

# The effect of current economic cuts to wound dressings and its impact on patients with epidermolysis bullosa: a case study

## KEY WORDS

- ▶ Epidermolysis bullosa
- ▶ Dressing regimen
- ▶ Patient story
- ▶ Wound healing

Epidermolysis bullosa (EB) is a rare group of genetically inherited skin fragility disorders (Denyer and Pillay, 2012). There are four major types of EB: simplex, junctional EB, dystrophic EB and Kindler (Fine et al, 2014). At present there is no cure for EB and patients suffer from lifelong wounding. Much of the clinical care is focused around symptom management: wound care, pain control, preserving function and palliative care. With this article, the author, an EB Clinical Nurse Specialist (CNS) working in a Tertiary Care Centre, gives an overview of the key issues and treatment regimens, while explaining the need for specialist care to help reduce the complications of living with this complex condition.

Patients with more severe types of EB will often have multiple wounds at various stages of wound healing, this requires complex dressing regime and the use of advanced dressings (Stevens, 2012). It is essential that atraumatic dressings are used to prevent further damage, pain or bleeding to their fragile skin (Denyer and Pillay, 2012). Risk of infection can be high due to large areas of open wounds. Antimicrobial cleansers, moisturisers and topical treatments are necessary to manage the wound bio-burden. Many patients require large quantities of dressings to cover the areas of skin affected and allow for daily or alternate day dressing changes. These patients are also at increased risk of developing squamous cell carcinoma which leads to a shortened life expectancy, regular skin surveillance and monitoring is required for these patients (Mellerio et al, 2016).

Many patients have carers who assist them with their daily wound management. This might be provided by a relative or care agency. District nurses and practice nurses can be involved with care of these patients on a regular or ad hoc basis. GPs are responsible for the ongoing provision of dressings and medication for the patients, often this would be recommended by the EB specialist team in the hospital.

## AN EB CASE STORY

Luke (not his real name to protect his identity) is a 41-year-old man with generalised intermediate recessive dystrophic EB (RDEB). Luke has a severe form, which affects his skin both externally and internally. RDEB is characterised by reduced or absent collagen VII, which is a major component of the anchoring fibrils at the dermal-epidermal junction (Petrof et al, 2013). Luke's affected areas are his hands, elbows, knees, lower legs and feet, where he has constant open wounds and blistering. These might be in the form of an acute blister or chronic wounds (*Figure 1* and *2*). Due to his constant open wounds, he is susceptible to recurrent infections that can delay healing, cause pain and have increased exudate and odour. The wounds on his knees, legs and feet are the most problematic for him and require dressings to cover all the skin on these areas.

Luke also suffers from internal blistering in the oral mucosa, oesophagus and skin around the anal margin. This can lead to difficulty in eating and maintaining optimal nutrition. Poor dietary intake and increased metabolic demands will also impact on wound healing (Pope et al, 2013).

## WOUND MANAGEMENT GOALS

The main objectives for Luke's wound management are to protect the skin from

ANNETTE DOWNE  
Epidermolysis Bullosa Clinical  
Nurse Specialist, St John's  
Institute of Dermatology,  
Guy's and St Thomas' NHS  
Foundation Trust, London



Figures 1. An acute blister



Figures 2. Chronic leg wounds



Figures 3. Dressing in place

friction and trauma, promote wound healing and prevent infection in accordance with the EB wound management guidelines (Denyer and Pillay, 2012). EB is a genetically inherited condition and Luke has tried all his life to find the most effective way to manage his skin. As a child, he used N/A dressings with Betadine which he found painful and ineffective. Luke talked about the time when silicone wound contact layer dressings were introduced and said that *"this made a huge difference, my dressings didn't stick to my skin anymore"*. The new Safetac® dressings improved Luke's skin integrity, increased comfort and reduced pain which enhanced his quality of life considerably. An essential dressing for Luke is Mepitel®, which is a flexible, polyamide net coated with soft silicone that is effective in staying in place over wounds without adhering to the wound bed or peri-wound skin (Abercrombie et al, 2008). This dressing provides a 'second skin' for Luke, where his skin is absent or damaged. He also finds that there is much less damage and trauma to his skin when using the silicone dressings. Luke's current wound management regimen is shown in *Box 1*.

