Investigation on skin-protective clothing that addresses needs of epidermolysis bullosa patients/children with epidermolysis bullosa and their parents

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Abstract

Epidermolysis bullosa (EB) is a rare inherited skin disorder characterised by skin fragility and blistering. In consideration of the daily wound caring issues of patients with EB, the aim of this study is to systematically investigating their needs in a functional apparel that alleviates the symptoms of EB through interviews with EB patients and children with EB and their parents so that they can express their concerns about treatment and aesthetics and analysing feedback from their use of wound healing garments that our research team had previously designed. The results showed that it is undoubted that the wound healing garment fulfilled the needs for functionality yet also aesthetics in apparel for EB patients. A proposed apparel system from the results of the investigation will not only be applicable to EB patients, but could also apply to other patients with skin diseases who desire to enhance the wound healing process and receive better protection against wounds and infections. The findings in this paper could therefore contribute to future apparel based materials development and research in the medical field.

KEYWORDS

Epidermolysis bullosa, functional clothing, wound healing, skin comfort

1. Introduction

Epidermolysis bullosa (EB) is an inherited skin disorder that leads to skin fragility and blistering. There are at least 25 subtypes of EB defined by clinical findings, and the three major types of EB are, simplex (EBS), junctional (JEB), and dystrophic (DEB). (1) EBS: blisters occur within the epidermis (outer layer of skin), on hands and feet, inheritance is autosomal dominant; (2) JEB: blisters develop within the upper portion of the dermoepidermal junction (second part of skin, the tissue area between the outer layer and deep layer of skin), inheritance is either autosomal dominant or recessive, caused death in early infancy; and (3) DEB: the blisters occur beneath the skin in the sublamina densa (the basement membrane area that attached to bones and blood vessels). Inheritance is autosomal dominant, and the disease causesdeath in early to middle adulthood (Eady & Tidman, 1983; Fine, 2007). Infants or younger children with EB are called “butterfly children” because their skin is as fragile as butterfly’s wings. Because there is no specific cure and therapy to help the patients, special wound care is very important. Previous studies on EB have focused

on its possible causes and treatment. Studies have also been conducted to determine the origins of EB and find a potential cure, such as the use of intravenous immunoglobulin therapy and the transplantation of genetically modified epidermal stem cells (De Rosa et al., 2014; Gupta et al., 2012; Hirose et al., 2015; Murauer et al., 2015; Umegaki-Arao et al., 2014). However, the only real treatment for patients with EB is daily wound care and bandaging to maintain their skin integrity and avoid infection (Denyer, 2010; Pagliarello & Tabolli, 2010; van Scheppingen et al., 2008; Williams et al., 2011). Little attention has also been given to daily apparel-based issues in terms of friction from clothing, which causes wounds discomfort and blisters, therefore requiring immediate care. Consequently, it is important to examine the daily apparel worn by EB patients so as to alleviate their symptoms and suffering.

According to the clothing requirements of EB patients, there are some points that worth to mention. The garment should be very soft with breathable material, and ease of donning and doffing with a wide neckline. Besides, it should not be overly warm or fit too tightly because sweat will contribute to the development of blisters (Denyer, 2010; Diem et al., 2009). The parents of these EB patients must purchase and modify the clothing. For example, they remove the bottom from the clothing and turn the seams inside out because friction from these may cause the formation of blisters and wounds. Furthermore, wound dressings are placed onto their skin with medical tape and this causes secondary abrasion which could result in blisters. It is difficult to reduce the body movement of newborn infants with EB and prevent injuries; thus, the burden of care lies on their family and medical personnel. As these EB infants grow up, they continue to face difficulties with finding appropriate clothing. In addition, when a new wound occurs on an EB patient, it is difficult to locate the wound due to the overall blistering and provide immediate treat. Blood clots from a wound resultant of blistering means that the skin will stick to clothing, so that regardless of the subsequent treatment, the separation of the wound from the fabric causes pain (Badger et al., 2013; Denyer, 2010; Goldschneider et al., 2014). These problems with wound care also occur in adult patients. However, little research work has been conducted by systematically studying the perspective of patients and their caregivers on textile use to examine the specific problems that they experience in daily life (Abercrombie, 2008; Blanchet-Bardon & Bohbot, 2005; Krakowski & Ghasri, 2015; Pope et al., 2012).

With the progress of science and technology, biomaterials for wound dressings are increasingly being applied, such as chitosan, which can be produced in the form of fibers. The spinning ability of chitosan fibers is also being constantly improved. This

is especially the case for wound dressing products that are garment based for EB which could alleviate the suffering of EB patients (Azuma et al., 2015; Dai et al., 2011) (Figure 1). The aim of this study is to therefore systematically examine the needs and vision of functional apparel, with expressive and aesthetic considerations taken into account (Lamb & Kallal, 1992), based on interviews with EB patients and their parents on daily wound care routines of EB by using a survey and analysing the feedback from the use of the donated wound healing garments. The results would contribute to future research and development of clothing based wound dressings and healing products, to be used as a second layer of skin, which will offer EB patients more freedom of wound care during their daily life activities.

