MSc Occupational Therapy

OT 6054

Occupational Therapy Project 4

Dr. Judi Pettigrew

11005246

2nd Year

Words 5146

23rd April 2013
**Title:** Examining the Occupational Perspectives of hospital-based support services for people with Epidermolysis Bullosa (EB) in Ireland.

**Background:** EB is a very rare genetic disorder characterized by blistering of the skin. In Ireland EB affects approximately 1 in 20,000 newborn children. Undoubtedly a condition such as EB has diverse effects on both patients and their carers. However currently there is little evidence of the effects EB can have on professionals working with the condition.

**Objectives:** This research endeavoured to explore the occupational perspectives of hospital-based professionals working with people with EB and identifies their view on current services available and highlights areas for possible change.

**Methods:** This study is one section of an innovative participatory action research study to explore evidence based on qualitative research in partnership with Debra Ireland from key stakeholder perspectives of support services. Nine individuals were recruited from hospital-based services to take part in semi-structured interviews.

**Results:** Thematic analysis highlighted that participants experienced both positive and negative aspects of working in hospital-based services for people living with EB. They experienced financial, bureaucratic and emotional challenges and each highlighted specific areas in need of change in order for the service to develop.

**Conclusion:** This paper presents an insight of professionals’ experiences of working with this rare condition and highlights areas identified in need of change. Participants acknowledged their passion for working in the area but discussed the feeling of powerlessness and lacking a voice when it came to the need for changes in service provision.
What are the occupational perspectives of hospital based support services for people living with Epidermolysis Bullosa (EB) in Ireland.

Introduction

Epidermolysis Bullosa, also known as EB, is a very rare genetic disorder characterized by blistering of the skin. (Irish Health 2012; Pagliarello and Tabolli 2010) The skin is extremely fragile and because of this fragility the skin can become injured easily from gentle friction, rubbing or knocking. This injury takes the form of large painful blisters which if become infected can cause numerous problems. (Foster and Holmes 2007) Currently there is no cure for EB.

In Ireland Epidermolysis Bullosa (EB) affects one in approximately 20,000 newborn children, making it a very rare condition. (Irish Health 2012) A condition such as EB has diverse effects on both patients and their carers. However there is little evidence of the effects EB can have on professionals working with people who live with the condition. This research endeavored to explore the occupational perspectives of hospital based professionals working with people who are living with EB and identify their view on current services available and highlight areas for possible change. An Occupational Perspective can simple be defined as “a way of looking at or thinking about human doing.” (Njelesani et al 2012) In this study an occupational perspective referred to the views participants had in relation to their work with EB patients and any specific feelings they had regarding this work.

Literature Review

Debra Ireland, who assisted with this research, is the national charity for EB and is celebrating its 25th year of establishment this year. Parents of children born with EB in a bid to provide patient support services and to raise funds to support research founded Debra Ireland. The mission statement of Debra Ireland is a very specific and powerful one. “DEBRA Ireland’s mission is to fund the development of treatments and cures for all forms of Epidermolysis Bullosa, and meanwhile to do all in its power to alleviate the suffering caused by EB.” (Debra Ireland 2012.)

Over thirty different subtypes of EB have been identified and generally can be divided into four categories. EB Simplex (EBS), Junctional EB (JEB) Dystrophic EB (DEB) and Kindler EB. (Frew et al 2009; Pagliarello and Tabolli 2010) Children, adolescents and adults of all ages regardless of the severity of their EB will face many
different and difficult challenges. A common issue that faces people living with EB is others lack of knowledge. Williams et al (2011, p701) highlighted how adolescents living with EB identified themselves as being different to their peers due to “a lack of understanding of others about the condition.” Similarly van Scheppingen et al (2008, p553) noted how this lack of understanding of the condition also affected and “tormented” parents. The authors made it clear that this lack of understanding and knowledge of the condition was not just evident among the greater public but was very much apparent among health professionals and care providers.