With the current pressure on GPs to make savings in their budgets and look for more cost-effective dressings, patients with EB can often be targeted due to the high annual cost of expensive wound dressings. When Luke recently went to collect a repeat prescription for his Mepitel, he was informed by the pharmacy that his repeat prescription had been cancelled and that they were only able to issue him two boxes that day, which would last him for one dressing change only. There was no communication from the doctor to inform Luke of this change or to discuss the importance of the need for these dressings. Luke contacted me in a highly anxious and angry state informing me of what happened, saying *"without the Mepitel, I am unable to dress my wounds and therefore cannot go out of the house."* He also has a fear of his skin being damaged or delayed healing due to inadequate dressing provision. He added *"I felt like I had reverted back 10 years to the previous unsatisfactory wound dressings I had to cope with."* *"It's like telling a diabetic patient that they can't have insulin anymore."*

The majority of GPs who have an EB patient on their caseload are very supportive and do

**Box 1. Wound management regimen**

- Cleanse with Octenilin® Wound Irrigation Solution
- Wash/moisturise with Dermol 500 Lotion
- Honey gel dressing to infected wounds — as required
- Cover with Mepitel®
- PolyMem foam dressing to absorb exudate, moisturise and protect vulnerable areas
- Secure with slinky bandages and Tubifast™

provide all the medications and dressings that they need. However, the issue of GPs being under pressure to make cuts particularly in areas such as dressing costs seems to be increasing which is a huge concern for EB patients. In the author's experience many GPs do not regularly assess EB patient's wounds and prefer to refer this to the nurses or specialist team. This may lead to a lack of understanding around how crucial these dressings are for the patients to protect their skin, reduce infection and improve their quality of life. Dressings represent a relatively small proportion of the total cost of wound management when you consider other contributing costs, but they have the potential to improve outcomes considerably (Wounds International, 2013). Without effective dressings, Luke is at risk of delayed healing due to infection and further skin damage.

A search of the literature was performed using the databases PubMed, CINAHL, Medline, The Cochrane Library and Scopus using the key words economic constraint\*, economic cost, cost-effectiveness, financial burden, financial constraint\*, GP commissioning, wound care, wound management, chronic wound, epidermolysis bullosa and clinical decision making. The limits were set to English language and human studies. Internet sites such as Google Scholar, Debra UK, DEBRA International, Department of Health (DH) and National Institute for Health and Care Excellence (NICE) were also searched for further relevant literature.

**THE BURDEN OF WOUND CARE**

The NHS is currently under extreme financial pressure. The success of advanced technologies and the increasing ageing population add to the financial demand. We are living in days of austerity

Table 1. Breakdown of dressing costs

Product	Size	Cost per item	Amount used per week	Total cost per week
Mepitel	20 x 32 cm	£15.95	30	478.50
PolyMem roll	10 x 61 cm	£13.10	24	314.40
PolyMem roll	20 x 61 cm	£30.90	12	370.80
Medihoney	20g tube	£4.02	3	12.06
Octenilin Irrigation	350 mls	£4.60	1	4.60
Slinky Bandage	10 cm x 4 m	£0.72	12	8.64
Tubifast	7.5 cm x 5 m	3.95	2	7.90
Total weekly cost	(approx)			1,196.90
<b>Total yearly cost</b>	<b>(approx)</b>			<b>62,238.80</b>

so the NHS is forced to deliver more but spend less. Lord Carter has set a target for the NHS to save £5 billion a year by 2019/20 (DH, 2015). He also identifies that there could be a £3 billion saving in medicines and suggests evidence base and modern systems for controlling purchasing and ordering (DH, 2015). This is already starting to have an effect on the potential restriction of wound care dressings by the development of a national formulary for wound care (While, 2016). While this can be a positive step in keeping with best practice, it can also restrict the range of wound products available to clinicians and patients (Butcher and White, 2014).