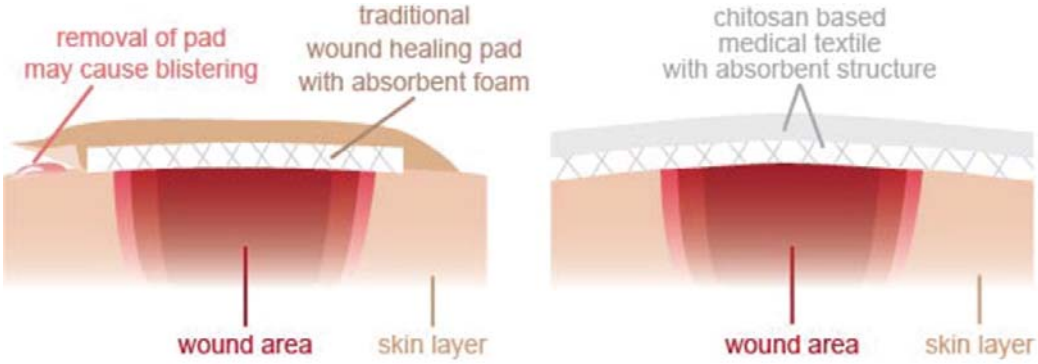

Figure 1. Traditional wound healing pad and chitosan based medical textile design for EB patients.

2. Methods

2.1. Preliminary experiment

In the previous study (Guo et al., 2016; 2017; Lam et al., 2017; 2018; Liu et al., 2015), yarn samples of four different fibre lengths of chitosan with cotton with a blending ratio of 50:50 in a ring spinning system has been studied. It is found that the yarn tenacity deteriorates with increases in the length of the chitosan fibre. Besides, chitosan fibres that are shorter in length (22 mm) or excessively long (46 mm) will bring about difficulties in yarn spinning, such as electrostaticity and fibres that stick. Chitosan fibres that are 30 and 38 mm in length are compatible for blending with long cotton fibres by the investigation of yarn cross-section. The chitosan fibres had high moduli and strong resistance to tensile force. It is found that, in the group of yarn samples spun by using the fibre-blending method, the yarn sample that contains chitosan fibre with a length of 30 mm provides better yarn strength and elongation among all the other lengths, while in the group of yarn samples spun by using the sliver-blending method, the yarn sample that contains chitosan fibre that is 38 mm in length has better yarn strength and elongation. The blending method of fibre components (fibre- or sliver-blending) directly influences

the yarn tenacity. Fibre-blending offers more evenness in the fibre distribution in the spinning process as opposed to the sliver-blending method.

2.2. Material and method

For the application of chitosan/cotton blend yarn in skin-protective clothing for EB patients, fabrics combining antibacterial properties and comfort were developed through jersey knitting technology. Fibre-blend yarn sample of 20% chitosan 80% cotton produced by cotton ring spinning system in a traditional spinning mill (Hismer Bio-technology Co., Ltd). Fibre-blending method was selected as it offers more yarn evenness based on previous study. The yarn sample production was using the standard mill spinning procedures. A series of yarn assessments were conducted and the properties of the yarn are given in Table 1. The yarn count, twist, strength, evenness, and hairiness of the yarn sample were investigated. The jersey knitted fabric was then produced and applied for wound healing garment in this study. The dinosaur print was created to bring happiness and positive imagery to the patients (Figure 2).

Figure 2. Skin-protective clothing for EB patients developed in this study.

Table 1. Properties of chitosan/cotton blended yarn.

Yarn Property	**CS/CO, 20:80%**
Yarn Count (Ne) [CV%]	17.85 [0.37]
Yarn Twist (tpm) [CV%]	660 [3.44]
Tenacity (cN/tex) [CV%]	22 [11.7]
Evenness (CVm%) [CV%]	10.3 [4.8]
Thin Places (-50%) /km [CV%]	- [-]
Thick Places (+50%) /km [CV%]	2 [-]
Neps (+280%)/km [CV%]	8 [-]
Hairiness (-) [CV%]	12.45 [22.15]

2.3. Design

A qualitative research design was adopted in the form of semi-structured interviews. The semi-structured interviews were carried out to collect data to gain an in-depth understanding of the problems encountered by EB patients and the parents of children

with EB. Some of the interview topics and leading questions were defined after a comprehensive literature review on EB, wound healing acceleration and related textile development. The interview and survey questionnaire consisted of seven topics with functionality, expressive and aesthetic considerations including: (i) the importance and satisfaction with current garments available on the market; (ii) comfort and aesthetics considerations proposed in clothing for EB patients; (iii) the functions of garments for EB patients; (iv) materials used in clothing for EB patients; (v) garment detailing and design for EB patients; (vi) special wound dressings for EB patients; and (vii) subjective and aesthetic concerns of garments for EB patients. The design model with functional, expressive and aesthetic considerations was illustrated in Figure 3.

