Contact at the borderline: psychoanalytic psychotherapy with EB patients

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The patient featured has given written consent for the use of her material.

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Abstract

Against expectation, the experience of setting up a psychotherapy service for adult Epidermolysis Bullosa (EB) patients at St.Thomas’ Hospital in London has been that take up is slow and wary. Prior indications from the wider team were that need is high. This may reflect differences in the experience of need on the part of patients and staff.

Published research on the psycho-social aspects of EB is minimal. This paper proposes a type of genetic trauma particular to this patient group. It then examines some clinical psychodynamics with regard to the capacity of some severely affected patients to experience and acknowledge feelings such as love and need. Some aspects of the psychological significance of the skin as an organ of the body will be discussed, with particular reference to what happens when it goes wrong.

Key words: epidermolysis bullosa, genetic trauma, psychological functions of the skin, mother-baby dyad, patient resistance to therapy, psychodynamics, staff trauma.

Introduction

Reviewing a novel about World War I, DJ Taylor (2007) notes the author’s particular expertise in describing ‘extreme physical trauma and the psychological damage that such trauma provokes.’ In sessions with patients, this phrase lingered in the air: extreme physical trauma, the psychological damage it provokes, and the expert description of that.
This paper draws on trauma theory to try and understand the difficulties encountered setting up a psychotherapy service for adults with EB; it incorporates ideas on the psychological functions of the skin; and includes composite case material to illustrate the themes presented. Some of that material takes the form of literary quotation offered by patients to make themselves better understood – the expert description.

**Trauma**

Usually, when we talk about physical trauma, of whatever degree, we refer to something that comes upon a person from outside, something they fall victim to - like war, for example. There has been a continuous experience of what we might call ‘normality’, and suddenly it is interrupted, by an accident, an attack, or an act of God. There is a before and an after. To reconnect to life, the psychological task involves adaptation: mourning the loss of the previous life, if it cannot be resumed; accommodating the event and going on. Recovering. Now consider inherited EB. It is not like that. There is no Trauma Treatment Protocol, as we might have for Post Traumatic Stress Disorder. There is no post-trauma. Instead the essence of EB is trauma, in the purest physical sense – skin fragility means damage at contact, even spontaneous damage. More than that, it is a trauma that has been there from the start of conscious life (birth), in fact from the earliest pre-conscious origins of that human being (from conception). It is an ongoing neurobiological trauma, from the inside, embedded in the DNA, for which, so far, we have no cure. It ends only with death.

What is the nature of the psychological damage caused by this kind of trauma? And one so highly visible. One of our nurses was shocked by the reactions of passers-by
to her patient, whom I will call Peter, when they went out. People said things like: ‘That shouldn’t be let out, it should be kept indoors.’ They could not bear what was evoked in them by the sight of someone with severe EB. Their coping strategy was to objectify Peter, dehumanise him into ‘it’ in order to put distance between themselves and appalling suffering. Peter’s coping mechanism was different, but equally radical: ‘it goes over my head’, he said. ‘I don’t notice it.’ In response to his nurse’s shock he offered words of comfort: ‘You don’t understand – I’ve always lived with this, this is normal life.’ This, it seems to me, is the tension we are caught in, working with EB. What is experienced as ‘normal’ by the patient is regarded by the majority population as horrific. It is not that Peter professes a false norm because to him this is the truth. Nor has he ‘normalised’ his condition, by coming to terms with it in order to live within its limits as best he can. This would represent an integration of the EB into a greater whole, implying a wider self-image, which we might regard as healthy – and which some EB patients certainly seem to manage. Rather, this patient has dissociated from the social reality he inhabits so that it ‘goes over his head’ – always a risk in wheelchair users. He has also, apparently, ‘split off’ from conscious awareness of his emotional response to rejection. Both these defence mechanisms, dissociation and splitting off, are classic trauma responses. I imagine that the shame of being viewed as a disgusting object caused Peter to play his part in the violence being done to possible links between self and other. A gap is maintained by both parties, preservative but also deadening.

