M.Sc. Occupational Therapy

OT6054: Dr. Judi Pettigrew

Module Leader: Dr. Judi Pettigrew

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Abstract

Title: Exploring the Occupational Experiences of Individuals living with Epidermolysis Bullosa (EB)

Background: EB is a rare genetic disease characterised by skin fragility. There are approximately 300 people living with EB in Ireland. The majority of services provided for these individuals are hospital based, as there is a need for continuous medical intervention with this condition. Most of the research conducted to date is biomedical based, focusing on finding a cure for EB. However, for individuals living with EB, this condition undoubtedly impacts on their occupational performance, choices relating to meaningful occupation and reaching occupational potential. This qualitative research sought to explore the occupational experiences of individuals and their families based on the support services available.

Method: This study is part of a participatory action research study, in partnership with Debra Ireland, to explore evidence based on qualitative research from key stakeholder perspectives of support services. Seven participants, made up of individuals with EB (n=4) and family members (n=3) were recruited for individual semi-structure in-depth interviews.

Results: Thematic analysis revealed that participants’ daily occupational experiences remain intact, and are a priority for them. However, two key issues emerged relating to service level knowledge about EB and access to bandages, which is a primary need of this population.

Conclusions: This paper presents insights of living with this rare disease through an occupational lens. It highlights how exposure to services impacts on participant’s use of and confidence in support services, which can impact negatively on the individual’s occupational experience.
Introduction
Epidermolysis Bullosa (EB), otherwise known as the butterfly disease, is a group of inherited skin disorders (Fine et al 2008). It is characterised by skin fragility, with the main feature being blistering of the skin as a result of little or no friction, often resulting in chronic pain (Fine 2010). Severe forms of the disease can affect many systems in the body, can be fatal in infancy and can result in dramatically reduced life expectancy and quality of life (DEBRA Ireland 2013). EB is considered a rare disease as it affects 1 in every 18,000 babies born in Ireland, which approximates to 300 people (DEBRA Ireland 2013).

DEBRA Ireland is an Irish charity which provides support services for people living with EB (DEBRA Ireland 2010). They are funding a two year project with the overall aim of developing a support service strategy for EB. This research is important as current support services in Ireland do not consider all aspects of quality of life, such as psychological and social aspects (Watson 2010b and Commission on Practice 2008). The project seeks to explore this impact, identify the adequacy of current support services for enabling participation in daily living, and use this information to develop a suitable service strategy.

This particular study is a component of phase one of this two phase project. It is concerned with conducting qualitative interviews with individuals living with EB and their families in order to gain an insight into their occupational experiences. The perspectives of other key stakeholders in service provision, namely hospital staff, community based staff, and policy administrators, are being gathered in parallel studies. These four studies will then be used in phase two of the overall project in order to aid in the development of the support service strategy.

Literature Review
A review of the relevant literature on EB reveals three main areas of research. These are the aetiology of EB, best practice for managing EB and the psychological and psychosocial impact of living with EB. Each of these three areas are now discussed.

EB is a result of mutation of protein coded genes at the dermal-epidermal junction (Fine et al 2008). These proteins are responsible for skin structure and integrity (DEBRA Ireland 2013). There are three major categories of EB, namely, EB Simplex (EBS), Junctional EB (JEB) and Dystrophic EB (DEB) (Fine et al 2008). Each subtype is classified according to which protein gene is affected, and at which layer of the skin the blisters form, as shown in figure 1. For example, EBS results from blisters occurring at the basal layer of the epidermis of the
skin as a result of mutation to keratins 5 and 14 (Fine 2010). Studies suggest that there are no discriminating or external factors, such as gender, race, or geographical location, which increases the risk of inheriting this disease (Sarkar et al 2011).