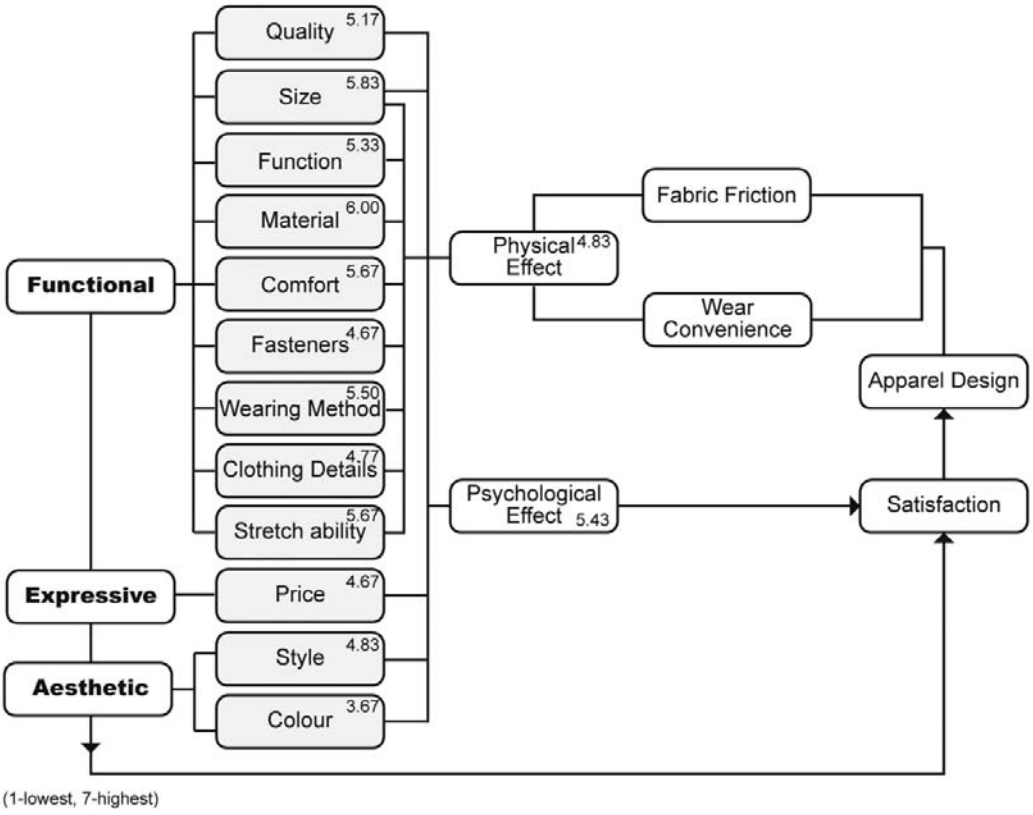

Figure 3. Design model with functional, expressive and aesthetic considerations. Scores indicate needs of EB patients and parents with 1 = lowest, and 7 = highest.

Four questions focused on personal demographics and type of EB. Twenty of the questions focused on their preferences, as well as the difficulties that they face in terms of the issues in the seven topics. Two sets of questions were designed; one set for the EB patients and one set for the parents (Appendix A). Four out of the 20 questions on preferences and difficulties were open-ended, and 8 were closed while the remaining 8 were based on a 7-point Likert scale. The design was to obtain a

better idea of the negativities and positivities of the various factors and their preferences (DeVellis, 2016; Djamba & Neuman, 2002).

2.4. Participants

The recruitment notice of participants was sent out to the patient database of the Taiwan Epidermolysis Bullosa Association. There were only six participants responded and willing to participate in this study. It is worth noting that there are difficulties to find patients who are willing to contribute to research because of their skin condition which needs professional medical care from time to time. Some of the skin medical condition is not suitable to travel outside and there would cause difficulties for public communication of both the patients and their parents. The six participants are all Mandarin native speakers and willing and motivated to participate in this study with informed consent. The definitive sample consisted of 2 children with EB who are 9 and 11 years old (Participants 1 and 2) at the time of the study, 1 female adult with EB who is 33 years old (Participant 3) at the time of the study and 3 parents of EB patients who range from 33 to 50 years old. The parents are a father of a 5 month-old male baby with EB (Participant 4), the mother of the 11 year-old female participant with EB (Participant 5); and the mother of a 17 year-old male youth with EB (Participant 6). Participant 1 and the 5 month-old male infant of Participant 4 were not diagnosed with any particular type of EB, while Participant 2 was diagnosed with Köebner subtype of EB simplex (EBS-K), Participant 3 with epidermolysis bullosa simplex (EBS), and the 17 year-old male child of Participant 6 with junctional epidermolysis bullosa.

2.5. Procedure

Ethical approval for this study was granted by the Departmental Research Committee at The Hong Kong Polytechnic University. The participants were informed about the purpose and contents of the study by means of an information sheet. Participation was voluntary and all of the participants were asked to sign a written consent form and informed that their personal details would be kept confidential. Each participant received a signed copy of the consent form. The interviews took place in a Chinese restaurant in Taipei after lunch with the participants, and the president and the secretary of Taiwan Epidermolysis Bullosa Association. This arrangement allowed familiarisation with the participants, or considered as an ice breaking opportunity, and also at the same time, reduced the time required to travel. The group interviews were conducted face to face in Mandarin which lasted 100 min. During the interviews, paraphrasing and reflective listening were used to obtain a better understanding of the conversation with the participants. At the end of the group interviews, each participant was given the opportunity to summarise the functions that s/he felt is most important

and would address their own needs or the needs of their child. The analysis was conducted along the lines of the seven topics of the survey questionnaire.

3. Discussion

3.1. Importance and satisfaction of clothing with current garments on market

The average ratings of importance and satisfaction with the features of garments that are currently available by the 6 participants are plotted in Figure 4a. The reference line is calculated by adding together the average ratings of importance and satisfaction (11 factors), which were first determined separately (see Figures 4b and c respectively). The fluctuations (differences) were then plotted in comparison with the reference line.