It seems likely that this kind of experience of chronic trauma from conception shapes and misshapes people, bending their entire being. How could it not, if we take the holistic view that body, mind, feelings and spirit form one whole?
Lindemann (1944) defines a psychological trauma as ‘a sudden, uncontrollable disruption of the affiliative bonds’ with all that this implies in terms of disordered attachments and violent feelings (De Zulueta 1993). The *genetic trauma* that is EB differs in terms of its ongoing rather than unique location in time, but it may perform an equal though different kind of violence within the developmental process. Children, although resilient, suffer from psychological trauma much as adults do, with the additional complication that it happens during emotional, intellectual and physical development.

With developments in brain scan technology we know that psychological trauma - of all types - causes damage in the mind that we can see. As far as we know there have been no studies of MRI brain scanning performed on the EB population with this in mind. Skin and psyche (mind) are closely associated because the skin derives from the same embryological layer as the cortex and the central nervous system. Given this, it may be useful to consider the psychological functions of the skin when thinking about the traumatic impact of EB.

**The psychological functions of the skin**

The importance of skin as a systemic regulator is clear when we consider that between one third to over three quarters of patients may have significant psychological components to their dermatological conditions (Koo 1989). Mind and skin are interlinked; upsets in one tend to reflect in the other. This thing that binds us round, shielding us from the slings and arrows of the environment, is broken in skin
patients, the thing that demarcates what is outside and what is inside, what is ‘me’ and ‘not me’, does not work properly. The primary function of the skin is as contact barrier, as regulator of what passes in and out, between self, environment and others. The title of this paper is ‘Contact at the borderline’ since it is this broken line that I have come to believe we must walk more consciously with EB patients than with most. Because their physiological boundary is so badly breached by forces beyond their control, it is not surprising if EB patients struggle with interpersonal boundaries. In family life, this may be manifest in enmeshed relationships with carers; in therapy, it shows up as difficulties with engaging, attendance and time-keeping, among other things.

Skin patients may also display a tendency to get under our skin, psychologically, when we come into close contact. In therapy, the patient will often make use of the therapist as an object, unconsciously replaying old conflicts in the hope of a better outcome. We call these dynamic interpersonal processes projection and projective identification – that is, putting disowned parts of oneself onto, or even into, another person, as a form of communication. It happens a lot with the more difficult, denied emotions – anger, or grief, for example. We all do it, because we are permeable, we are not self-contained islands, but people whose actual skin is poorly may do it even more helplessly, more unconsciously, more directly, than the rest of us. In EB perhaps the key question for professionals is: how can we remain open to the intense trauma that re-presents the patient’s early experience, without becoming so traumatised ourselves that we fall ill, or otherwise become damaged, and useless to the patient? How do we bear the unbearable in our experience of being with the patient so that the relationship can be sustained?
Skin, touch and human development

Freud (1923) said that we begin as a body ego: that is, what we tend to call our ego starts life as a mental projection of our physical self. Didier Anzieu (1989) has gone on to think specifically about a ‘skin ego’. A large body of literature investigates skin disorders as they affect child development, the parent-child relationship and family dynamics. Body psychotherapists, backed up by neuroscience, believe skilful, attuned touch to be one of the most highly developed instruments of human communication and healing, playing a major role in emotional and physiological regulation of the infant and child (Carroll 2007).

The research (Montagu 1986) shows that certain kinds of cutaneous stimulation are necessary for the healthy development of mammals, including us. Lack of stroking, snuggling, petting and grooming, especially in the immediate post-partum period, has serious physical and behavioural effects. Missing out on touch can lead to raised neuromuscular tension, heightened anxiety and irritability, greater inclination towards fear, a tendency for the sustaining bodily systems not to function too well, and reduced life expectancy. Tactile experience is an essential food for the cortex, stimulating its growth (Carroll 2001).

Crucial early development is mediated by touch. The baby assures itself that all is well with the world largely through the messages it receives from its skin. Montagu (1986) describes:
'the primacy of the infant’s first perceptions of reality through the skin... The messages he receives through that organ must be security-giving, assuring and pleasurable if the infant is to thrive.'