![Diagram of skin layers](image.png)

**Figure 1:** Primary sites of blister formation for EB subtypes (DEBRA of America 2012)

There is no known cure for EB. Therefore, medical treatment is concerned with management of the condition and producing information on best practices. Best practices focus is on avoidance of factors that provoke blistering, wound care and promoting general health (Fine 2010, Sarkar et al 2010, Denyer 2009 and Ramirez et al 2013). Skin checking and wound care and dressing is essential in the management of EB in order to promote skin healing, prevent further skin damage and secondary infections and reduce pain (Ramirez et al 2013, Dietz 2004 and Fine et al 2004). The role of Occupational Therapy (OT) in EB management is not well documented. However, a book describing OT interventions has been recently published, which concentrates on OT treatments in the areas of motor development and hand functions (Weib and Prinz 2013).

EB treatment in Ireland is provided by two specialised clinics in Dublin (Watson 2010a). Considering the medicalised nature of EB, services are mainly hospital based and include quarterly multidisciplinary outpatient clinics, with a dedicated EB patient treatment room (Watson 2010b). The HSE provides information on EB and direction to the current services and treatments available on their website (Health Service Executive 2013). However, there is currently no official specific service policy available from the Health Service Executive (HSE) or the Department of Health on EB. Ireland is currently involved in a three year project to develop a National Strategy for Rare Diseases by 2013 (Europlan 2013 and the Department of Health 2013). This strategy aims to establish a national clinical programme for rare diseases.
Comparing the EB services available in Ireland to other countries, there are several differences in approaches (eb Haus Austria 2013, Castiglia and Zambruno 2010 and Brunckner-Tuderman 2010). In Italy and Germany, there are regional rare disease centres which are tasked with diagnosing EB (Castiglia and Zambruno 2010 and Brunckner-Tuderman 2010). In addition, these centres also manage training of health professionals, patient records and raising of awareness. The Australian government recently launched a pilot programme to provide families of individuals suffering from EB with free wound dressings (DEBRA Australia 2013). In comparison, EB is not currently considered a long term illness in Ireland. A decision in this regard is on hold until the implementation of the rare disease strategy. The result is that individuals are not automatically entitled to a medical card (Citizens Information 2013). This means that they have to fund the cost of dressings themselves, which can be as much as €1,000 per month (DEBRA Ireland 2013).

As well as the financial burden, EB has significant impact on quality of life for individuals living with the condition, even for the mild to moderate forms (Denyer 2009, Horn and Tidman 2002, Frew et al 2009, Tabolli et al 2009 and Frew and Murrell 2010). Quality of life, according to the World Health Organisation, is a holistic view of health which reflects the physical, psychological and social aspect of living with a disease (Commission on Practice 2008). A commonality between EB studies is a recommendation for more research into the psychological and psychosocial impact of EB, in order to achieve a better picture of the total impact on quality of life (Frew and Murrell 2010 and Horn and Tidman 2002). For example, the constant daily requirement of wound checking, dressing, and the pain that this causes in itself is a great burden on the whole family (DEBRA Ireland 2013). This burden on family members and caregivers can result in negative psychosocial and psychological implications for them, with a high frequency of divorce rates and depression reported among families with members living with EB (Margari et al 2010 and Dures et al 2011).

It is clear from this literature review that EB impacts on quality of life. It has been recommended that services that concentrate on psychological and psychosocial elements, for example social skills and counselling, would benefit individuals and family members (Dures 2011). However, the current services available in Ireland are primarily focused on the physical aspect of quality of life. There is a gap in the literature about how this impacts on the occupational experiences of individuals living with EB. This study aims to bridge this gap in knowledge by gaining a perspective on the occupational experiences of individuals living with EB, and their view on current services and supports available.
Methods
Research Paradigm and Ethical considerations

This research is conducted within a participatory paradigm. A participatory paradigm values shared experiential knowledge on the research subject (Guba and Lincoln 2000 and Heron and Reason 1997). This approach is suitable for this study as the aim of the overall project is to develop a proposed support strategy taking into account the views from all the key stakeholders.