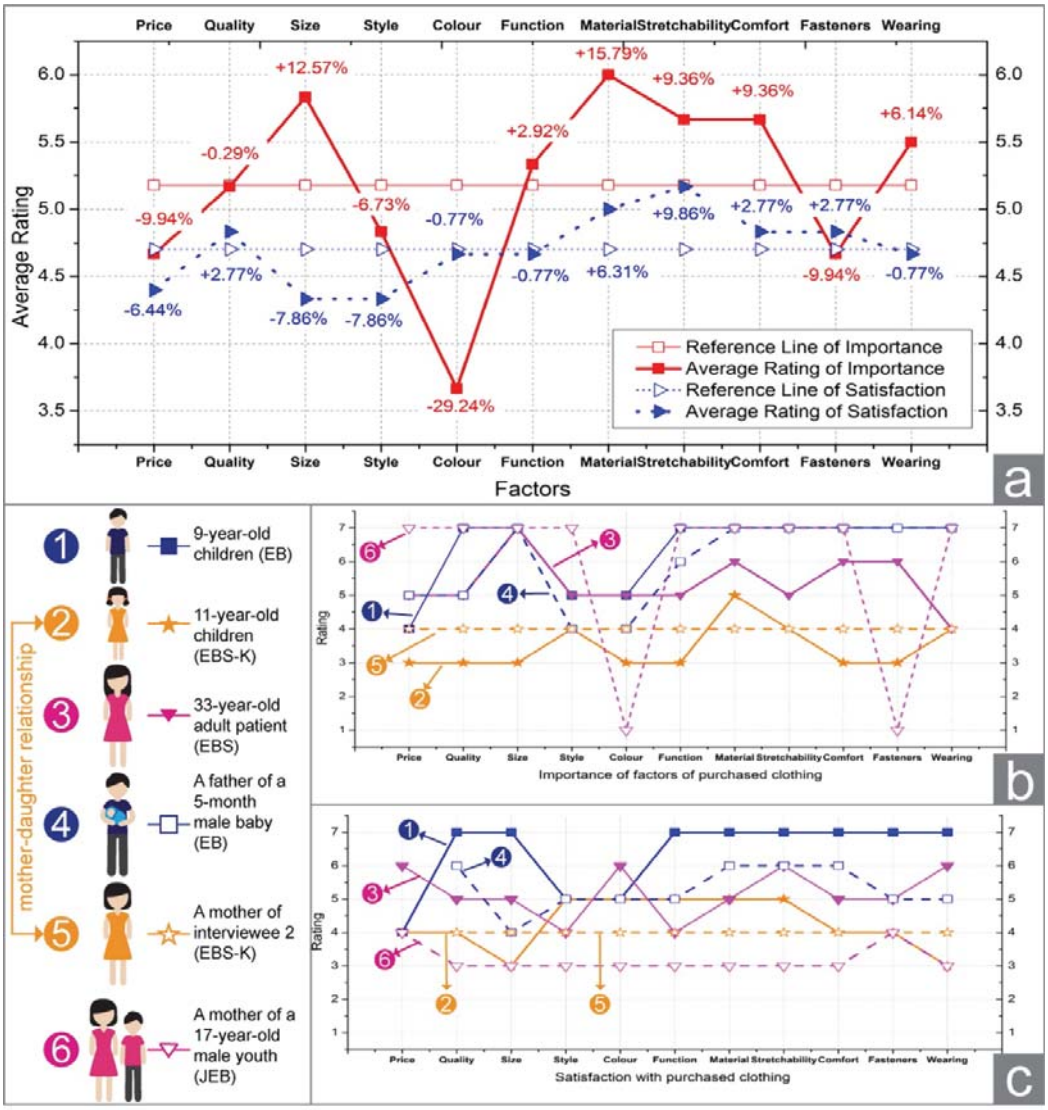

Figure 4. Plotting of (a) average rated importance of issues related to clothing.

According to the average ratings of importance of issues related to clothing on the market, the participants show less concern with five factors: price (-9.94%), style (-6.73%), colour (-29.24%) type of fastener (-9.94%) and quality (-0.29%) (Figure 4a). However, they indicated that function (+2.92%), size (+12.57%), material (+15.79%), stretchability (+9.36%), comfort (+9.36%), and method of donning and doffing (+6.14%) are comparatively important which could affect their motivation to purchase. The stretchability of clothing is related to the material (fabric), while method of donning and doffing and stretchability are directly in response to the comfort performance of the clothing. These 5 factors all indicate the intended function of clothing and that EB patients or their parents have specific needs and requirements in terms of clothing features (Figure 4a).

In terms of the previous clothing purchase experiences of the participants (Figure 4a, average rating of satisfaction), it was found that they are not satisfied with the price (-6.44%), size (-7.86%), and style (-7.86%). However, they are moderately satisfied with the quality (+2.77%), colour (-0.77%), function (-0.77%), comfort (+2.77%), type of fastener (+2.77%) and method of donning and doffing (-0.77%). On the other hand, they are relatively satisfied with the material (+6.31%) and stretchability (+9.86%) (Figure 4a).

