“It is such an all-encompassing condition to have”: Investigating the Experiences and Perceptions of Community Service Providers Who Work with People with Epidermolysis Bullosa (EB) in Ireland
Abstract

Background: Epidermolysis Bullosa (EB) is a rare genetic condition, resulting in painful blistering of the skin. The two main specialised hospital services for those with EB are located in Dublin. Community services are provided nationally. The multi disciplinary team, who encourage a person’s occupational engagement, also deal with wound care, nutritional status, bathing regimes, pain management and psychological support for the client and family. Many professionals find that this possesses a variety of challenges.

Objectives: As one component of innovative participatory action research exploring the development of a support service strategy for people with EB in Ireland, this study aimed to investigate the experiences and perceptions of Irish community service providers, working with people with EB.

Methods: Semi-structured interviews sought to identify nine community service providers’ aims, interests and motives for service involvement, establish positive and challenging aspects of the system, and inform future service development.

Results: Following thematic analysis, four themes emerged: 1) Aspects of Time, 2) Tools for Preparation, 3) Emotional Impact on Professionals, 4) Importance of Relationships

Conclusions: The participants acknowledge the importance of building relationships of trust with the patients, their families and other professionals. Community service providers may only work with one or two people with EB, however the physical and emotional support required for this group needs to be fully understood and recognised. There is need for evidence-based, timely training and preparation, and continued supervision and support for these professionals, for them to do justice for people with EB in Ireland.

Introduction

Epidermolysis Bullosa (EB) is a rare group of genetic skin disorders that causes skin fragility and blistering of mucosa and the skin following mild trauma (Horn and Tidman 2002). It is estimated to affect 1 in 18,000 live births in Ireland (Debra Ireland 2013). Two specialised hospital services for those with EB are located in Dublin and community services are provided nationally. Those with EB face many challenges and require support with occupational engagement when dealing with wound care, maintaining their nutritional status, implementing bathing regimes, managing pain and coping psychologically.
According to the Health Service Executive (HSE) (2012a), a national EB service is being planned. This is a proposal that could potentially improve the quality of life for many patients and it is hoped that it will link in with the needs and wants of Irish service providers and EB patients. Schober-Flores (1999) interviewed health professionals who work with EB and 96% of the participants found their work emotionally intense. This study will contribute to formulating the support service strategy for people with EB in Ireland by establishing the perspectives and experiences of community based service providers who work with people living with EB.

**Literature Review**

**What is EB?**

There are three main types of EB: Epidermolysis Bullosa Simplex (EBS), Junctional Epidermolysis Bullosa (JEB) and Dystrophic Epidermolysis Bullosa (DEB). Each type and subtype carries varying degrees of severity and require unique methods of management. For example, the sufferers of a subtype of EBS, Dowling Meara present with widespread blistering at birth, which gradually ameliorates. Those with Weber-Cockayne and Köbner subtypes present with mild blistering, without improvement throughout the lifetime (van Scheppingen et al 2008). EB can have a detrimental effect on many aspects of the patients’ occupations, and those of their families, caregivers and friends, even for people whose cases are non-lethal (Pagliarello and Tabolli 2010). Presently, no cure has been found for EB (Reddy et al 2011).

**Impact on occupational performance of patients**

As a consequence of persistent blistering of the skin, those with EB can experience progressive hand and foot deformity (Atherton and Denyer 2003). Scarring and contraction of tissue follows the healing process. This often results in the formation of claw-like hands and feet, as there can be contractures of the digits, leading to pain, reduced function and mobility (Denyer and Stevens 2010). Dental caries, oral blistering and skin cancer are common within this population. (Reddy et al 2011; Maritsi et al 2011; Dures et al 2010; Azizkhan 2007; Horn and Tidman 2002).