Before this research began, ethical approval was granted by the University of Limerick. Throughout the project, two main ethical considerations informed the way in which the research was conducted. The first was managing ethically important situations, which are dynamic situations that arise during interviews which can have substantial ethical consequences to a project (Guillemin and Gilliam 2004). A particular concern for the author in this regard was managing the impact on participants surrounding the disclosure of sensitive or distressing information. Therefore, participants were provided with time to consider the meaning of participating in this project. As a result, one individual declined to be interviewed. In addition, at the beginning of each interview, participants were reminded that this project was voluntary, and that they could decline to answer or withdraw their consent at any time.

Secondly, maintaining participants’ privacy was important as the population of individuals living with EB in Ireland is small. Therefore, in the details of participants’ demographics shown in table 1, identifying information such as location and age are not revealed. In addition, careful consideration was given to the inclusion of participant quotes to ensure that they did not include any discernible identifying factors.

Table 1: Details of the seven participants

<table>
<thead>
<tr>
<th>Participant</th>
<th>Type of EB</th>
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<tbody>
<tr>
<td>Family Member</td>
<td>EB Simplex</td>
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<tr>
<td>Family Member</td>
<td>Recessive Dystrophic EB</td>
</tr>
<tr>
<td>Family Member</td>
<td>Dominant Dystrophic EB</td>
</tr>
<tr>
<td>Individual with EB</td>
<td>EB Simplex (Subtype: Dowling Meara)</td>
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<tr>
<td>Individual with EB</td>
<td>EB Simplex</td>
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<tr>
<td>Individual with EB and Family Member</td>
<td>EB Simplex</td>
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<tr>
<td>Individual with EB and Family Member</td>
<td>EB Simplex</td>
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Data Collection and Analysis

A convenience sample of eleven participants was recruited from the Debra Ireland database to participate in in-depth interviews (Creswell 2007). The eleven participants were invited by post using an information letter. Eight participants initially agreed to be interviewed, however, one later declined. Table 1 outlines the seven participants.

Data was gathered using a semi-structured interview guide, as shown in table 2 (Gowran 2012). This is an appropriate method of data collection as it allows information to be gained on different individual’s perspectives of the same situation, which is in line with the participatory paradigm of this study (Britten 1995, Eysenbach and Wyatt 2002 and Conneeley 2002). The interviews were conducted at locations convenient to the participants, which included participants’ homes, cafes and, in one case, a participant’s workplace.

Each interview took the form of a conversation, structured around the semi-structured interview guidelines. These were on a one-to-one basis, except for one interview, which included the participant’s partner and parent. Interviews varied in length from 30 minutes to over one hour in duration. Each interview commenced by the researcher explaining the overall project, the participant’s potential contribution, and signing of a consent form. All participants were invited, although only one subscribed, to attend a workshop to clarify information provided.

All interviews were taped, and subsequently transcribed verbatim by the author. Detailed checking of the transcripts against the tapes ensured familiarity with the data. It also enabled the author to provide the participants with a detailed one page summary in order to perform member checking (Creswell 2007). This one page summary was designed to include a summary of the main discussion points, and included stories that highlighted the evolving narrative. Participants were requested to provide feedback in relation to accuracy, and one participant responded with a factual correction.

The data was analysed using thematic analysis. This approach was chosen as it does not require in-depth experience, allows highlighting of similarities and differences across data, and can generate unanticipated insights (Braun and Clarke 2006). Themes were identified in a bottom-up fashion from the data. This is appropriate for this study as it is not based on validating a pre-existing theory. All analysis was performed using the qualitative software package NVivo9 (Salmon 2012).
Table 2: Semi-Structured Interview Guidelines (Gowran 2012)