In Figures 4b and c, it can be observed that Participant 6 does not have any preference about the clothing colour and the edging of garments, but is greatly concerned about some of the aspects of clothing that she had already bought, such as price, quality, size, etc. This result is not consistent with the consumption patterns of female consumers in general because colour is a key element that could affect the purchase decision of a normal consumer, but in this case, the mother places no importance on colour. Therefore, the results could subconsciously reflect the concerns of a mother with a child who has EB about the functionality of clothing. From the data that we collected, there is no obvious relationship between the parameters from Participant 5. Participant 4 is very concerned about the features of infant clothing, such as quality, size, functionality, material, comfort, stretchability, type of fastener and method of donning and doffing, but his ratings for colour and style are slightly under the mean, which indicates that he is more concerned about the functionality of clothing than colour and style, and requires infant clothing to be functional. The response of Participant 1 reflected the needs of a normal child, as he has least concerned about the price of clothing nor does he mind the style and colour. Participant 2 provided slightly higher ratings for style, material, and method of donning, which shows that she is also very concerned about the functionality of clothing. Participant 3 provided higher

ratings for size, material, comfort, and type of fastener, which indicate that she is very concerned about the functionality of clothing and has a need for clothing to be functional.

Overall, the patients and the caregivers of the children patients are very concerned about size and material of clothing. They are also concerned about the stretchability, comfort, function, and method of donning and doffing (Figure 5). Therefore, it is obvious that there is the need to reduce friction between the skin and clothing surface for EB patients. However, the friction between skin and clothing is more concerning as this could contribute to the formation of blisters, so materials that offer sufficient stretchability and cause less friction between two layers would be appreciated. The method of donning and doffing and size of clothing are two factors that were considered important because they could affect the wear comfort.

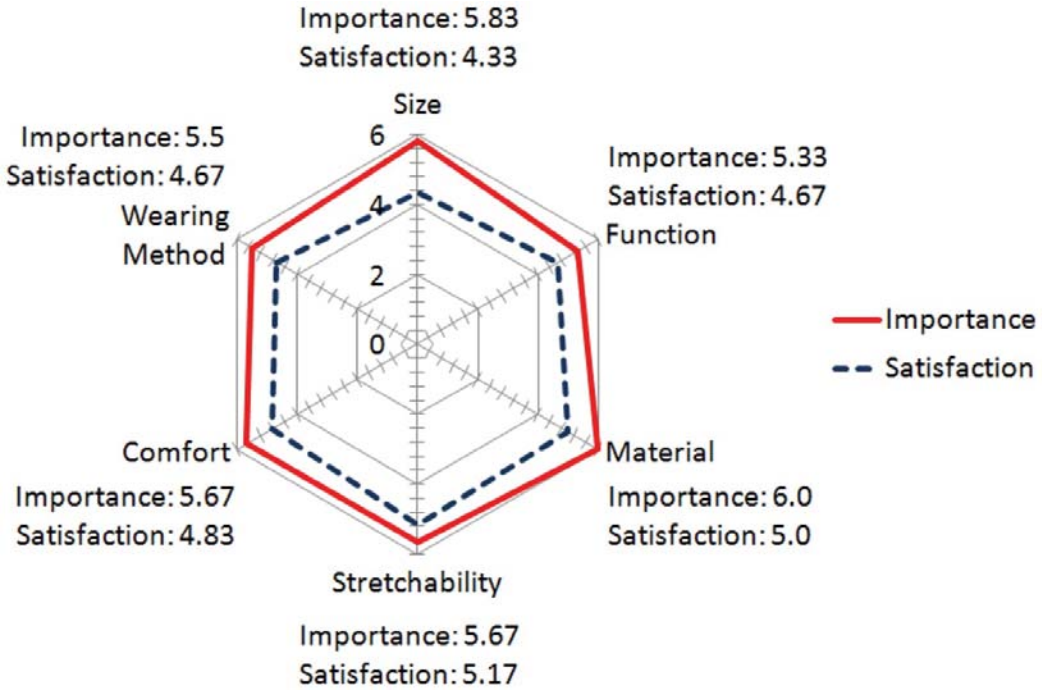

Figure 5. Rating of importance of six factors that affect clothing purchase and satisfaction with purchased clothing.

3.2. Proposed garment detailing for comfort and aesthetics

The average ratings given to comfort and clothing aesthetics by the 6 participants are presented in Figure 6a. The garment detailing include the design of the collar and shoulders, seam design, edge finishing, and type of fastener (Figure 7) which are used as the variables. The reference line was calculated by adding together the average ratings of comfort and aesthetics which were first determined separately (Figures 6b

and c). The fluctuations (differences) were then plotted in comparison with the reference line.