Occupation encompasses activities of daily living, which are purposeful and meaningful to each individual (Hinojosa et al 2003). The above symptoms of EB can lead to barriers of a person’s occupational engagement. For instance, the following occupations can be impacted upon; bathing/showering, writing, eating, shopping, sleeping, sexual activities, mobilising
indoors and outdoors, dressing and oral hygiene (Frew et al 2009; Herod et al 2002). Psychologically, it has been noted that patients experience frustration, embarrassment, anxiety, and depression, often as a result of teasing and staring (Frew et al 2009).

**Involvement of the Multi-Disciplinary Team (MDT)**

Once a treatment plan has been established in one of the specialist centres of Our Lady’s Hospital, Crumlin and St. James’ Hospital, Dublin, and the patient’s symptoms improve or become stable, the MDT in the hospital liaise with the patient’s GP. Appointments or treatment should be arranged locally. However, for the more severe types of EB, this may not always be feasible (HSE, 2012b).

Current treatment of EB encompasses prevention of blistering, promoting wound healing, improving nutrition and enhancing general quality of life (Ramirez et al 2013; Schober-Flores 1999; Frew et al 2009, Goldschneider et al 2010; Sarker et al 2011). This involves input from a wide range of healthcare professionals (Denyer 2006). For example, pain management is a crucial element of the service required by patients (Herod 2002). The sources of pain can be acute, a result of the blistering, or chronic, particularly regarding surgical procedures. Physiotherapy aims to optimise mobility and avoid contractures (Herod et al 2002). Occupational therapy looks at hand and grip function, as well as perceptual and motor development (Weiss and Prinz 2013) and well-being (Ramirez et al 2013). Speech and Language therapists are concerned with dysphagia (Haynes 1998).

**Rare disease**

The rarity of the disease can cause tensions between healthcare providers and the patients and their families, as it is a condition that is poorly understood (Dures et al 2011). Yuen et al (2012, p. 91) found that parents of newly born children with EB felt that the non-specialist healthcare professionals in the Netherlands lacked in competency in taking care of their child as they lacked the “knowhow”. This resulted in inappropriate management and treatment methods on the part of the practitioners. This is a prime example of how the rarity and lack of knowledge of EB can lead to difficulties working with affected children and adults. It also highlights the need for specialist services to provide the high quality care for these patients that they need. On the other hand, there is a need for high quality and highly informed community based services. This is particularly relevant in the Irish context as both specialist centres are located in Dublin.

The quality of service provided to a patient can be impacted by the support that the service providers receive for their own needs (Sorensen and Iedema 2009). However, there is a
paucity of research exploring the experiences of professionals providing a service to patients with EB. Current research calls for greater attention to therapists’ self-care is a recurrent theme (Skovholt 2005). Staden (1998) notes that healthcare professionals must not only deal with the physical needs of those they care for, but they must also respond to the emotional needs. As previously mentioned, Schober-Flores (1999) found that 96% of the health professionals working with those with EB found their work emotionally intense.

With this in mind, the aim of this study is to investigate the experiences and perspectives of community based service providers who work with people with EB.

**Methodology**

This research is part of a larger participatory action research partnership with Debra Ireland, the Irish charity organisation for people with EB, and the University of Limerick. It aims to develop a proposed strategy for support services for people with EB in Ireland. The larger study involved inviting key stakeholders to participate in individual interviews, follow-on workshops (See visual 1) and a national survey to investigate current Irish services provided.

According to Bassett (2004 p.155) “people cannot be reduced to simple numbers”. Therefore, the use of naturalistic forms of inquiry is appropriate when the goal of research is to examine the experiences of participants (DePoy & Gitlin 2005). Qualitative research methods are considered more attuned with naturalistic inquiry than quantitative methods.

**Participants**

A convenient sample of eleven community based service providers was identified by Debra Ireland. A list was provided to the researcher supervisor and this was passed on to the
researcher. Of the eleven, nine agreed to participate. Two of the remaining were uncontactable. Convenient times and locations for participants were agreed upon for the interviews to take place in August 2012. As one participant was unavailable to do an interview in August, and due to time demands on the researcher, the research supervisor interviewed this participant in spring 2013. Eight of the participants are currently working with people with EB. One has had recent previous experience. See visual 2 for the participants of the study.