Wound care imposes a substantial health economic burden for the NHS (Guest et al, 2016). In the UK between 2013/14, Guest et al (2015) estimated that there were approximately 2.2 million wounds managed by the NHS, which cost an estimated £5.1 billion to treat. In addition, Guest et al (2015) found that 66% of the total cost was incurred in the community, managed by GPs and nurses, where wound care remains a nurse-led speciality.

With the introduction of clinical commissioning group (CCGs) as part of the DH's new Health and Social Care Act in April 2012, GP practices have become part of the CCG and have taken over local service commissioning (Royal College of Nursing, 2012). Some of the suggested reasons for GP-led commissioning are to increase clinical leadership, greater competition, appropriate local patient-focused care and reduce costs (Charlton, 2013).

CCGs are responsible for making choices about how money is spent and resources are assigned to gain maximum benefit (Wounds International, 2013). As mentioned earlier, wound care has a significant effect on healthcare costs, particularly in chronic wound management (Butcher and White, 2014). With the majority of wound care undertaken in the community CCGs have to find ways to be cost effective in wound care expenditure. This could have significant consequences for patients with EB who have lifelong wounds.

Two studies have sought to explore the cost of wound care dressings in EB. A recent study tried to determine the social and economic costs of EB in eight countries in the EU, including the UK (Angelis et al, 2016). They recruited 204 patients for their cross-sectional study and sent out questionnaires for patients and carers to complete. The annual cost ranged from €9,509 to €49,233, which also included non-healthcare costs such as care givers time, transportation and social care services (Angelis et al, 2016). Although the data is helpful in giving further information on the economic costs of EB, because they have included all ages and types of EB in the study, it can dilute the true costs of management for the more severe forms of EB due to the significant differences between the types of EB and age ranges. Because Luke has a severe form of EB and has large areas of open wounds, his dressings alone cost approximately £62,238.80 per year (Table 1) which is more than the average annual costs for all care in this study. The study does, however, highlight that EB has a consistent impact on the quality of life of patients and their carers, as well as on direct and indirect healthcare costs (Angelis et al, 2016).

Kirkorian et al (2013) reviewed the cost of daily wound care supplies in children with RDEB in the US. They found that the daily costs ranged from \$22.15 to \$270.92 for an infant and from \$54.54 to \$668.23 for a 10-year-old (Kirkorian et al, 2013). This is a study with paediatric patients in the US, so it is difficult to transfer the data accurately, however, similar wound dressing products were used including Mepitel, which Luke uses. The study highlights the range of costs of dressings, which in some cases is considerable. They seek to justify the costs of the dressings due to the importance in prevention of scarring and contractures through optimal wound management (Kirkorian et al, 2013).

This article was written in part fulfilment of the MSc Skin Integrity & Wound management at the School of Life & Medical Sciences, University in Hertfordshire

A current study underway in the UK includes estimation of the health economic burden of dressings in RDEB and has identified that adult patients may require in excess of £500,000 worth of dressings per annum (Mellerio, 2017).

### LIVING IN PAIN, LIVING IN FEAR

Pain and quality of life is also a key justification for using non-adherent wound care products (Kirkorian et al, 2013). Pain is an integral part of many patients' experience of having a wound and can negatively impact on their quality of life (Butcher and White, 2014). Patients with EB live with painful interventions on a daily basis but wound pain is identified as the most prominent complaint of pain in EB (Goldschneider et al, 2014). Pain at dressing change and trauma from dressing removal is a central and significant factor (Butcher and White, 2014). Luke talked about the fear of going back to the days when his dressings were painful to apply and remove. Patients like Luke who, since childhood, have suffered hours of painful dressings changes are often in as much psychological pain as physical pain (Abercrombie et al, 2008). The negative impact that pain, chronic wounds and living with the burden of a devastating condition like EB have on patients cannot be underestimated.

For Luke, the thought of having to manage without his dressings that protect his skin was a highly stressful event for him. Research has shown that stress is associated with impaired wound healing (Walburn et al, 2009).

