Quick Tips for Nurses: Caring for Patients with Osteogenesis Imperfecta

General:
- Enlist parent or adult patient support when caring for a person with OI.
- Use pediatric-sized equipment as indicated for adolescents and adults with OI who are short in stature.
- It is preferable to use manual BP cuffs unless the patient has past successful experience with automatic BP cuffs. Bowing of a limb may result in a higher than expected BP.
- Insertion of IVs may require additional stabilization of the skin over the insertion site. Be aware that the patient’s skin may be more elastic and fragile than that of patients without OI.
- Short stature may affect the proper dosage of medicines. Weight more than age should be taken in consideration.
- Do not rely on the patient’s appearance to indicate the patient’s physical or intellectual age.
- Patients may have a higher baseline temperature and may sweat more/be more sensitive to warm temperatures than other patients. Fever, however, should not be dismissed.
- If a patient is self-splinting an extremity, it may indicate a fracture. However, the patient may not show outward signs of pain when a fracture occurs.
- Fractures may not be immediately evident on x-ray.
- Measure lengths instead of heights for patients who cannot stand. Leg lengths may differ. Length should be measured on both sides of the body.
- Late fontanel closure is seen in some patients. The fontanels may remain open until age 3 or 4 years.
- Fractures can occur with a remarkable lack of force. Patients may fracture due to a sneeze, standing on tiptoes, or even by turning a page in a book.
- Address the patient at their height by crouching, kneeling, or sitting.
Handling:
- Do not underestimate the fragility of patients with OI; patients with mild OI may have few visible signs of their fragility.
- Never twist, jerk, or bend a limb.
- Head, trunk and buttocks should be evenly supported when lifting a baby.
- When handling a patient with OI regardless of age, move in a slow, methodical and gentle manner.
- Listen to the patient/parent for assistance with safe handling.
- Do not grab the ankles when changing a diaper. Lift with one hand under the child’s bottom.
- Do not attempt to straighten a bowed limb or try to force a contracted joint to straighten.
- Parents may prefer to wrap or splint the child’s fracture themselves, instead of having the fractured bone casted. However, this warrants good judgment and ability of the parent to splint/wrap the fracture properly.
- Signage indicating the diagnosis of OI and “fragile bones” should be placed on the child’s bed, wheel chair, and hospital chart.
- Head control may develop late and may be complicated by a relative macrocephaly. Care and caution are advised when supporting the child’s head.
- Avoid bouncing or sudden movements when handling the patient.

For more information about osteogenesis imperfecta contact:

Osteogenesis Imperfecta Foundation
804 W. Diamond Avenue, Suite 210, Gaithersburg, MD 20878
Tel: 800-981-2663 (free of charge) or 301-947-0083
Fax: 301-947-0456
Internet: www.oif.org
E-mail: bonelink@oif.org