Visual 2: Participants

Data Collection

A semi-structured interview guide was followed (Appendix 1). This was developed by Gowran (2012) and was influenced by a political reasoning tool by Kronenburg et al (2005) and reflective consciousness (Capra 2003). Therefore, the interviews considered stakeholders experiences of working with people living with EB, specifying, for example, their aims, interests and motives, level of involvement, issues which motivate and frustrate and what changes if any would they like to see in the services they provide. This type of interview greater enabled the researcher to initiate a narrative account of the participant’s experiences, as well as allowing for a better rapport to be built, than in a structured interview (Taylor and Kielhofner 2006).

Data Analysis

Each interview was transcribed by the researcher. Thematic analysis was guided by Braun and Clarke (2006). During the first phase, familiarisation with the data and the initial search for meanings occurred by the transcription of interviews. Each interview was listened to and read multiple times. This assisted with familiarisation of the data. Phase two incorporated the
initial production of codes from the data through use of Nvivo software. This enabled the files to be coded extremely finely (Richards 1999). Elements of data were coded only if they related to the aims of the study. For example, some participants spoke at length about some elements of their careers, which were not related to working with people with EB.

The third phase involved the compilation of themes and sub-themes. A theme illustrates something in the data that is central to the research question (Braun and Clarke 2006). This phase involved focusing on how the codes related to each other, and combined together, creating overall themes. Phase four involved refinement of these themes, establishing how they intertwined to tell the story about data collected. The aim of the fifth phase was to clearly define and name the themes and sub-themes. This facilitated the researcher to be certain the themes were consistent with the research question. Production of this report is the sixth and final phase.

**Ethical considerations**

Ethical approval for this study was granted by the Clinical Research Ethics Committee of the University of Limerick. Participants were given a Participant’s Information Sheet (Appendix 2) and each was explained that participation was voluntary and they could withdraw from the project at any time.

To ensure validity, transcriptions were sent to participants who wished to approve their content prior to the completion of the analysis. As the community of persons with EB is considerably smaller than that of other conditions in Ireland, every care was taken to ensure as much anonymity as possible of the participants of the study. All participants will be referred to as “professional” or “participant”.

The interviews were made anonymous by the researcher during the transcription process, by replacing any confidential information, such as people’s names and names of towns and counties. Following transcription, each interview was saved to a password protected computer and the tape was destroyed.

**Credibility and Trustworthiness**

The use of semi structured interviews reduced the potential for researcher bias, with the interview guide being used for all interviews. With regards to member checking, all participants were given the opportunity to review their transcripts, of which, two took up on the offer. This ensured that the information and experiences gathered were captured in the voice and words of the participants (Dillaway et al 2006), and that they were satisfied with the end product of the interview.
Reflexivity

Reflexivity is deemed essential within qualitative research. It enables the researcher to consider the phenomenon under study further (Watt 2007). After completing a review of the literature, the researcher was aware that the content of the interviews would potentially be emotional. For this reason, a reflective diary was kept. It provided an outlet for any issues that arose throughout the interview and coding process which may have influenced data analysis.

Findings

Visual 3: Themes

Theme 1: Importance of Relationships

Sub-theme 1: Importance of relationships with patients

The professionals recognised how crucial it is that a relationship of trust is built with their patients. The participants recognise that it takes time to build this relationship.

At this stage he’s getting to know me better. He used be very frightened at the beginning … but like you’re going in there and a complete stranger so you have to understand that. It just takes a wee while to build up confidence with him.

One participant acknowledged that there was an element of nervousness on her part when she first met the patient with EB, particularly around moving and handling that may cause blistering.

…it really is a relationship of trust that needs to develop before the child is comfortable.
Sub Theme 2: Importance of relationships with family carers

One participant described the importance of forming a positive relationship with the family carers as “paramount”. When this relationship was built, it motivated one particular professional to work with her patient in the “best way I knew possible”. Another felt that it was necessary to be realistic with the family carers about the condition and what it entails.

