THE CHALLENGE OF MANAGING CHRONIC WOUNDS WHEN QUALITY OF LIFE IS A SIGNIFICANT ISSUE

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Epidermolysis bullosa
Epidermolysis bullosa is a group of inherited bullous disorders characterized by blister formation in response to mechanical trauma. There are approximately 5,000 sufferers in the UK and around 500,000 worldwide (equivalent to 1 in 17,000 live births). Patients with recessive dystrophic EB (RDEB) lack the gene that encodes for the protein collagen VII. Without collagen VII, minimal trauma or friction causes the epidermis to separate from the dermis and so blisters form with ease which may then develop into wounds. The internal mucosa is also affected, including the mouth, the oesophagus and corneas. Development of chronic wounds is common as is healing with scarring. Treatment is symptomatic with skin and wound management forming a large part of care. Wound management in RDEB patients is a complex process and wound care becomes a way of life for affected individuals and their carers. For some patients, symptom control is a more realistic objective than healing. Wounds typically seen in EB range from superficial blister sites that heal with the application of non-adherent dressings to chronically wounded areas that never seem to heal1. Pain, infection and exudate management all present immense challenges. Furthermore, dressings are limited to those that do not adhere to the fragile peri-wound skin. This communication describes the challenge of wound management in a young patient with severe RDEB.

The patient
A 24 year old female patient with severe RDEB suffered head wounds following pediculosis (infection of head lice). The wounds have gradually become worse over the past 6 years. Many dressings and ointments have been tried, with no improvement. The challenges faced in managing the wounds include, excessive exudate which can leak into the aural canals and eyes causing ear infections, conjunctivitis and blepharitis; infections, in particular Pseudomonas, and possible biofilm formation; extreme sensitivity of the scalp with pain on dressing change; application of a hat or wig which the patient finds very hard to tolerate especially in hot weather.

Treatment with Flaminal®
Although there is no data on the use of Flaminal® in EB patients, existing data supports the use of Flaminal® in heavily exuding wounds and in wounds at high risk of infection. Further, studies have shown that dressing-associated pain may be reduced with Flaminal®. With the patient’s full agreement, it was decided to change the plan of care to using Flaminal® as the primary dressing. Flaminal® Hydro was applied as a thick layer with extreme care using a soft swab and then very carefully smeared onto the scalp wounds. Mepilex and Mepilex Transfer were selected as secondary dressings as Flaminal® did not adhere to them and ActivWrap bandage was used to secure the dressings.

4 weeks after Flaminal® treatment:
RDEB patients in the community are often self-managing, either dressing their own wounds or having a carer dress the wounds, with the decisions ultimately being made by the patient. It is not surprising therefore, that as the patient found a treatment that offered her greater benefits over existing treatments, that she extended the use of Flaminal® to the management of some of her other wounds.

Conclusion
Flaminal® has become a much welcomed addition to the highly limited armamentarium of wound care products suited for the management of chronic wounds in RDEB.

DebRA
Registered Charity No: 1084958.
www.debra.org.uk Telephone No; 01344 771961.
DebRA is a registered charity and provides information, practical help and advice from specialist nurses, social and welfare workers.
It is also a means of supporting patients, families and allied healthcare professionals via a website, newsletters and conferences, patient group meetings, home visits and specialist clinics.

Reference List
2. Ly J, Su X. Dressings used in epidermolysis bullosa blister wounds: a review. J Wound Care 2008 Nov(17(11)):482, 484-6, 488.