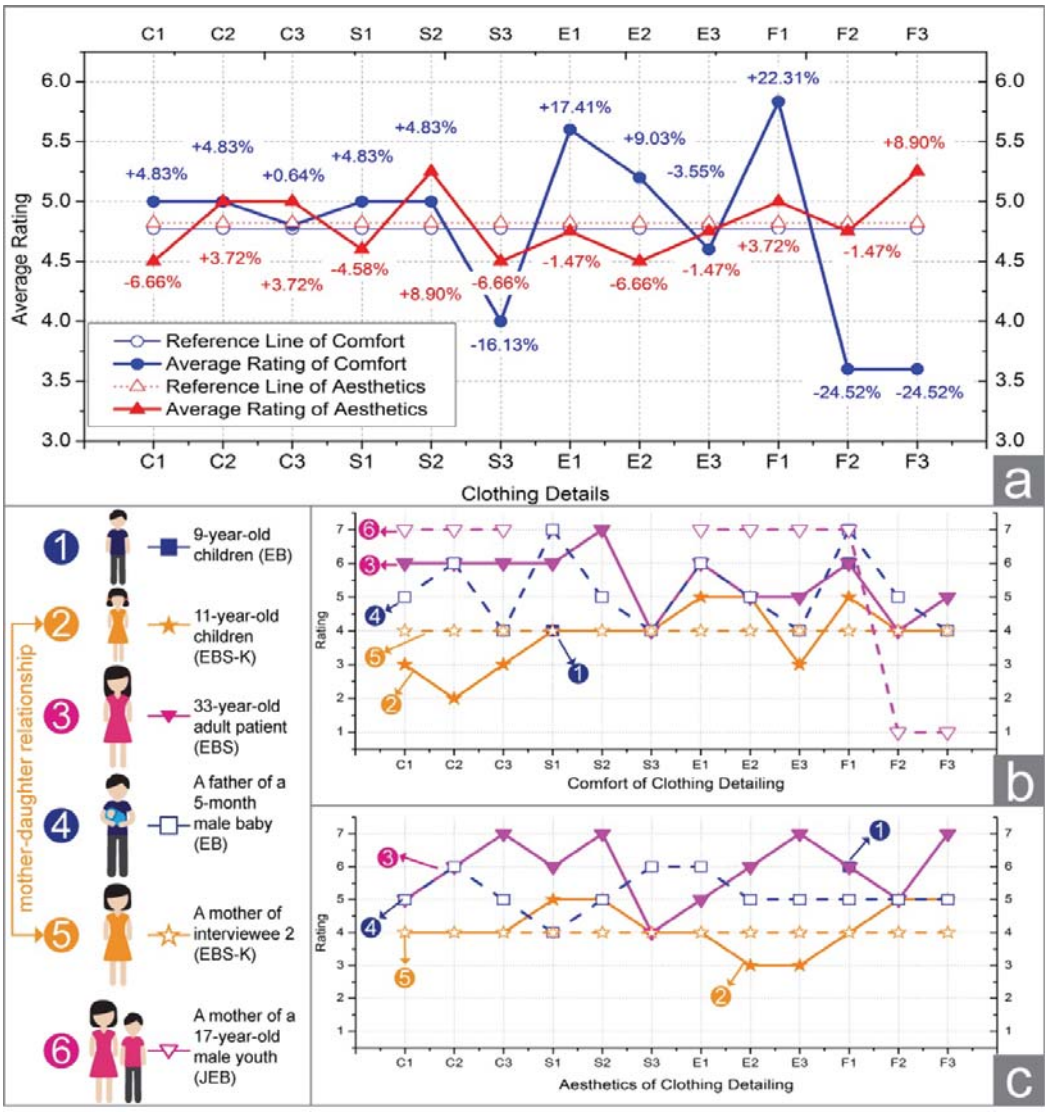

Figure 6. (a) Average rating of comfort and aesthetics of clothing detailing. (b) Rating of comfort of clothing detailing. (c) Rating of aesthetics of clothing detailing.

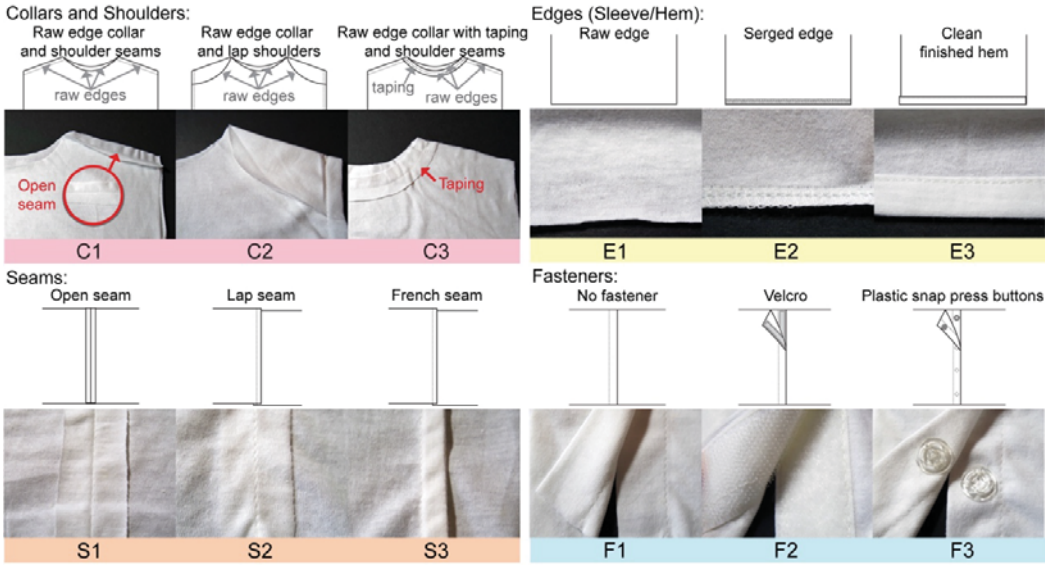

Figure 7. Diagram and photos of clothing details.