Clinical commissioning is purported to be about improving clinical outcomes and ensuring quality care to patients (Charlton, 2013). While there may be many areas where this applies, Luke's dressings being withheld from him clearly does not ensure quality care to the patient. This also does not comply with the DH's White Paper 'No Decision About Me Without Me' (DH, 2012), which states that patients should be involved in partnership working and decision making with clinicians about their care. EB patients are experts in their own care and their knowledge is invaluable (Abercrombie et al, 2008). One of the problems EB patients have to contend with is because their condition is so rare, most clinicians have no understanding of the complexity of EB, even their own GPs. They

are reviewed by the specialist team who have expert knowledge about their condition, this information is then sent to the GP with advice and recommendations on appropriate management, but occasionally and more increasingly, the recommendations are not adhered to due to local restrictions on wound dressing formularies. This is a frustrating situation for both the patient and clinician where local governance restricts the outcome of the specialists' recommendations. This goes against the principles of the DH's strategy for rare diseases, which sets out to improve patient experiences, management of their condition and on-going care (DH, 2013).

Effective wound care is an essential part of management in EB (Stevens, 2012). Wound management is complex due to the fragility of the skin, which severely limits the choice of dressings and methods of care (Abercrombie et al, 2008). The best practice guidelines for skin and wound care in EB affirm the importance of listening to patients as they are experts in their care after many years of trying various dressing regimes (Denyer and Pillay, 2012). Abercrombie et al (2008) suggest that failure to listen to patients can lead them to feel alienated and could even cause potential physical and psychological harm. Luke said that he feels his GP is not interested in learning about EB. This resulted in Luke becoming angry and frustrated when he is told that he cannot have dressings like Mepitel from his surgery and reinforces his belief that the GP isn't aware of the impact this has on his life.

Luke contacted the EB nurses for help in this stressful situation. Specialist nurses have an important role in acting as an advocate and support to ensure that patients have fair access to available resources (Schwartz, 2001). Hyland (2002) states that patients are often afraid to voice a need to a doctor and that nurses are best placed to act as an advocate due to the closer and prolonged access that they have with patients. This resonates with the role of the EB CNS where close nurse-patient therapeutic relationships are built up. EB nurses spend a lot of time liaising with GPs and practice nurses to ensure that the patients obtain the right size, quantity and brand of dressings that they need. The surgery and the local Tissue Viability Nurse (TVN) were contacted. The local wound

## Box 1. Recommendations for practice

- Greater collaboration between GPs, CCGs, pharmacists and other stakeholders to raise awareness of wound management in EB
- Meetings, teaching and education around the best practice guidelines
- Wider awareness through DEBRA UK and conferences
- Advocating for patients and allowing their voice to be heard
- Discussion with NHS England regarding strategies for rare diseases such as special budgets to assist CCGs with expensive patients
- Develop a pathway as a team to have standardised procedure and response for any future issues with cost of treatment from CCGs
- To be mindful of costs of dressings when we recommend new treatments for patients
- Evaluate effectiveness of dressings
- Teach patients and carers how to use appropriately
- Keep wastage to a minimum by not over-prescribing

care formulary didn't list Mepitel, so it was required to be a specialist item. The TVN was helpful and responsive when it was explained to her how important the dressings were for Luke. A copy of the EB best practice guidelines for skin and wound care (Denyer and Pillay, 2012) to raise awareness of the evidence base for the choice of dressing. Increasingly, GP surgeries are employing their own pharmacists to manage the medicine and dressing orders to keep in line with formulary restrictions and cost savings directed by the local CCGs.

### GOOD OUTCOME

In this instance, working with the TVN, GP surgery and patient resulted in Luke receiving his Mepitel dressings. Agreement was also reached to fund his dressings without restriction due to the best practice guidelines and necessity of Luke requiring these dressings for his fragile skin. However, this initial refusal to provide dressings is becoming an increasingly familiar scenario. Providing evidence for cost-effective wound management is a challenge to clinicians due to lack of robust evidence (Butcher and White, 2014). Because dressings are generally classified as medical devices the level of evidence is lower than that of medicines which is reflected in the

