the scalpel blades, sutures or inject needles. This will help reduce any tearing of the epidermal layers when making incisions, suturing or injecting the local. The surgical technologist will need to prepare for having extra blades, sutures and injects available, as well as testing the tissue scissors, biopsy forceps, and the like, that will be used during the case.

Any scope or instrument that will be placed into the air-

way, urinary tract or GI tract, will need to be well lubricated so there is no shearing. The lubricant used will need to be a water-based lubricant without lidocaine. The scopes and instruments used will need to be smaller, typically pediatric sizes, to help prevent shearing and bullae formation. The meatuses also will need to be well lubricated with cream, such as hydrocortisone topical cream, or a water-based lubricant.<sup>6</sup>

A reduction will need to be made in regards to the use of electrocautery, particularly the monopolar electrocautery since heat can destroy the surrounding tissue, causing more bullae formation. The use of monopolar electrocautery requires a grounding pad, which is an adhesive gel pad placed on the patient, and can damage the skin of the

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patient with EB. While a bipolar electrocautery is safer in this case, it is still recommended that its use be minimal so that the risk of epidermal layer damage is reduced. To help reduce the need for electrocautery, ties and hemostatic agents will need to be readily available. However, if monopolar electrocautery is necessary, the OR team can use a reusable grounding pad, such as a reusable pad, which is set on the operating room table underneath the linen. It is indicated for use in patients weighing more than 25 pounds and has with no weight maximum.<sup>4</sup>

#### **Airway Procedures**

Although laryngeal involvement is rare for patients with EB, maintaining the airway is a critical concern as oral and pharyngeal mucosal scarring and microstomia may lead to difficult intubation during and after surgical procedures. EB patients are unable to open their mouth very wide, even when given muscle relaxants, because the scarring has limited the movement of the muscles involved in opening the mouth and due to the congenital presentation of a small oral cavity. Since EB patients are highly susceptible to scarring of the mucous membranes, there is the added risk of post-anesthesia laryngotracheal scarring as a result of endotra-

cheal intubation. This may lead to stenosis of the lower airway, and subsequent respiratory failure and death.<sup>6</sup>

Treatment of laryngeal stenosis under general anesthesia is the most common airway procedure. This typically involves a direct laryngoscopy to assess the airway, followed by a rigid bronchoscopy and dilation. While dilation may be achieved using a laryngeal balloon or filiform or bougie dilators, the risk of shearing the mucosal layer of the airway is high, so the surgeon may opt for dilation using a rigid bronchoscope. With the rigid bronchoscope, the doctor will be able to control the airway, dilate the larynx and reduce the formation of friction blisters along the anterior commissure.<sup>10</sup>

Some patients may experience anterior commissure and glottic webbing. This webbing can cause strictures and difficulty breathing so the surgeon may opt for sharp dissection or the use of a carbon dioxide laser to release the webbing. Once this has been accomplished, evidence suggests that the use of the topical chemotherapy drug Mitomycin C may help stop granulation of the tissue at the site of application and prevent the recurrence of webbing.<sup>5</sup>

In some more severe cases of EB, such as Herlitz junc-

The hands and feet are most commonly affected by EB, leaving patients with blisters and ulcerations, erosion, scars and the absences of nails.

tional EB, the laryngeal involvement may become so severe that a tracheostomy will be needed, or in pediatric cases, parents may elect to have a tracheostomy tube placed before the airway becomes occluded to prevent respiratory distress or death. When preparing for a tracheostomy procedure, the surgical technologist will need multiple sizes of tracheostomy tubes, as well as various kinds of drain sponges or barrier products to be used between the skin and the tracheostomy tube phalange. Having umbilical tape or other tube holders that are soft and flexible available will help secure the tube after the procedure. Tube holders will provide more of a cushion than just umbilical tape and may be preferred.<sup>3</sup> Other considerations for the surgical team will be the type and placement of the tube, such that long-term care without bullae formation under the chin is possible.