Figure 6a shows that the participants gave three types of garment details the lowest rating, including S3 or French seams (-16.14%), F2 or velcro (-24.52%) and F3 or plastic snap press buttons (-24.52%). French seams, Velcro and plastic snap press buttons might induce higher friction on the body of the patients, and may lead to painful blister formation. In this case, they gave higher ratings to E1 or raw edge (+17.41%), and F1 or no fastener (+22.3%). In terms of the seam design, the respondents indicated that they prefer S1 or open seams (+4.83%) and S2 or lap seams (+4.83%).

According to Figure 6b, Participant 6 gave high ratings for comfort to most of the clothing details, except for Velcro and plastic snap press buttons as clothing fasteners. She explained that Velcro and snap press button on clothing are not a good choice for her son because they put pressure onto his body. Participant 4 preferred C2 or raw edge collar and lap shoulder seams, S2 or a lap seam, E1 or a raw edge and F1 or no fastener. Participant 3 similarly gave higher ratings to C2, S2 (lap seam), E1 and F1 for comfort, and C2, S3 (French seams) and E1 for aesthetics. Aesthetically pleasing clothing are important to consumers, but from the data acquired, comfort from garment detailing is a greater concern for EB patients (Figure 6b and c).

There is no doubt that the participants are concerned about the aesthetics of their clothing. However, they also understand that they face restrictions in choosing clothing because of their skin ailment. Some clothing detailing will provide a better appearance, but may increase the chances of skin-to-fabric friction and cause

discomfort during wear at the same time, such as F3 or plastic snap press buttons (comfort: −24.52%; aesthetics: +8.90%). Nevertheless, based on the data obtained, there are some compromise between comfort and aesthetics, such as C2 or raw edge collar and shoulder seams, S2 or lap seam, E1 or raw edge and F1 or no fastener (Figure 8).

Figure 8. Rating of comfort and aesthetics of clothing detailing with raw edge collar and shoulder seams, lap seams, raw edges and no fasteners.

3.3. Functions of garments for EB patients

Participants 4 and 6 believed protection of the skin of EB patients can be possible through the use of clothing (Figure 9a), while Participants 1 and 3 felt that it is somewhat possible, and Participants 2 and 5 neither agreed or disagreed. In Figure 9b, it is obvious that all of the participants agree on the importance of 5 different functions of clothing for EB patients, including providing antibacterial property, moistening and deodorising, promoting healing process, assisting immunity and protecting by adsorption. Besides, they indicated that they are more likely to purchase clothing with these functions (Figure 9b). Four out of the 6 participants indicated that these functions are extremely important and are very likely to purchase clothing with such functions. The other 2 may not have truly understood the functions and do not agree that they are important (Figures 9c and d). With regard to the response of Participants 2 and 5 (daughter and mother) to the clothing functions, they both gave a

rating slightly under the average rating of the rest of the participants, which could be explained by a negative psychological tendency.