…let them know this is a problem that isn’t going to go away…what they can expect.

The need for “involving the parents to the maximum” was recognised, to ensure that therapy is understood and followed through at home.

…considering the long term need, for them to really comply with some of the therapy programmes is huge, so you need to really have that kind of understanding of the family members for them to follow through with the programmes…

One professional described the moral dilemma associated with the service he provides as there are finances involved.

…but you wouldn’t do it because you’d have no relationship and it would be very difficult.

Morally, I’d have great difficulty with that.

Sub-Theme 3: Importance of relationships with professionals

Having a positive relationship with other professionals was recognised as it ensures that there is communication between all teams in relation to the care of the patient. Some participants held huge value to the knowledge of the staff in the specialist centres.

Once I speak with them, they’re so, so good.

…the team down in Crumlin were very welcoming of our opinion and they also provided some contacts for us to pursue...

Theme 2: Aspects of Time

Sub-theme 1: Time to prepare

Time was identified as an issue, particularly as it is such a rare disease that they may have never encountered before. Due to the demands of their jobs, some found it difficult to find the time to access resources in order to become entirely familiar with the condition.
... you don’t necessarily think you have a handle on it unless you have the time to go away and get the books out and with the best intentions in the world, sometimes, the time doesn’t occur for it...

Sub-theme 2: Time for attending meetings

The need for regular contact with specialist professionals was identified. One professional considered herself lucky that she was given permission from her manager to attend a MDT meeting in Dublin, given the time constraints.

...it was a full day...to take out of our working week. So it is difficult.

Sub-theme 3: Life-limiting nature of the condition

Many of the participants acknowledged the inevitable shortened lifespan of their patients and it is their wish to help their patients to live as normal a life as possible.

The child is going to have a very shortened lifespan, you know, therefore it would be nice if the child could experience nice things and normality because he’s not getting it at the minute.

Some professionals reflected on the amount of time it takes for family carers to care for their family members with EB. Two participants reflected on time the pressures that they often place on parents when ensuring that their child is engaging in their individual area of therapy.

I need to take a step back and think, look at the bigger picture with this child. There’s so much else going on, maybe my area isn’t the most important area at this time

It’s a full time job for nearly every single person in that family...

Theme 3: Emotional Impact on professionals

A range of emotions were expressed by the words; “over whelming”, “hard”, “difficult”, “emotional”, “upsetting”, “frightening”, “tough”, “fearful”, “nerve-racking” and “humbling”.

Two professionals spoke about how they need to accept the condition and the impact it has on the patient in order to do their jobs to the best of their ability.

It's sad. But when you have a situation like that, you have to live with it, accept it, and get on with it. Like, it’s all you can do for the child’s sake.

...it can be very draining, very emotional so you do have to keep one foot on the bank and you know, keep grounded.
Some participants were affected by the impact that having a family member with EB has on family carers.

…I think it’s a huge amount to take on and I think it’s very over-whelming and I think we as therapists or you know, people helping the family, I think, we expect an awful lot of them…

Participants remarked on how difficult they find it to see their patients with new blisters.

I suppose I’m kind of expecting it. Sometimes when you see him though, some wounds look worse than the... it’s difficult for me when I see it on his lips, his mouth and his tongue and things like that, I find that quite tough because I can imagine he must be in pain when he is talking…

You never want to see a child in pain, you know?

One participant commented on the importance of supervision when working with people with EB.

…so the impact... will always have to be supervised so that you’re not absorbing too much, ... as human beings we’re like barometers, we soak it up and I think having the correct external supports helps keep me grounded…

Working with people with EB encourages some participants to value their health and that of their families and gives new perspective on life.

I’m a father with three sons...it kind of makes you realise how lucky you are, that my sons are very well.

You don’t take the little things for granted when you’re working with a child with EB.

…don’t sweat the small stuff.