<table>
<thead>
<tr>
<th>Questions</th>
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<tr>
<td>Describe your typical day?</td>
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<td>What activities do you attend/ do you engage in?</td>
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<tr>
<td>- Tell me about the today.</td>
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<tr>
<td>- What do you think about it?</td>
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<tr>
<td>- How do you feel about it?</td>
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<tr>
<td>- Tell me about what you like and dislike about being involved in support services for</td>
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<tr>
<td>people with EB</td>
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<tr>
<td>Tell me about why you got involved in (EB) services?</td>
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<tr>
<td>What interests you most about your involvement?</td>
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<tr>
<td>Describe an experience that motivates you about what you are doing?</td>
</tr>
<tr>
<td>Describe an experience that frustrates you about what you are doing?</td>
</tr>
<tr>
<td>What changes, if any would you like to see in developing support service?</td>
</tr>
<tr>
<td>- Can you give me an example</td>
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**Reflective Practice**

Reflection is an active process throughout the whole research project and enables the examination of assumptions, expectations, and unconscious responses, in order to analyse the influences of these on research outcomes, and thus enhance the trustworthiness of the research (Finlay 1998 and Guillemin and Gilliam 2004, Creswell 2007). Reflection was an important part of this research given the limited experience of the researcher and the emotional aspects of the research.

To perform reflection, reflective journaling and field notes after participant contact were maintained. These recorded the interviewer’s expectations and emotional responses to the narrative. These were referenced during analysis, and also continually updated to evaluate and reflect on the research process. For example, there was an expectation from the initial research performed that EB was going to be the most prominent difficulty the participants
encountered daily. However, when reflecting during data analysis, the author realised that EB was not the only story that these participants had to offer. The participants divulged often difficult and traumatic stories, which invoked strong emotional reactions from the author. For example, participants revealed details of death and grief, along with feelings of being scared and frightened. These stories forced the author to confront emotions of anger, outrage, unfairness and sadness, which were often mirrored from the participants. During the process of assimilating the results, the author was deeply influenced by these unconscious feelings and initially interpreted participant’s statements to reflect a mistrust of the health services and health professions. However, using reflection, the author was able to reveal the real source of these feelings which lead to one of the themes surrounding an increased need for EB awareness. These findings are now discussed in more detail.

Findings
Three key themes emerged during the analysis of the participant interviews. The first, ‘Occupational Experience’ describes the impact of living with EB on participants’ occupations. All areas of occupations were impacted upon. However, participants describe engaging in compensating strategies in order to maintain participation in occupations. The second, ‘A need for Increased Awareness’ describes the recognition that all participants have in regard to increasing EB awareness. The final theme, ‘Primary Need Provision’ describes the participants fear and anxiety regarding inconsistent service delivery and around a primary need for this population. These themes, along with illustrative quotes are now presented.

Theme 1: Occupational Experience
The occupational experience of individuals was influenced by many factors. At a broad level, all participants discussed the impact of EB on occupations in relation to hands and feet. For those with a diagnosis of EB, these two areas were affected most, as blistering was most common in these areas. Participants also described a difficulty with finding suitable footwear. Another commonality for the participants was the impact of pain and skin management. Pain was mentioned in relation to bursting blisters and its impact on occupations such as sleep. For the participants, bursting blisters simply became part of their daily routine, being one of their main self-care occupations. This was a factor for both participants living with EB, and those caring for them:

….you just sit her [daughter] on your knee if you see one [a blister] and you know, you just burst it. She screams and that’s annoying. It doesn’t take you long but you have to do it all day…
Five participants recognised that their skin has changed and toughened over time, which led to a changed impact on their occupational experiences. For example, a daily part of one participant’s life is checking her skin and dressing wounds every day. However, she has recognised that the skin on some parts of body has changed over time resulting in an impact on her daily life:

*Years ago my skin wouldn’t have been as tough. I would have had everything inside out and every little seam cut off. I am getting away with it better now as long as I have 100 % cotton this part … I am fit to wear anything then over it.*

Some participants discussed gaining an individual perspective on the effect of EB and certain occupations on their own skin, and using this perspective to develop compensating strategies. In general, these strategies were indicative of a belief from participants that EB was not “going to hold them back” and “it was not a disability”. For example, one participant recognised that heat was good for his skin, and therefore described going on two foreign holidays a year. On the other hand, another participant, a parent, described how she recognised that her daughter’s skin responded better during colder weather, and described limiting outdoor leisure activities during the summer months. The compensating strategies are also present in day to day leisure occupations. One participant, an avid golfer, described switching golf shoes half way through a round of golf in order to relieve pressure on his feet.