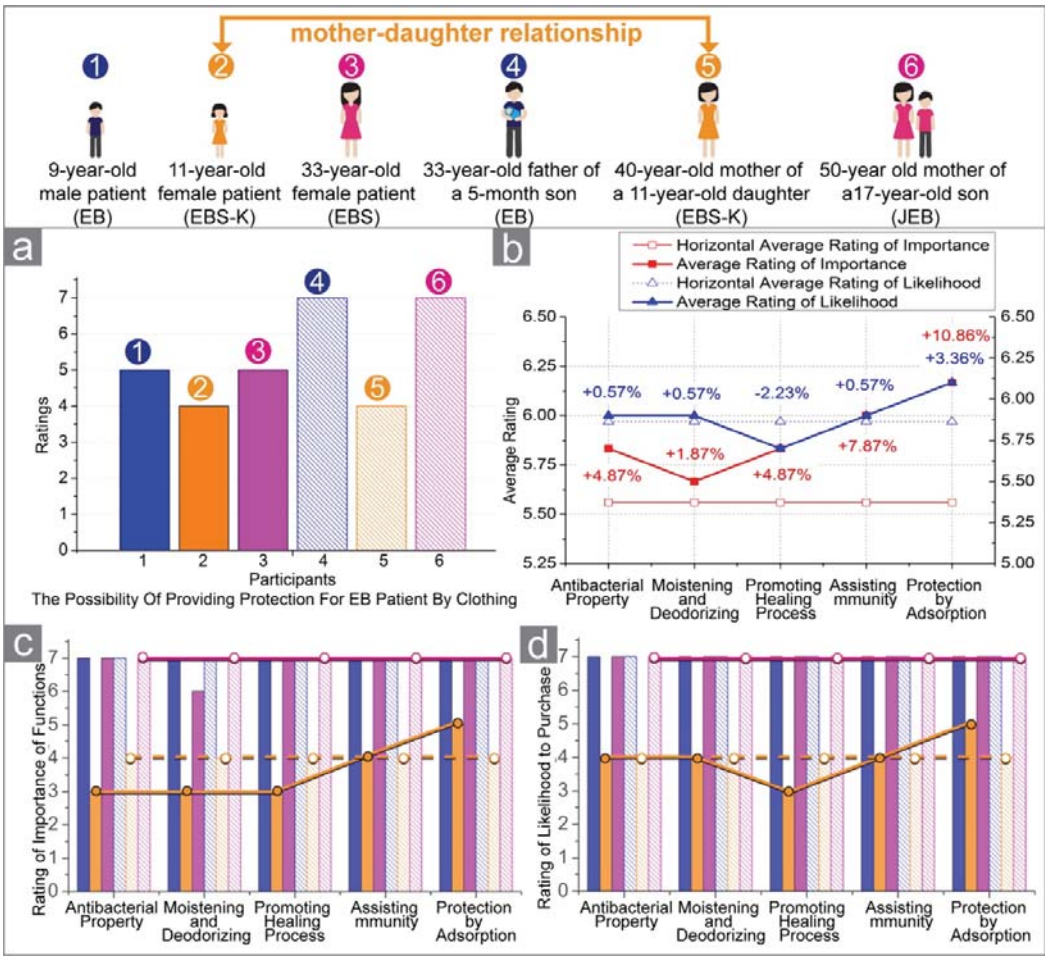

Figure 9. (a) Rating of possibility of using clothing protect EB patient skin. (b) Average rating of importance of different functions of clothing for EB patients and likelihood of purchasing clothing with said functions. (c) Rating of importance of different functions of clothing for EB patients. (d) Rating of likelihood to purchase clothing with said functions.

From the interviews, it can be found that there is a significant demand for clothing features that would help the conditions and symptoms of EB, such as the right type of material and style. In terms of the expressive considerations of clothing, we found that the normal consumer theory (clothing value added) could also be applied to these patients. The desire for functional clothing that would help EB patients is greatly reflected in the responses of the interviewees (Table 2).

Table 2. Demographics of interviewees.

Interviewee	Age (years)	Gender	Age of child (years)	Gender of child	EB type	Remarks
1	9	Male	–	–	Unknown*	
2	11	Female	–	–	EBS-K	
3	33	Female	–	–	EBS	
4	33	Male	5-month	Male	Unknown*	
5	40	Female	11	Female	EBS-K	Mother of interviewee 2
6	50	Female	17	Male	JEB	

*Unknown: not diagnosed.

EBS: epidermolysis bullosa simplex; EBS-K: Köebner subtype of epidermolysis bullosa simplex; JEB: junctional epidermolysis bullosa.

3.4. Materials used in clothing for EB patients

In terms of materials, Participant 3 indicated her preference for natural fibers which is directly related to wear comfort. The three EB patients, Participants 1, 2 and 3, felt that the fabric for clothing could either protect or injure. This is because the fabric could stick to their wound(s), which causes secondary abrasion, and is painful both emotionally and physically. Most put their wound dressing on at home and use soft fabric, since rough fabric can easily scratch their skin. Breathable fabric that will not stick to their skin and wounds are preferred. Therefore, their quality of life could be improved through the use of apparel technology, such as cooling fabric that allows rapid drying of perspiration and provides deodorising effects. Ease of washing is also preferred since it is difficult to wash out blood stains after a period of time.

3.5. Garment detailing and design for EB patients

The participants expressed their special requirements in terms of the clothing detailing. They prefer long-sleeved tops and long pants to cover their wound scars and protect their skin; primarily covering the hands and arms, legs and feet, chest, abdomen and back. Garments should not have buttons and zippers as the opening and on the collar. A loose cut is preferred. Seamless elastic tubular compression bandages (probably because tape will cause secondary abrasion) are also preferred for wound dressing. An aesthetically pleasing design that combines clothing and tubular bandages (since the bandage cannot be worn alone and after a skin injury, the use of wound dressings, tubular bandages and then outer clothing result in increased amount of thermal heat which is unpleasant) is favoured, so that the patients can address their skin ailment with only one item. There were requests for sweat shirts and men's underwear for EB patients.

3.6. Special wound dressings for EB patients

Participants 4, 5 and 6 indicated that traditional bandages cannot meet the requirements of EB patients for wound dressings, and they use seamless elastic tubular compression bandages for better coverage. In this study, the parents of the children with EB mainly used stockings and wrapped them with gauze on the four limbs of their child, but this is inconvenient for everyone.

3.7. Subjective and aesthetic concerns of garments for EB patients

Without a doubt, the patients and their family members have repeatedly stressed that the importance that clothing can address their needs and symptoms. The most vulnerable parts of the body to injury are the limbs and back. They also repeatedly stressed that long-sleeved tops and long pants that could cover and protect their body parts at the same time are important. In terms of garment appearance, cartoons and fun graphics will fulfil the aesthetics expectations of children patients. The feedback from these patients and their parents therefore reflect the need for functionality yet also aesthetics in apparel for EB patients.

4. Conclusion

This is the first study that has obtained an in-depth understanding of EB patients and their parents on their needs in functional apparel, with expressive and aesthetic considerations. The results of this study contribute to skin disease patients by providing information towards a more suitable apparel system that would reduce their physical and psychological pain in daily life, so as to enhance their quality of life. The proposed items in this study for an appropriate apparel system do not only apply to EB patients, but also to other patients with skin diseases who need to improve wound healing and require greater skin protection, such as burn victims or patients with pressure ulcers. Technological advancements in materials studies promote developments in the medical industry and thus human welfare. As for textile technology, improvements in materials and mechanical technologies innovate product variety which benefit human beings. From the perspective of functional apparel design, the results in this study better show the current situation of EB patients and their parents as well as their needs, by analysing the potential problems and providing details that could contribute to future apparel based materials development and research in the medical field. This is also interdisciplinary research work in the hopes of reducing human pain and suffering.

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