**Theme 4: Tools for Preparation**

**Sub-Theme 1: Rarity of the condition**

Some professionals felt they could have been better supported in preparing for working with a patient with EB, as for the majority of the participants; they would only have one patient with the condition.

I suppose if you have a child diagnosed with EB and we got a letter saying this is what we’d like your role to be, to kind of crystallise it a bit more, you know?
Sub-Theme 2: Emotional preparation

Some professionals acknowledged that very little can be done to be emotionally prepared for working with these patients.

So I did feel physically prepared to deal with it but it was emotionally, it's emotionally that there is a problem.

Sub-Theme 3: Supports

The professionals valued the work of the hospital based staff, particularly the EB nurses, and Debra Ireland, in helping them prepare for working with people with EB.

...all this information in fact I got from the EB nurse. So incorporating that information into the therapy sessions is what really helped working with children with EB.

Debra Ireland were there any time I needed to ask any questions.

Suggestions were made as to how professionals working with EB could be better prepared. These included: case studies, letters crystallising the role of the professional, more training, handover and up-to-date information on therapy interventions from specialist professionals, more regular meetings with the specialist centres, a study day or EB conference “with a practical side to it”.

Discussion

The four themes identified throughout this study intertwine to tell the story of the perspectives of community based service providers who work with people with EB in Ireland.

Trust is a foundation for therapeutic relationships (Linley and Joseph 2007). Evidence indicates that effective patient–practitioner interaction is beneficial to many outcomes (Matthews et al 2009). Dures et al (2011) note the importance of therapeutic relationship of patients and their families with healthcare professionals. Yuen (2012) found that parents wished for professionals to inform them as honestly as possible about the diagnosis and fatal prognosis. One professional in particular found this to be a necessary strategy in building the therapeutic relationship with parents of their patients.

While the literature review outlines the occupational performance issues of patients with EB, this study highlights some of the occupational performance issues of the community service providers. Dealing with such a rare condition, with little or no experience with the condition, brings about challenges, such as maintaining confidence in the interactions between professional and the patient (Sumison 2006). Handling a patient with EB can result in trauma
and skin loss (Stevens and Denyer 2010). One participant felt that the therapeutic relationship was negatively impacted on as a result of nervousness felt through fear of injuring the patient’s blisters further when transferring. This study recognises this potential barrier to client centredness within this client group as blisters are a reality for every patient.

Therapists strongly emphasise empathy and rapport as vital roles in the therapeutic relationship (Cole and Mc Lean 2003; Yerxa 1980). In this study, these are also held in high regard by the community based service providers interviewed. This is evident in relation to working both with the patients and their family carers givers. The participants spoke about the need to take a step back and look at the bigger picture in relation to the demands placed on family carers. They recognise the time demands of dressing regimens are intricate and time consuming (Stevens and Denyer 2010). There is a huge sense of empathy on the part of the professionals for the work the family carers undertake to take care of their family member with EB. This illustrates the awareness of the impact that living with EB and caring for a person with EB has on the people they provide services to.

In line a study of practitioner’s experiences by Taylor et al (2009), who reported experiencing at least some interpersonal challenges within their professional life, this study illustrates a clear moral dilemma experienced by one participant in particular. The medical card in Ireland only covers acute and necessary treatment. Therefore it is not for on-going chronic disease management. If a patient with EB needs to be seen by a GP, whether it is to simply monitor blistering or for the family carers to touch base with the GP, there is a substantial charge. The importance of building a positive relationship with the patients and their families means that a GP considers it immoral to charge this money, thus outlining the need for EB to be recognised as a chronic condition in Ireland.

This study has shown that while working with people with EB can be “humbling”, there is a significant emotional element to the work, both professionally and personally. Many spoke about how working with people with the condition help them to appreciate the small things in life, appreciate that their own families are healthy and “don’t sweat the small stuff”. Undoubtedly, there was a sense of some acceptance of the appalling nature of the condition by two participants. This enabled them to build a strong therapeutic relationship with their patients. A theme identified in the work of Dures et al (2010) was the need for professionals to look after themselves when working with people with EB. One participant in this study identified that it is necessary to bring the worries and burdens to supervision.