Care of people living with EB in Ireland is provided by a national service that is based on the model of care for children and adults with EB in the UK. The service for children living with EB is based at Our Lady’s Children’s Hospital Crumlin and has been in existence since 1996, while the adult service is based at St James’ Hospital and was established in 2002. Debra Ireland played a significant role in the development of these services. Children and adult services are available to people living in both the north and south of Ireland, while “patients in Northern Ireland have free access to all supplies including dressings, medications and topical products via the UK National Health System.” (Watson 2012) Currently in the Republic of Ireland all patients living with Recessive DEB have free access to wound care materials and prescriptive and non-prescriptive drugs. Patients living with other forms of EB are entitled to apply for a medical card however this is means tested and will only cover the costs of prescriptive drugs and a limited number of wound care materials. In comparison, in the 2009/2010 Australian budgets, the government began the development of The National EB Dressing Scheme. This scheme was developed, as a means of supporting people living with EB by delivering required specialist dressings on a monthly basis to the patients home. The scheme is eligible to people with all subtypes of Simplex, Junctional, Dystrophic and Kindler EB. (BrightSky Australia 2012)

Currently the Health Service Executive (HSE, 2012) describe a multi-disciplinary team for someone living with EB in Ireland being comprised of the following: dermatologist, dentist, dietician, geneticist, paediatrician, podiatrist, cardiologist, ophthalmologist, psychologist, social worker, plastic surgeon, pharmacist, physiotherapist, play specialist and specialist nurse. In contrast to this extensive list St James’ Hospital Dublin (2012) describe their MDT for patients living with EB of being comprised of: Three consultant dermatologists, liaison nurse, clinical nutritionist, occupational therapist, physiotherapist, psychologist, and social worker.
These two lists highlight the current standard of care that is available for patients of EB in Ireland, and the standard of care that should be made available. The HSE list comes directly from the provision of care available from the National Health Service (NHS 2012) in England, for EB patients. Although the NHS provides a comprehensive list of hospital-based services, the EB Haus Austria demonstrates a center of excellence of which to base future services on. The EB Haus Austria forms part of the Department of Dermatology of the Paracelsus Medical University, Salzburg. According to the “Final report on European Countries of Expertise (ECZ) from RDTF Expert Group”, the EB Haus Austria meets all required criteria. It is an interdisciplinary clinical unit for diagnosis, medical care, academic affairs and research related to EB. (Pohla-Gubo 2010). The EB Haus Austria treats patients both nationally and internationally and offers a range of procedures and therapies to promote optimal health for the EB patient. (EB Haus Austria 2013)

There has been research conducted and evidence provided that highlight the adverse effects that can be experienced by professionals who encounter people with pain and suffering at work. (Valent 2002) It can also be noted that these experiences not only affect the health professionals themselves but can also affect the quality of patient care that they provide. (Sorensen and Iedema 2009) A recent study focused on the impact of working with people living with EB for health and social care professionals identified three themes. These were the intensity and amount of involvement with patients; how they had to manage on limited resources; and the need they felt to look after themselves. (Dures et al 2010) This research endeavors to explore the current experiences had by health professionals working with people living with EB in the Republic of Ireland.

**Methods**

This study was conducted using a qualitative approach and a critical theory paradigm. Critical theory aims to positively transform social and political issues within society. (Kielhofner 2006) In order to explore existing phenomena critical theory suggests that the researcher conducts an ideology critique and action research as research methods. (Dash 2005) This study was a section of a larger study that wishes to inform the development of a proposed strategy towards change. The study was conducted in partnership with Debra Ireland and the University of Limerick. The overall study seeks to develop a proposed strategy for support services for people with EB in Ireland. The purpose of the overall study is to review the support services available to
people with EB in the broadest sense by inviting key stakeholders to participate in individual interviews and a series of workshops. Stakeholder groupings included:

<table>
<thead>
<tr>
<th>Group 1</th>
<th>Individuals (age &gt;18) with EB or their representatives (parent/guardian)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group 2</td>
<td>Hospital Based Support Services</td>
</tr>
<tr>
<td>Group 3</td>
<td>Community Based Support Services</td>
</tr>
<tr>
<td>Group 4</td>
<td>Policy Development and Administration</td>
</tr>
</tbody>
</table>

Table 1. Stakeholder Groupings

In addition to enhance the qualitative data, a national survey was carried out to explore health and social care services available in Ireland for individuals and their families living with EB.