**Theme 2: A Need for Increased Awareness**

During the analysis of the results, each participant acknowledged that there was a need for an increased awareness of EB. For participants living outside of Dublin, where the specialist EB services are located, the need for awareness is in terms of more knowledge in general hospitals around early diagnosis and treatment. For example, one participant was told that her daughter had eczema. It was not until a very bad infection occurred that it was discovered she had EB. Another participant, who lives in Northern Ireland, experienced difficulty accessing the EB services as it required the NHS to provide funding:

*The dermatologist - she wasn’t any help. I had to go over [to her] and say you better send them [medical files] down now [EB clinic in Dublin]…. because why are you making me come over here when I can go to Dublin and see the experts.*

A parent of a deceased child described his experiences of navigating EB services. For him, knowing the disease and experiencing first-hand the impact of lack of knowledge of EB in the hospital system, motivated him to get involved with EB support services so that
awareness of EB can be increased. This view is also echoed by a young woman and college student living with EB. They have lived with EB for many years and have had to navigate hospital systems with no awareness of EB:

...[name of child] was a couple of months old when he required a blood transfusion. We were told by the consultant that under no circumstance should adhesive tape be applied. We researched alternatives and found a sticky dressing that was being used in England for blood transfusion. When I arrived into the hospital, my wife asked me to chat to the phlebotomist as she was insisting on applying tape. I tried to explain about EB and that the sticky dressing that we researched could be used instead. However, she point blanked refused to listen to me and applied tape, causing damage to his skin.....

Contrast this with two of the participants with children with EB, living in Dublin and who also have a diagnosis of EB themselves. Both of these participants described growing up and successfully managing EB. Due to these participants having a prior knowledge of managing EB, they were able to help their children manage the disease, and knew which services and support services to contact. However, they still describe a need for knowledge awareness in terms of wanting to explain to their children the cause of the disease, and also to be aware of any new treatment development that would benefit their children.

Theme 3: Primary Need Provision

“Bandage” is a word that was repeated by all participants. EB requires expensive skin friendly materials which, depending on an individual need, could cost a family in excess of €1,000 a month (DEBRA Ireland 2013). Due to the expense of the bandages, the overarching sentiment associated with them was fear and anxiety. It was a subtle and never named emotion, and when participants discussed bandages, it was in terms of service delivery and access. Four of the participants described situations where they had to navigate the HSE medical card process to access bandages. The process of getting a medical card was described as a “battle”, and the procedure for applying as “over complicated”. One participant described situations where the medical card did not cover access to all bandages, and at times had to apply for a supplementary hardship grant. The participant also described situations where he would stock pile bandages in case of bandages becoming unavailable.

When discussing access to bandages with another participant, her situation was highlighted as one of increased anxiety. She had been trying to access bandages for several weeks
and, since her current stock of bandages was running low and her child was starting school in the next week, the situation was becoming urgent:

…[name of child] is back to school on Thursday so I’ll be panicking now from Monday onwards if I don’t have them [bandages]…

This feeling of anxiety was also echoed by two other participants, both of who were in the process of navigating the medical card process. One of the participants bandage needs were being satisfied by going directly to the EB clinic whereas the other participant was personally funding any needs that arise.

In contrast, two participants from Northern Ireland currently have access to materials from local pharmacies, with all costs funded by the NHS. However, one of these participants described a situation where she had “to fight” with the NHS to obtain funding access to very expensive bandages, and the other described a possible future situation that may see access to bandages in the North curtailed. In response to this she had already contacted Debra Ireland and has arranged for bandages to be shipped directly from England.

In addition, it is interesting to consider that some participants described this situation as impacting on their occupational experience. This included having to take time out of their day to directly access bandages from the EB clinic, due to not having a medical card and the bandaging being too expensive to purchase in a pharmacy.