At the heart of professional attachment of a therapist is the vital ability to care, which must be maintained by the helping professional throughout the process of helping (Skovholt 2005). There is no denying the emotional impact working with EB has on professionals and
is clearly illustrated in the findings of this study. In the same vein, Linley and Joseph (2007) surveyed therapists to investigate both the positive and negative aspects of their well-being. Those who received formal supervision or support from work reported to have higher levels of personal growth. Supervision allows therapists to reflect on, critically look at and discuss their experiences (Hunter and Blair 1999). Craik (1988) found that supervision was seen as a coping approach for stress. The need for supervision to maintain professional’s wellbeing is recognised in this study, in line with the research of Linley and Joseph (2007).

Another challenge faced by people with a rare condition, is lack of knowledge on the part of the professional on the rare disease and has been shown to damage the therapeutic relationship (Budych et al 2012). While all participants have the core skills for working with people, there is another layer of preparation needed for working with people with EB. The community based service providers recognise the need for tools for preparation; identifying case studies, more detailed letters from the specialist hospitals crystallising the role of the community based service provider, more training, handover and up-to-date information on therapy interventions from specialist professionals, frequent meetings with the specialist centres and a study day or EB conference, as useful supports to their practice.

Practice based on evidence can decrease the uncertainty that clinicians experience in a complex healthcare system (Melnyk and Fineout-Overholt 2005). This study has outlined the need for community based service providers to have quick access to the current evidence-base regarding working with people with EB. It is especially needed by therapists, as some find it difficult to access up-to-date information, regarding equipment for bathing, for instance. Participants honestly stated that they do not have the time within working hours to obtain this information. They acknowledge the work of the hospital based staff, who have the expertise, and wish for the knowledge and experience they have to be more accessible to them.

For the above to become a reality, time is needed. Unfortunately, time appears difficult to come by for the community based service providers. The expressed wish for more time availability to firstly, have more regular MDT meetings in the specialist hospitals, and secondly, be allowed the time within working hours to attend these meetings, demonstrates a pressing issue. The fact that the specialist centres are located in Dublin pose a problem with regards to time. These meetings provide community professionals with invaluable information about the condition from an MDT perspective, from professionals who work with many people with EB on a daily basis. Dures et al (2010) also established that time is a limited resource when working with people with EB.
The participants were very clear on the positive aspects of being able to attend meetings. Some professionals illustrate this need for meetings to be more regular, not only when an issue has arisen with a patient. A relationship with other professionals can be built at these meetings, which help with implementing client centredness, as teamwork allows difficulties to be shared and individual strengths to be used (Sumison 2006) and this is echoed throughout the current study.

Limitations of the study

A number of the participants were based in the same locality, working with the same caseload of people with EB. The results of this study are therefore somewhat limited to experience working with a particular number of people. Future research could yield results from a participant group scattered further nationwide and from a larger sample size.

Conclusion

“Healthcare is filled with uncertainty” (Melnyk and Fineout-Overholt 2005 p. 3). This statement is true for healthcare in general, and this study illustrates that it is also true in relation to the healthcare of people living with EB in Ireland. This current study outlines the experiences and perceptions of community based service providers of the work they do with people who live with this life-limiting condition. In line with other research, the need to build a therapeutic relationship of trust with patients and their family carers is crucial with this population. Patients need to trust the health professionals, particularly as much of the intervention and treatment can be painful. Family carers are often responsible for ensuring that therapy is followed through, thus there needs to be trust and rapport with the service providers.

Consistent communication must exist between community and hospital-based professionals, to continuously maintain a high standard care for patients. For this to happen, there is a voiced requirement for more time to be granted to the community professionals to attend MDT meetings in the specialised hospitals. There is no doubting the necessity and importance of these meetings. The other strategies suggested should also be taken into account, to help prepare and support the community professionals with working with a person with EB. This is crucial, because more often than not, they may only work with one person with the condition.