Skin mediates touch, touch mediates maternal love, and maternal love affects the laying down of crucial neural pathways (Stern 1985, Gerhardt 2004). It is the context in which the baby grows and flourishes. Or not. So for each EB mother-baby pair, we need to consider what kind of attachment patterns get inscribed through their skin interactions and persist in later life, getting reactivated by encounters with institutional care, be it nursing, social work or therapy. Does baby go on to become an adult who avoids physical contact and takes refuge in the world of the mind – like some academics? What follows for the mother-baby relationship if the skin looks repulsive and breaks at the slightest touch? How does mother bear the knowledge that her gentlest, most loving caresses are harming her child? Does guilt lead her to reject the child? Wittingly or unwittingly the parents have passed down an awful thing. They are not a benign couple in their legacy: what they have generated has monstrous aspects. The semi-conscious fears of so many mothers-to-be are of not producing a ‘normal’ child: here it has come true. If uncomplicated bodily contact while nursing lays the foundation for the infant’s sense of security and ongoing continuity of being, EB complicates things. Maternal ambivalence is a tricky topic: few mothers will admit to ‘bad’ feelings - for example, rage or disgust - towards their babies, yet many feel these. With EB, the mother can only be ambivalent. It is a life sentence, for both parties. The parent cannot look forward to celebrating the usual milestones, simply, as the child grows. Does the pain of that cause her to cut off,
emotionally, from her baby’s need for simple love? What does the baby learn about itself when it looks into mother’s eyes and sees its reflection?

Attempting to convey how he felt about himself, a patient provided a sketch called *Cactus Man* by the French symbolist painter Odilon Redon (Fig. 1). Identifying with the image he said:

‘He looks so sad and miserable; he must feel repellent and hostile.’

Another person said they were known in their family as ‘the prickly pear’ – a phrase perhaps reminiscent of *Cactus Man*. What do these people come to believe about how the world will receive them, if Mum’s gaze is sad, frustrated, avoidant or overwhelmed?
Fig.1. Cactus Man by Odilon Redon, 1881, Charcoal 49 x 32.5 cm

The Woodner Family Collection, New York.
From the first day, a mother’s beliefs about, and attitude to, her child’s condition will affect both parties as they adjust to and manage it. Apart from rare cases of spontaneously arising EB acquisita, EB is inherited genetically, thus many parents are guilt-stricken at the legacy they have passed down. They are implicated in the child’s suffering, and this can complicate the usual maturational processes of separation and individuation. Children sometimes exploit parental guilt. A further level of complexity enters the picture for those EB patients who are medically unable to live independent lives and will remain physically and financially dependent on their parents, families or the state for life.

Donald Winnicott, paediatrician turned psychoanalyst, suggested (1956) that mother only need be ‘good enough’, not perfect. But a mother who cannot convey her love to her baby in the most natural manner - by stroking - for fear of damaging it, a mother who has inadvertently ‘caused’ this affliction through her genetic legacy – can she feel ‘good enough’, at all? Can the child forgive her the harm done? It is not easy, for those patients who wrestle with these things as adults. Some of them take decisions not to have children of their own, to avoid the risk of passing EB on down the line. They say, in effect: it stops with me. These kind of patients, in therapy and in their relationships with professionals representing caring institutions (ie. substitute parent figures), may be more likely than most to demand what they never had: the missing, mythical ‘perfect’ mother. Then woe betide us if we fall short: then we may face tantrums, enactments or passive aggression. It may help to bear in mind that we are not, in these moments, dealing with an adult, but a very hurt child part of the patient, still very much alive and active.
The psychological ramifications of these kinds of skin conditions, then, are far-reaching. A useful image to keep in mind may be that of the skin as a kind of ‘container’. With EB, this skin container has gone wrong. In many senses, these patients feel untouchable: like the Dalit caste in India, the Untouchables, they are outcasts, not just socially, but cast out from things that the more fortunate majority population takes for granted. Like simple physical contact. What does that do to a person’s evolving sense of self? How do they hold themselves together, literally and figuratively? And how do they separate from those they depend on to tend their broken skins - usually Mum, but also us?

There is a general embryological law which states that the earlier a function develops, the more likely it is to be fundamental – the functional capacities of the skin are some of the most basic of the organism, necessary for survival. When the skin cannot fulfil its enveloping function, the need for containment does not subside. It seeks another provider. In other words, EB patients may need and seek emotional containment more than people with intact skins. They do not have a skin that works: we may find ourselves invited to become their ‘second skin’, a kind of emotional dressing. (There is a wound dressing actually called Second Skin). One can understand their need for a container that does not break, blister or go wrong. That does not mean we have to become it; but it may help us understand some of the dynamics arising.