**Limitations**

The study has some limitations. It had a particular focus and purpose, which undoubtedly led to the neglect of some aspects of living with EB, such as the psychological implications of living with a rare disease. As already acknowledged, this research is being completed by a student. As such, there was a time limit attached to the completion of this work. Therefore, saturation of ideas during the coding period may not have been achieved (Creswell 2007).

The study is further limited by the inclusion of only one participant who had a past experience of living with a severe form of the EB. However, other studies in the area tended to concentrate on the impact of living with severe forms of EB (Van Scheppingen et al 2008). Therefore, the inclusion of five participants out seven living with EB simplex raises several areas of discussion that are not heavily focused on in the literature. Finally, it should also be noted that the sample is biased by self-selection (Creswell 2007). Participants were first approached and allocated to take part in this study by Debra Ireland.
Discussion

The presented study suggests that living with EB results in an impact to occupations regardless of severity. This finding is broadly consistent with existing literature that describes living with EB, the impact on daily occupations and overall quality of life (Tabolli et al 2009, Frew et al 2009, Horn et al 2002, Margari et al 2010, Dietz 2004, Denyer 2009, Fine et al 2004 and Dures et al 2011). This study also highlighted an interesting point in that there was sense from some participants that EB was not a disability. Considering that the majority of participants in this study were diagnosed with EB simplex, participants were able to maintain occupations. However, most participants described doing so by adopting certain strategies. This result is also reflected in a qualitative study of the psychosocial impact of living with EB (Dures et al 2011). Several of their occupation based findings are congruent with this study’s findings, such as the use of compensating strategies to manage occupations and managing EB based on personal experiences.

The study also suggests that individuals living with EB struggle to manage a disease when services have poor awareness of EB outside of the specialised clinics. This lack of awareness and the challenge of diagnosis have been previously studied. Denyer (2009) described the aftermath of infants born with EB in the UK as “a shock for staff and parents”. The article reports that, since the disease is so rare, staff are often not equipped to deal with a baby born with EB. The lack of confidence in hospital staff highlighted by Denyer (2009), leading to parents becoming more stressed and angry, is also reflected in this study.

Another finding highlighted is that navigating a health service with poor knowledge can also lead to traumatic consequences for the individual living with EB. This was demonstrated when participants described not being listened to by health professionals, even though they themselves had a high level of knowledge on EB, resulting in unnecessary skin damage. This finding is consistent with previous studies that recommend that, due to the dynamic nature of chronic illness, services should cater to the subjective experience of the individual living with the disease (Paterson 2001 and Dures et al 2011).

Inconsistent service delivery around provision of bandages for participants results in an unnecessary psychological impact of increased fear and anxiety. Participants experienced fear of increased financial burden due to the complicated medical card procedure, and anxiety over being unable or restricted in participation in occupation due to a shortage or lack of bandages. This finding is echoed in previous studies that suggest a lack of understanding of EB leads to inefficient health care and support services, where poor allocation of funding and resources compound the burden on individual with EB and their
family members (Tabolli et al 2010, Tabolli et al 2009, Moss 2008, Dures et al 2011, Fines et al 2005). One point of difference from previous studies is that participants named accessing bandages, which is fundamental for survival, as a difficulty, whereas the other studies concentrated on the general financial burden of caring for an individual with severe form of EB.

Implications for practice
One clear implication for day to day OT practice is the understanding of how occupation engagement is sustained by individuals living with EB. In order to reach occupational potential, occupational engagement requires compensatory strategies. Therefore, when OTs are working with this population, there should be an expectation that compensatory strategies may be required.

A more significant implication for occupational therapy practice is revealed when the broader scope of the unmet primary need of bandages is examined. According to Maslow’s hierarchy of needs, primary needs are psychological needs that are required for human survival (Huitt 2007). This study has shown that the inconsistent provision of services around primary needs has a significant impact for individuals living with EB. They attempt to deal with this issue by raising awareness. However, there are issues which are difficult for them to exert influence over, such as institutional practices that are currently being driven by economic conditions. The lack of clear guidelines from national bodies on service provision around primary needs in Ireland compounds this problem.