## Oral Procedures

Although only the more severe cases of EB present with microstomia and bullae formation in the oral cavity, all types of EB are susceptible to dental caries due to a defect in the enamel. The enamel does not form to the proper thickness, leaving the dentin exposed, making teeth prone to yellowing, chipping and sensitivity.<sup>2</sup> Dental restoration typically includes fluoride varnish, restorations and caps. EB patients will be encouraged to use a small-headed, soft-bristle toothbrush soaked in hot water to brush their teeth and help prevent further damaging of the teeth and gums.<sup>2</sup> Some patients have overcrowding of teeth, which can make it more difficult to maintain good oral hygiene.

Due to bad oral hygiene, tooth extraction and irrigation and debridement of oral abscesses may be necessary. The liberal use of a hydrocortisone cream or a water-based lubricant for the lips will be necessary throughout the procedure. The lips and cheeks will need to be gently retracted using blunt retractors requiring little force or pressure, such as a Minnesota cheek retractor, Obwegeser retractors or Army-Navy retractors. The use of self-retaining cheek retractors may lead to shearing of the mucosal lining of the cheeks and

are not recommended.<sup>2</sup> Oral blistering and dysphagia may lead to other health problems, and ultimately, to the need for the placement of a gastrostomy tube.

## Esophageal and Gastrointestinal Procedures

Strictures within the esophagus are not uncommon, especially in patients with dystrophic EB. Nearly 70% of patients with dys-

trophic EB will have esophageal strictures at some point in their life.<sup>2</sup> Most strictures occur in the proximal esophagus and also lead to failure to thrive in children, malnutrition and aspiration. Typically, a barium swallow is the first step to diagnosing and evaluating the number and severity of esophageal strictures. The traditional way of alleviating any strictures is to dilate with well-lubricated bougies, gradually going up in size and being cautious not to traumatize the mucosal lining of the esophagus. General practice is the three bougie rule, that is, not to use more than three bougies in a single procedure so as to minimize risk of tearing and other trauma.<sup>11</sup> Another common way to treat stenosis is with an endoscopically guided balloon. However, there has been a movement within the otorhinolaryngology community to move toward fluoroscopy-guided hydrostatic esophageal balloon dilation. The hydrostat-

ic balloon offers larger size of balloons, allowing for a better functioning esophagus and longer intervals between dilations, as well as less oropharyngeal trauma.<sup>2</sup> Patients with bad oral care also have an increased risk of bullae formation, oral ulceration, poor mastication, diminished appetite and poor nutrition, which leads to an increased need for a gastrostomy tube. Gastrostomy tube placements are associated with dysphagia and esophageal strictures. Its primary purpose is to increase quality of life and help the patient maintain proper nutrition. However, this is seen as a last resort for patients with EB, as normal ingestion of food is encouraged. While either open or percutaneous gastrostomies may be performed, most patients do better with eventually replacing them with low profile gastrostomy buttons. EB patients are at higher risks for infection and rejection due to the breakdown of tissues surrounding the gastrostomy site.<sup>2</sup>

### **Hand and Foot Procedures**

The hands and feet are most commonly affected by EB, leaving patients with blisters and ulcerations, erosion, scars and the absences of nails. As mentioned previously, pseudosyndactyly is very common. Pseudosyndactyly typically forms as a result of epithelization, healing by growth of epithelium over the injured site, after recurrent epidermal injuries. Over time, a layer of epithelium forms between the digits, as well as around the whole hand, causing the hand to contract. This is also called “web creep” or “cocooning of the hand,” and starts in childhood.<sup>9</sup> Procedures to correct pseudosyndactyly are the most common surgical procedures among patients with EB. Even newborns are afflicted pseudosyndactyly as a result of intrauterine movement or trauma from the delivery.<sup>3</sup>