In the film documentary The Boy Whose Skin Fell Off (Kennedy and Collerton 2004), about a man with recessive dystrophic EB, there is a striking early sequence where Jonny Kennedy is planning his funeral. He takes great care designing his coffin, as if
it were one last, good container, a skin that he can control and build intact, to see him out with dignity.

**The hothouse flower**

How do we understand what it is really like to have EB - and how it might impact a person’s decision whether to take up therapy? One answer comes from an expert witness whom I will call Emma. She is a bright, personable young woman. She has severe recessive dystrophic EB with the usual disfiguring disabilities. To describe her experience of EB she referred me to a passage from Huysmans 19th century cult novel, *Against Nature*.

The narrator is tired of artificial flowers mimicking real ones, and wants some natural flowers that will look like fakes. He orders hothouse flowers:

‘The gardeners brought in still more varieties, this time affecting the appearance of a factitious skin covered with a network of counterfeit veins. Most of them, as if ravaged by syphilis or leprosy, displayed livid patches of [mottled flesh]; others had the bright pink colour of a scar that is healing or the brown tint of a scab that is forming; others seemed to have been puffed up by cauteries, blistered by burns; others again revealed hairy surfaces pitted with ulcers and embossed with chancre; and last of all there were some which appeared to be covered with dressings of all sorts, coated with black mercurial lard, plastered with green belladonna ointment, dusted over with the yellow flakes of iodoform powder.'
Gathered together, these sickly blooms struck [him] as even more monstrous than when he had first come upon them, mixed up with others like hospital patients inside the glass walls of their conservatory wards.’ (transl. Baldick 1959)

This is a powerful set of images. Emma, in tears, said this was the best description she knew of EB and of the process of having dressings applied. She feels like these ravaged hothouse flowers.

This is someone with an unusual degree of psychological awareness and maturity, more than many young women without EB might have. Here, illness has resulted in a wisdom beyond her years – not entirely a good thing, but helpful as a coping method and very helpful for our therapeutic purposes. With a prior positive experience of therapy and the capacity to think symbolically as well as literally, she is a ‘good’ patient – punctual, responsive, imaginative, grateful. The therapy feels creative and the timing has worked – she has a need to make meaningful contact with someone now. This contrasts with the more usual response I met on initially promoting my service to patients. We could summarise it as something like: ‘if you can’t cure me, eff off.’ Guarded, suspicious, sometimes sullen or contemptuous. These patients seemed out of touch with their need for significant human contact, perhaps having had that need failed in the past. Few things are more painful than to reach out and not be met, as Redon’s *Cactus Man* (Fig. 1), with his walled off, defended look, seems to convey.
Thoughts on patient resistance to psychoanalytic psychotherapy

Assessing several prospective candidates for therapy these themes emerged: a reluctance to entertain hope and risk disappointment (‘I know I need help, but I don’t think anyone can help me’); a preference for immediate, concrete, external action (like better dressings) over the slow, immaterial, internal work of therapy; and a desire for the inappropriate known quantity (advocacy with statutory authorities) rather than an unknown therapeutic relationship. Even with Emma, reaching her initial appointment was a complex, protracted business - many cancellations, miscommunications, reschedulings. Once she arrived, a rapport was reasonably easily established, and yet, although she presented as someone wearing her emotions close to the surface, I noticed a certain distance maintained between us by her. Here, as with the dozen or so others who have got as far as actual therapeutic engagement, the maximum tolerable frequency of sessions has so far proved to be fortnightly, sometimes monthly – frustrating and much harder work than the more usual higher frequencies. In these hesitant gyrations around the therapeutic encounter, in the need to control the approach to and the distance between self and another mind, we may notice the signs of ambivalent and avoidant attachment patterns (attachment theory being a framework used to describe affectionate relations between humans). Perhaps this makes sense in light of earlier points on the importance of skin in mother-child bonding.
Therapy as ‘second skin’

Why might analytic work seem particularly frightening to this patient group?