poor quality of research in this area (NICE, 2016). The development of best practice guidelines assist in adding expert knowledge to the management of patients, however, in a rare condition such as EB, many clinicians can be unaware of these guidelines. Stephen-Haynes et al (2011) recommend an integrated approach to optimising wound care by collaboration, implementation, education and monitoring. They also advise use of advanced dressings in line with best practice guidelines to improve outcomes (Stephen-Haynes et al, 2011). Guest et al (2015) also suggest that referral to specialist services and the training of non-specialist clinicians will help achieve better health outcomes and reduce costs. When wound management is implemented properly based on appropriate interventions it produces benefits to the patient (Wounds International, 2013). Ultimately, this will lead to cost savings by reducing inappropriate management. Holistic management of patients would also achieve better health outcomes and potentially reduce costs (Guest et al, 2015). It is vital that the nurse specialists are involved in raising awareness of optimal wound management and treatment of patients with EB by collaborating with other healthcare professionals and educating them about the condition at a local level and national level with the support of DEBRA UK charity. As clinicians we have to be aware of the huge financial cost of wound care and ensure that the patient has the best management but at the same time to be resourceful to try to minimise cost. This does not always mean that it has to be the cheapest option. An expensive treatment such as antimicrobial dressings could be seen as initially expensive but if the benefits are greater and infections are reduced, there is an overall cost saving (Wounds International, 2013; Butcher and White, 2014). Cost-effective wound management will continue to be a challenge in the current economic climate. Wound care specialists have an important role in raising awareness to CCGs and the wider healthcare systems of the benefits of appropriate, evidence-based wound care dressings to improve outcomes and quality of life in patients living with wounds.

### CONCLUSION

The cost of wound care is significant and there is mounting pressure to maintain quality of care

while spending less. Cost effectiveness in wound care is difficult to quantify from the cost of dressings alone, which are relatively inexpensive compared to the wider associated costs. However, they seem to be an easy target in an effort to reduce costs. We are fortunate in this country to have advanced dressings available such as Mepitel but due to their significant cost they are increasingly questioned as a result of restriction on budgets and wound formularies where cheaper options are recommended. Other additional underestimated costs need to be factored in such as delayed healing, pain, infection as well as the impact on the patients' quality of life when evaluating wound care cost-effectiveness. Pain and quality of life issues are very difficult to place monetary value on. EB wound care is expensive as specialist nurses we often recommend treatment and wound management plans for the patients. Studying the literature concerning the need to reduce costs highlights the importance of appropriate wound management and prescribing quantities of dressings to prevent any wastage of products. Patients and carers also need to be educated around appropriate use of products to reduce costs where possible. Incorrect/inappropriate use of dressings is a costly issue, the dressing is less effective and there is no benefit to wound healing or the patient. With increasing demands on the NHS and CCGs this problem is not likely to go away. Specialist nurses are ideally placed to advocate for patients and develop integrated approaches to wound care.



REFERENCES

Abercrombie E, Mather C, Hon J, Graham-King P, Pillay E (2008) *Recessive Dystrophic Epidermolysis Bullosa. Part 2: Care of the Adult Patient*. Available at: <http://ebnedit.com/wp-content/uploads/2015/12/105.pdf> (accessed 28.02.2017)

Angelis A, Kanavos P, Lopez-Bastida J, Linertova R, Oliva-Moreno J, Serrano-Aguilar P et al (2016) Social/economic costs and health-related quality of life in patients with epidermolysis bullosa in Europe. *Eur J Health Econ* 17(Suppl 1):31–42

Butcher M, White R (2014) Factors affecting cost-effectiveness in wound care decision making. *Nurs Stand* 28(35):51–58

Charlton R (2013) GP commissioning in England. *Royal College of Physicians* 13(1):24–6

Denyer J, Pillay E (2012) *Best Practice Guidelines for Skin and Wound Care in Epidermolysis Bullosa*. Available at: [http://www.woundsinternational.com/media/issues/623/files/content\\_10609.pdf](http://www.woundsinternational.com/media/issues/623/files/content_10609.pdf) (accessed 28.02.2017)