Solving this is as much a political issue as it is a medical one, as it requires changes to local and national health care strategies. National legislation has been identified as one of the barriers to an individual’s right to occupation, known as occupational justice, by the World Federation of Occupational Therapists (WFOT and Townsend and Whiteford 2005, p.112). In this regard, Kronenberg and Pollard (2005) propose that all health professionals should present themselves as advocacies for their clients to combat social and occupational injustices (Kronenberg and Pollard 2005).

The question then arises, how can OTs become more political engaged to ensure that occupational injustice does not occur? Answering this is outside the scope of this paper, and is indeed one of the main aims of the overall research project. However, this section will conclude by considering a broad framework that exists for occupational therapists to become politically engaged, known as the Political Practice of Occupational Therapy (PPOT) (Pollard et al 2009).
The PPOT is a framework that allows occupational therapist to systematically learn how to become politically involved. Three practice competencies for political engagement are proposed. Firstly, OTs need to be able to identify the key stakeholders, their motives and positions. Secondly, OTs need to develop analytical and reflective skills to explore their personal, professional and political motivations. Finally, using the information gleaned from the previous two steps, OTs need to be able to collaborate with key stakeholders in order to negotiate a desired outcome (Kronenberg and Pollard 2005, Kronenberg and Pollard 2006, Pollard et al 2009 and Sakellariou and Pollard 2012).

As a practical example of this, PPOT provides the “3P Archaeology” as a tool to develop analytical and reflective skills. This tool, highlighted in figure 2, encourages the exploration of past situations to better inform and develop political reasoning. As per figure 2, understanding and connecting with personally important values and how this relates to the OT profession, allows for the identification of the core values of the stakeholders in a given situation. The political dimension is then concerned with identifying which of these values each stakeholder is willing to fight for, or relinquish, in order to negotiate a desired outcome. To gain this understanding allows OTs as a profession to develop their practice by strategically forging collaborations with stakeholders in local and global communities who can benefit from occupational therapy.

**Figure 2:** The “3P Archaeology” tool (Pollard et al 2009)
Conclusions
The purpose of this study was to examine how existing EB services in Ireland impact on the occupational experiences of individuals living with EB. This is important as the current services provided are primarily concentrated on one aspect of living with this disease, mainly the physical aspects of managing and treating the condition.

The stories shared by seven participants through in-depth interviews reveal interesting insights. The overarching finding is that there is a significant impact for individuals living with EB on occupational engagement. Occupational experiences across all areas of occupations were impacted upon. Individuals then developed compensating strategies in order to engage in occupations.

In addition, the study found that a lack of awareness about EB leads to inconsistent service delivery around bandages for these participants. Bandages are an example of a primary need for individuals living with EB. For this population, bandages are considered a second skin, as without them there is increased chance of blisters, pain and secondary infection (Ramirez et al 2013). This unmet primary need impacts on an individual's right to occupation. Removing barriers that impact on an individual’s right to occupation is an avenue for all health professionals to consider, and requires political involvement. This study concluded with describing one mechanism that health professionals can utilise to learn how to become politically engaged, known as the Political Practice of Occupational Therapy (PPOT) framework (ref). An example demonstrating this framework in practice was provided using the ‘3P Archaeology’.

As discussed in the introduction, this study is a component of phase one of a larger research project. Phase two will focus on using the information gained in phase one to develop a support service strategy for EB. This will be done by facilitating a series of workshops featuring the key stakeholders including the participants from this study, policy makers and support staff. This study has highlighted that dealing with different stakeholders is as much a political issue as a medical one. Therefore, careful consideration will need to be given to the potentially conflicting perspectives from the different stakeholders, and the tools for becoming politically involved, such as those highlighted in this paper, will also need to be considered. This is the focus of future work.
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