 Crudely characterised, we could say that a successful psychoanalytic psychotherapy traditionally has three parts. First, an easing out of socially validated ‘independence’ into a regressive but necessary state of dependence on the therapist. If things go well, this may allow a second phase where the unresolved conflicts of infancy, childhood and adolescence are re-experienced within the relationship and worked through with the therapist more successfully than the patient has hitherto managed. A final stage might be the gradual return from this preoccupation with the internal life to a fuller participation in the external realities of love and work generally thought to be signifiers of health. It is an intensive, painstaking endeavour and takes time, often at high frequency over several years. Latterly, clinicians have adapted the model to take account of the realities of modern public healthcare in the UK, with its focus on providing limited benefit using cost-efficient methods. Brief psychoanalytic psychotherapy now exists: whether this is treatment of choice or making a virtue of necessity is still up for debate (Mander 1995). Either way, brief or long, high or low intensity, perhaps it becomes clearer now why some EB patients may instinctively fight shy of psychoanalytic work: they have spent a lifetime building up defences against touch because it is painful, or against its absence (even more painful), and then someone comes along saying: ‘Let’s make contact, let’s be in touch with each other.’  ‘You must be joking!’ is a reasonable response.
During its middle phase, psychotherapy patients often liken the containment of analytic sessions to having their mind held in a benign sheath, a kind of hand-in-glove experience. We could call this a ‘second skin’. But those patients usually have intact skins. Let us imagine how this degree of containment, this much close contact, might be experienced by someone with skin fragility, someone with the physical and psychic sensitivities of a burns victim (as Emma’s quotation indicates), someone who has had to develop significant compensating defences. They might yearn for a metaphorical second skin, a good sheath for their mental and bodily torment. Jonny Kennedy seemed to anticipate his coffin finally performing such a function for him.

But where one’s actual experience is of having a physical skin container that does not work, it may be impossible to imagine an experience whereby one’s own capacity for emotional self-containment, one’s psychic skin, can be enlarged. So, disregarding psychotherapy might result from a failure of imagination at a genetic level – a basic fault in the imaginative faculty born from particular, limited, bodily experience. Or, in those patients more overtly contemptuous of therapy (and sometimes of their entire care team) it might be a self-sabotaging protective strategy born of the need to remain in the dark, not to know, to maintain intact longstanding defences of denial, dissociation, projection and projective identification, the crucial cornerstones in a self-care system that preserved life in the face of primitive trauma. Such a patient resists interpretation and shared knowledge about their defence mechanisms, because taking back and owning their split off feelings entails depression: rather than experience melancholy the patient prefers to leave the bad feelings in the other – eg. the therapist feels a failure because the patient does not turn up. The analyst Wilfred Bion (1993) speaks of ‘an implicit hatred of emotion and the need to avoid awareness of it.’
For these patients, a little knowledge can feel like a very dangerous thing.

**What is it like for the therapist? Trauma for staff**

Faced with the levels of disability and defence before me, I should admit my first thought was: how can anything I know be of any use to this patient group? And how am I going to cope? We should not forget the risks of secondary or vicarious traumatisation among professionals and others close to the designated patient, and I think that the unusually comprehensive plight of EB patients requires maximal training and supervisory support among the professionals involved in their care.

Arriving in post my fears were of being swamped by demand. The multidisciplinary team expressed quite strongly the need they perceived for psychological input to this patient group. But the initial take-up from patients was slow, patchy and frustrating. I have expressed some thoughts on the well-founded psychological reasons for EB patients’ resistance to opening up emotionally. There are other explanations, of course. Building trust with any population takes time – and this is a very disenfranchised group. EB patients often have close, long-established relationships with specialist nurses and physicians. You would not expect them to leap into a new relationship with yet another clinician. The practicalities of time-consuming dressings and difficult travel arrangements mean something new has to be seen as adding real value to be worth making the effort – I was an unknown quantity. The shape of the psychotherapeutic frame - constancy of time, place and frequency of sessions - is alien to patients used to the more chaotic environment obtaining in medical outpatient settings, where cancellation from both parties has become routine. On our side there
were, too, the usual start-up problems and ‘sick system’ errors – a sometimes malfunctioning, ponderous bureaucracy to be penetrated before the patient could access therapy. These combined factors regularly defeat the able-bodied and must be even more daunting for the disabled – add in the unconscious fears particular to EB outlined above and you have a patient group that is difficult to access psychologically.