Since this is a genetic disorder that affects the epidermal cells, it may become necessary to have repeated hand surgery on average every 2.5 years. The older technique of degloving has been replaced with a limited approach of interphalangeal and palmar contracture releases. Removal of the upper, hardened dermal layers, or degloving, traumatizes the lower layers, resulting in more webbing. The limited approach simply dissects the tissue between the phalanges to return mobility. While full mobility not achieved, it is less traumatizing to the epidermal layers and increases time between surgeries, which is better for the quality of life of the patient.<sup>9</sup> In some cases, the muscle layers are exposed and a full thickness skin graft may be required. Despite the possible complications with harvesting skin, cleaning and defatting the graft and suturing the graft, FTSGs typically heal well and are used when necessary. The graft is placed on a piece of greased tulle – commonly

used as burn wound dressing – and placed over the receiver site. Many surgeons choose to leave the dressing on and wrap the wound in place of suturing.<sup>9</sup> The tulle dressing can be used over the donor site as well.

After surgery, post-operative splinting and careful placement of dressings will be necessary for a time to prevent re-webbing during the healing process. Typically, the hand is wrapped using a soft bandage to provide downward pull on the web spaces and around the palm. The open wounds will first be covered with non-adherent dressings, and then the hand is prepared with a layer of emollient – a non-cosmetic moisturizer – before the application of the bandage.<sup>3</sup> Webbing, and eventually digital fusion, frequently occurs that as adults many EB patients begin to refuse surgical treatments and live with the limited mobility caused by pseudosyndactyly. While the feet often are affected by shearing and blister formation, many surgeons recommend against any surgical procedures to correct webbing between the toes, as healing after surgery is usually difficult and the procedures show no long-term success.<sup>3</sup>

### **Dermatological Procedures**

Despite the severe involvement of the skin, most forms of skin cancer do not affect patients with EB any more than the normal population. However, patients with EB have an elevated risk of squamous cell carcinoma or SCC.<sup>2</sup> SCC is typically seen in patients with more severe forms of EB, and appears mainly over boney prominences. Due to the decreased immune response and altered skin cells, SCC is typically aggressive and occurs in the majority of all EB patients who reach adulthood.<sup>2</sup> Several treatment options include the most common, less-invasive treatment such as radiotherapy or chemotherapy. However, some surgeons feel these treatments may weaken the good skin cells, making surgical treatment later on more difficult.

Some doctors may choose to perform a Mohs procedure if they feel the SCC is more isolated. The Mohs procedure involves surgically removing an area of skin and then examining the tissue layer by layer to ensure the margins are clear. While this can take some time, it is considered one of the better treatments for skin cancer, and is fairly safe for patients with EB as it is performed as an outpatient procedure while the patient remains awake. Reconstruction after Mohs typically involves a primary closure for smaller wounds or a full thickness skin graft for larger wounds, which has proven to be successful in the majority of cases.<sup>2</sup> Since many patients with EB struggle with malnutrition,



anemia and poor wound healing, SCC can metastasize quickly, leading to the need for amputation.<sup>2</sup>

The surgical team needs to ensure that cancer precautions are taken, so that the accidental spread of cancer cells does not occur. Typically two setups is recommended, with a change of gloves in between. The subcutaneous layers are closed with an absorbable suture, and the final skin closure is made with a finer, non-absorbable suture. While a compression dressing made of medicated gauze and a cotton wrap is recommended, the surgical team will need to take care not to wrap the wound too tightly as it may cause the tissue to necrose.<sup>2</sup>

Currently, there is some research being performed on Alloderm skin grafts. While it is not seen as a panacea for EB, it does show some promise for those who have more severe forms of EB. Alloderm grafts have been used after surgery to correct pseudosyndactyly and Mohs. For those who did not reject the graft initially, the grafts took well and the need for future surgeries was diminished.<sup>2</sup>



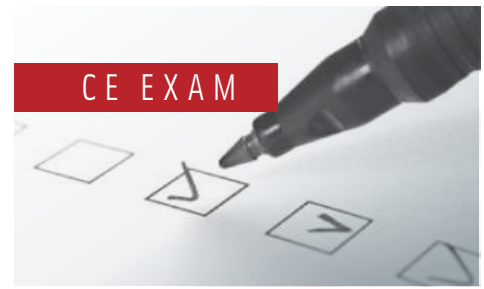
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