These concerns must be taken seriously to ensure emotional wellbeing of the professionals. The physical and emotional support required for this group needs to be recognised and
understood. The value of continued supervision is highlighted, to help the service providers with their own occupational performance and emotional wellbeing. This study looked beyond the needs of the service users and their families. It was stakeholder-centred, to provide research which will inform future policy to improve the quality of the services for people with EB in Ireland and their families. To reiterate the findings of the study, there is major need for evidence-based, timely training and preparation, and continued supervision and support for occupational therapists and other professionals, for them to “keep one foot on the bank... keep grounded” in order to do justice for people living with EB in Ireland.
References


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Appendix 1

Developing a Support Service Strategy for DEBRA Ireland through Participatory Action

Interview Guide

The Interview will consider stakeholder experiences of participation and or connection with support service for people with EB, indicating for example their aims, interests and motives for involvement in the service (this could be family member; medical services; therapy services, budget management or policy development related to supporting people with EB manage their live). Some stakeholders will have closer direct links with EB support service than others. Questions below are a guide for the interview and may change slightly depending on the individual stakeholder.

1. Demographic questions: age, length of time utilising or working with support services.

2. Semi Structured Questions

Describe your typical day.

What activities do you attend/ do you engage in?

- Tell me about the today.
- What do you think about it?
- How do you feel about it?
- Tell me about what you like and dislike about being involved in support services for people with EB

Tell me about why you got involved in (EB) services.

What interests you most about your involvement?
Describe an experience that motivates you about what you are doing.

Describe an experience that frustrates you about what you are doing.

What changes, if any would you like to see in developing support service?

- Can you give me an example
Would you like to take part?

This information sheet is about a participatory action research which is taking place with DEBRA Ireland. It wishes to invite key stakeholders connected with in service for people with EB to take part. Before you decide to participate, it is important for you to understand why the research is being done and what your participation will entail. Please take time to read the following information carefully. Please ask about anything that is not clear or if you would like more information.

What is the purpose of the study?
This study is being completed as part of masters and postdoctoral research at the University of Limerick.

DEBRA Ireland is

- The purpose of this study is to review the support services available to people with EB in the broadest sense by involving key stakeholders.
- The lead researcher will work in partnership with Debra to connect key stakeholders.
- Key stakeholders will be actively involved in contributing to the development of a strategy document by identifying key issues involved in provision of support services with the view to creating opportunities for improved support service.

What will I have to do?

As a key stakeholder, if you agree to participate, the lead researcher, Rosie Gowran, will invite you to participate in an individual interview which will be carried out by Masters students from the MSc Occupational Therapy (Professional Qualification) programme at the University of Limerick, and initially one workshops with a possible invitation to a further 5 workshops.

Interviews

- Interviews will be conducted at a time and place of convenience to you.
- The interview will last a maximum of 90 minutes.
- You will be asked questions about your connection to service for people with EB.
- The interview will be recorded using audio equipment and later transcribed by the researchers.
- Transcriptions will be returned to you to check and ensure that they accurately reflect what you have said and allow you to make any changes.
- Analysis of the interviews will be combined with other participant interviews.
- The collective findings from the interviews will be presented to you and all key stakeholders involved in interviews at a 1 day workshop facilitated by Rosie Gowran the lead researcher.
- If you decide not to participate in the workshop you can on request have the information collected from your interview removed from the process.

Workshops:

- Following the 1 day workshop you may be invited to participate in a serious of 5 (1 day) workshops with other stakeholders (this will depend on the outcomes of workshop 1).
- These will be carried out over a 6 month period and require your active participation on workshop days in developing a support service strategy document for DEBRA Ireland.
Once the strategy document is formulated you will be invited to review the draft and make comments and attend a final workshop with all stakeholders involved in the interview process.

Your individual input in any of the workshops will remain confidential and you are free to withdraw at anytime.

Lunch will be provided.