This may be partly why meaningful research on the psycho-socio-relational aspects of inherited EB is thin on the ground. One study (Andreoli et al 2002) of 20 patients with simplex, junctional and dystrophic EB, aged between 7 and 52, concludes:

The majority ... show an intellectual development above the norm, an adequate scholastic and work achievement, a normal affective maturity, a developmental and social adaptation consistent with their chronological age, and the absence of structured psychopathological disturbances. It also appears clear that these patients are able to accept their disease in a positive manner and to confront the consequences with an aware commitment. They display adequate levels in all areas of personal development as well as of social integration and affirmation, often definitely above the norm.

If this is so, it would seem there is no problem. Yet the consequences of severe EB include: extreme disfigurement (a stunted body, its raw skin blistering off and, when infected, smelling foul), high levels of disability and pain; significant developmental delay or arrest, impaired mother-child bonding, reduced possibilities of occupational affirmation, unlived lives and premature death. The psychosocial and psychosexual consequences of these things are large, for the individual. Impact on the family system is high, as a line is walked between normative consensual reality and what some patients call ‘the world of EB’ (just as cancer patients refer to ‘Cancerland’).
My observations differ from the study findings above. This may be due to methodological difference: clinical psychology tends to favour psychodiagnostic testing, as in the study, whereas I would emphasise psychological defence mechanisms, some of which I have touched on. We see what we look for. It is perfectly possible to score as high-functioning in one or more life dimension while remaining bound within a highly encapsulated, wounded personality structure – the principle of compensation. We tend to think of the role of the psychoanalytic psychotherapist being that of participant-observer. This means partly that, in any psychotherapy, the patient’s particular ways of relating to others and causing others to respond will be enacted time and again with the therapist (Welldon and van Velsen 1997). For example, a man who found his mother unreachable in infancy may repeat the experience with his female or male therapist, inducing neglectful behaviour in them. We also take account of what it feels like to be in the room with each patient. Other professions may not be trained to acknowledge and heed their own emotional reactions before attending to the patient, yet the range of felt responses to spending time with EB patients is wide and strong. An informal survey among colleagues uncovers: compassion, revulsion, admiration, relief it is not one’s own family, an irrational fear of contagion (a common response to skin diseases), impotence, frustration at not being able to cure, hopelessness, and more. All this is information about what the patient meets in the real world, outside the protected confines of the care team, and we should be mindful of the deep-laid anthropological and evolutionary reasons why the more difficult of these responses may occur.
Impact on the possibilities for psychotherapy - difficulty making use of the service

A year in, it remains an open question how useful depth psychology can be to this patient group; how much use they can make of it, of me. What is clear is the need to pace things very slowly, and to allow the patient to regulate the space between us - the contact gaps - to make things bearable and to prevent premature termination. It has long been recognised that prolonged early traumatic experience with serious developmental repercussions makes it particularly problematic to work through the trauma – in place of remembering its full impact patients repeat it in their daily lives and in their therapy: repetition compulsion. It may be that EB poses particular problems for patient and therapist, limiting what can be done, as we seek to reconstruct, understand and come to terms with the past.1

While what we might call more ‘ordinary’ traumata certainly cause emotional freezing and distortions, genetic trauma seems often to remain especially unspeakable, unthinkable even – the experience remains ‘linguistically and cognitively starved’ (Hollan 2000) and thus cannot be integrated by the person into their conscious levels of self organisation. Operating out of one’s unconscious - automatic, unthinking, reflex behaviour – has implications, especially when failure to register one’s impact on others affects social integration. Implications within the consulting room of trauma that cannot be thought about include relatively mild defences like rationalisation (which can often be worked with), and more disturbing ones. An example: the patient may project out his tendency to attack his own capacity for thought and reflection,

1 Psychoanalyst Ken Wright believes that symbol formation and, following that, the coming into being of a self, follow on from separating from early objects, ie. the capacity to think symbolically depends on the creative stimulation of object loss. Severe RDEB patients with typically enmeshed mother-child
directing attacks instead against the therapist’s capacity to think and reflect. The therapist is then likely to feel confused, numbed and unable to make any useful interpretations. Such primitive behaviour may or may not yield to the constancy of regular sessions, if the patient can bring himself to attend and the therapist manages to withstand the attacks without retaliating. Ultimately, the patient has to want the therapy, and maintaining the pathological status quo may seem easier than change.