Department of Health (2012) *Liberating the NHS: No Decision About Me Without Me*. Available at: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/216980/Liberating-the-NHS-No-decision-about-me-without-me-Government-response.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216980/Liberating-the-NHS-No-decision-about-me-without-me-Government-response.pdf) (accessed 28.02.2017)

Department of Health (2013) *The UK Strategy for Rare Diseases*. Available at: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/260562/UK\\_Strategy\\_for\\_Rare\\_Diseases.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/260562/UK_Strategy_for_Rare_Diseases.pdf) (accessed 28.02.2017)

Department of Health (2015) *Review of Operational Productivity in NHS providers*. Available at: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/434202/carter-interim-report.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/434202/carter-interim-report.pdf) (accessed 28.02.2017)

Fine JD, Bruckner-Tuderman L, Eady RA et al (2014) Inherited epidermolysis bullosa: Updated recommendations on diagnosis and classification. *J Am Acad Dermatol* 70(6): 1103–26

Goldschneider KR, Good J, Harrop E et al (2014) Pain care for patients with epidermolysis bullosa: best care practice guidelines. *BMC Medicine* 12(178):1–23

Guest JF, Ayoub N, McIlwraith T et al (2015) Health economic burden that wounds impose on the national health service in the UK. *BMJ Open* 5(12):1–8

Hyland D (2002) An exploration of the relationship between patient autonomy and patient advocacy: implications for nursing practice. *Nurs Ethics* 9(5):472–82

Kirkorian AY, Weitz NA, Tlougan B, Morel KD (2013) Evaluation of wound care options in patients with recessive dystrophic epidermolysis bullosa: a costly necessity. *Pediatr Dermatol* 31(1): 33–7

Mellerio JE, Roberston SJ, Bernadis C et al (2016) Management of cutaneous squamous cell carcinoma in patients with epidermolysis bullosa: best clinical practice guidelines. *Br J Dermatol* 174(1):56–67

Mellerio JE (2017) Personal communication

National Institute for Health and Care Excellence (2016) *Chronic Wounds: Advanced Dressings and Antimicrobial Dressings*. Available at: <https://www.nice.org.uk/advice/esmpb2/chapter/key-points-from-the-evidence> (accessed 28.02.2017)

Petrof G, Martinez-Queipo M, Mellerio JE et al (2013) Fibroblast cell therapy enhances initial healing in recessive dystrophic epidermolysis bullosa wounds: Results of a randomized, vehicle-controlled trial. *Br J Dermatol* 169(5): 1025–33

Pope E, Lara-Corrales I, Mellerio JE et al (2013) Epidermolysis bullosa and chronic wounds: a model for wound bed preparation of fragile skin. *Adv Skin Wound Care* 26(4):177–88

Royal College of Nursing (2012) *What does the Health and Social Care Act Mean?* Available at: [https://www2.rcn.org.uk/\\_data/assets/pdf\\_file/0008/461798/HSCA\\_FINAL.pdf](https://www2.rcn.org.uk/_data/assets/pdf_file/0008/461798/HSCA_FINAL.pdf) (accessed 28.02.2017)

Schwartz L (2002) Is there an Advocate in the House? The Role of Health Care Professionals in Patient Advocacy. *Journal of Medical Ethics* 28(1):37–40

Stephen-Haynes J, Bielby A, Searle R (2011) Putting patients first: reducing the human and economic costs of wounds. *Wounds UK* 7(3): 47–55

Stevens LJ (2012) Access to wound dressings for patients living with epidermolysis bullosa – an Australian perspective. *International Wound Journal* 11(5):505–8

Walburn J, Vedhara K, Hankins M et al (2009) Psychological stress and wound healing in humans: a systematic review and meta-analysis. *J Psychosom Res* 67(3):253–71

While A (2016) Productivity in health care. *Br J Community Nurs* 21(3): 162

Wounds International (2013) *International Consensus: Making the Case for Cost-Effective Wound Management*. Available at: <http://www.woundsinternational.com/consensus-documents/view/international-consensus-making-the-case-for-cost-effective-wound-management> (accessed 28.02.2017)