**What are the risks and benefits?**

- There are no apparent risks in participating in the study.
- As with any interview process questioning may trigger issues that may cause an emotional response – find a sentence to describe this
- The direct benefit to you from taking part in this study is active participation in strategy development.
- The information you provide will be very valuable in developing a strategy for DEBRA Ireland’s support services
- There is no guarantee at this stage that the strategy will be implemented.

**What will happen to the results? Confidentiality**

- All the information you provide will be kept confidential at all times.
- The results of the study will be reported to the University of Limerick and DEBRA and presented as part of Master’s thesis’
- The potential of these results will be published at a later date.
- In order to maintain your confidentiality, your personal details i.e. your name, address and any other obviously identifiable information about you will be removed from all reports.
- Pseudonyms will be used, however given the nature of the small community involved in this area complete anonymity is not always possible.
- All audio tapes will be destroyed after information has been transcribed. Transcriptions will be stored on a password secured computer and hard copies will be stored in a locked cabinet.

**Do you have to take part? Refusal or Withdrawal**

- Taking part in this study is completely voluntary.
- You are entitled to refuse to participate in the interview and workshops and you are free to withdraw at any time during the study.
- You may do so without fear of prejudice, this will not affect your relationship with DEBRA Ireland
- Only those involved in interviews will be invited to participate in workshops.
If you wish to take part or request for further information

- If you wish to take part please sign the attached consent form and return it in the stamped addressed envelope provided.
- Should you require further information about this study please feel to contact Rosie by phone 061-202959
- The Department of Occupational Therapy at the University of Limerick is also supervising this research on an ongoing basis.
- A steering committee set up by DEBRA will also monitor the progress of this work, however they will not have access to any identifiable information you provide.

Lead Researcher

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Appendix 3:

CONSENT FORM

STUDY TITLE: Establishing the occupational experiences of community service providers on the services they provide to people with epidermolysis bullosa.

Consent Form

Developing a Support Service Strategy for DEBRA Ireland through Participatory Action
I ____________________________ am aware that I am being invited to participate voluntarily in a research study about my perspective on the current support service available to people with EB.

- I have read and understand the Information Sheet.

I have been informed by the researcher that:

The purpose of this study is to explore stakeholder participation in current support service available to people with EB and invite them to participate in individual interviews and workshops with the view to developing a Support Service Strategy for DEBRA Ireland.

The findings will be used for master’s thesis, for service change, for educational purpose and published in a variety of research journal.

**My participation will involve:**

**The Interview:**

The interview will involve a discussion with the researcher about my involvement with and perspective of the current support service available to people with EB and will last for up one hour and thirty minutes.

The interview will be recorded with handwritten notes and an audio device.
I will get the opportunity to review and comment on all transcripts and analyses of the interview before the findings are disseminated.

Workshops

I agree to participate in one facilitated workshops involving other stakeholders who have been involved in the interview process.

I agree to work in partnership with them to enable the development of a Support Service Strategy for DEBRA Ireland

I am aware of the risks and benefits associated with the research.

- My participation and responses will be kept confidential at all times. I will not be identified nor will any identifying information about me to the organisation or be reported in any publications arising from this research.

- I am aware that pseudonyms will be used, however given the nature of the small community involved in this area complete anonymity is not always possible.

- My participation in this research is completely voluntary and I am free to refuse to participate.

- If I agree to participate, I can withdraw at any time, without any negative consequences.
I UNDERSTAND THAT BY SIGNING THIS FORM, I AM GIVING MY CONSENT TO PARTICIPATE IN THE STUDY DESCRIBED ABOVE.

Please complete the statements below to ensure fully informed consent:

• I am aware that I am volunteering to take part in a study that will explore:

__________________________________________________________________________

• If at any time I was to feel unable to take part in the study I could:

__________________________________________________________________________

I have received two copies of this form, one for me to keep and one to return to the researcher.
_____________________

Signature of Participant

Date


_____________________

Printed Name of Participant

_____________________

Signature of Witness

(Staff/Family/Friend)

Date

_____________________

Signature of Researcher

Date