For some, the physical practicalities of daily life as an EB sufferer may preclude the time or inclination for therapy. This patient group may have to be ‘reeled in’ to therapy with especial delicacy, much as they have special wound dressings. Needful adaptations to classical technique have included cultivating a deliberately visible presence on the ward and in clinics: becoming a familiar face in order to reassure a tentative and tight-knit community. Fears of having private thoughts extracted without consent, commonly encountered by psychotherapists meeting prospective patients, are not peculiar to EB, but these patients’ sensitivity to such imagined psychic ‘stripping’ or ‘skinning’ may be higher than most. With highly defended patients, it may be more helpful to the family unit to offer therapy to other family members.

**Conclusion**

While we all have some degree of psychopathology - most of us managing to hide it in order to function in the world - in EB it is unavoidable, written all over the body, in dyads may have particular difficulty with this. Cf. Wright, K. (1991) *Vision and separation: between mother and baby*, London: FAB. p.xii et passim.
full view. Even relatively mild forms, EB pruriginosa for example, invite unwanted inquiries from strangers: ‘what happened to you?’

We cannot easily generalise about what has happened, psychologically, because the question really should be: how is this particular manifestation of EB at work in the psyche of this particular individual? No two people respond identically to the same happening. It is less the event, than the experience of it, that determines traumatic aftermath. However, some relevant factors can be listed (Jaffe et al 2005):

- severity – how bad is the EB
- the individual's personal history
- the larger meaning the trauma represents for the individual, if any (Emma feels she has a mission to teach professionals so future patients suffer less)
- their coping skills, values and beliefs
- the reactions and support from family, friends, and/or professionals

‘Physical and emotional torture’ is one patient’s description of living in an EB family. So much hospital care of EB patients can be an attempt to palliate the unbearable, to make it a tiny bit better for them, better for us. Without thought, this can become a kind of manic defence. Sometimes, perhaps, we have to stop, and look the horror in the face – face up to the patient’s sense of being ugly, untouchable, unlovable. Face up to Cactus Man (Fig. 1).
I have mentioned the critical importance of mother-infant bonding in fostering a sense of being lovable, and how EB may impinge on that process. I want finally to consider Emma’s use of books in this light. Literature serves a vital purpose in her internal world, functioning both as necessary escape from, and creative adaptation to, her condition. It is a way to feel, and be, connected to other lives. She seemed to draw particular comfort from the passage quoted, as if she had imbibed its imagery, allowed it to infuse her psyche. As she said, that description of hothouse flowers was written by someone who had probably never seen EB, but with whose sensibility she could feel an affinity, a link. Linking, according to the analyst Wilfred Bion, is profoundly erotic, that is, life-affirming, where so much in EB seems to reflect what Freud called the death drive – those forces within the organism that tend towards its dissolution. Bion felt that associating ideas, binding them together, is at the heart of thinking, of living and so of psychotherapy. Emma discovers an author, a man, who could find beauty in something leprous. She said she had never been able to regard herself as beautiful, until she read this. And, perhaps, feeling a sense of kinship with a mind that could be fascinated by the monstrous, that could appreciate this kind of damaged beauty, she could imagine, for the first time, a man who could love her, love her marred body, with its torturing blisters even on her eyeballs.

**Key points**

The psychological ramifications of EB are far-reaching: the psychosocial legacy of *genetic trauma* in EB needs further study.
It is less the traumatic event, than the experience of it, that determines traumatic aftermath.

The mother’s ability to digest and adapt to the birth of a child with EB has implications for that child’s capacity to thrive.

The unusually comprehensive plight of EB patients requires maximal training and supervisory support among the professionals involved in their care.

Creative adaptation of some traditional psychotherapy boundaries may be needed in order to engage EB patients.

References