This study employed semi-structured interviews as a means of investigating and understanding the experiences encountered by health professionals working with EB. (Appendix A) The semi-structured interview schedule was developed by Gowran (2012) and was derived from influences of Kronenburg et al (2005) political reasoning tool and Capra (2003) reflective consciousness. Therefore the interviews considered stakeholders experiences of participation in support services for people living with EB, indicating 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. Questions were open ended which enabled the participants to take the lead while also ensuring the interviewer remained somewhat in control of the process. (Dean et al 2006) By their nature interviews are quite interactive and the interviewer needed to employ a range of skills to ensure success; building rapport, active listening and determining when it was appropriate to probe. (Lysack et al 2006)

Convenience sampling identified the participants who took part in this study. Convenience sampling has been described as a less rigorous technique when identifying participants. It involves selecting the most accessible participants relevant to a study. (Marshall 1996) As the sample group were professionals working in hospital services for people with EB it was difficult to identify them independently. Debra Ireland assisted with identifying possible stakeholders within the specialist service and making the relevant connections. Once in contact with the key stakeholder a generic email was sent requesting the participation of the relevant professionals. A cohort of nine participants were identified and recruited. Table 2. It is not clear how many professionals received the email but chose not to participate.
The criterion for participants’ inclusion in the study was simply that they were a health professional working with EB patients in a hospital-based service.

<table>
<thead>
<tr>
<th>Title</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Occupational Therapist</td>
<td>2</td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>2</td>
</tr>
<tr>
<td>Specialist Nurse</td>
<td>2</td>
</tr>
<tr>
<td>Consultant Dermatologist</td>
<td>1</td>
</tr>
<tr>
<td>Dietician</td>
<td>1</td>
</tr>
<tr>
<td>Secretary</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 2. Participants

Each participant was emailed and offered a hard copy of an information leaflet and a consent form. (Appendices B & C) The interviewer retained a signed consent form from each participant. All participants were made fully aware of the aim of the research as well as any known limitations it may pose. Participants were also made aware that anonymity would be upheld to the best of abilities but, due to the small community of EB patients and professionals working in the area, it was made clear that it could not be guaranteed. With this in mind all participants were made aware of their ability to cease the interview at any time they felt necessary.

Interviews took place at the convenience of the participants with help and support from Debra Ireland. The interviews lasted between 10 and 40 minutes and were audiotape recorded and later transcribed verbatim. As discussed previously anonymity was maintained to the best of abilities by omitting, where possible, any identifiable features.

The study used thematic analysis to identify, investigate and report on different themes that emerged from the data obtained during the interviews. Boyatzis (1998) described thematic analysis as a process of “encoding qualitative information.” (p. vii) This involved developing codes and themes from the data collected. This was done through six different stages and was guided by Braun and Clarke’s (2006) six phases of thematic analysis. Table 3.

<table>
<thead>
<tr>
<th>Phase</th>
<th>Description of the process</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Familiarising self with data</td>
<td>Interviews were transcribed verbatim &amp; initial ideas were noted</td>
</tr>
<tr>
<td>2. Generating initial codes</td>
<td>Transcripts were manually coded identifying interesting &amp; relevant features</td>
</tr>
<tr>
<td>3. Searching for themes</td>
<td>Codes were grouped &amp; connected to identify potential themes</td>
</tr>
<tr>
<td>4. Reviewing themes</td>
<td>Ensuring the codes &amp; themes share an appropriate relationship to address the hypothesis of the research</td>
</tr>
<tr>
<td>5. Defining &amp; naming</td>
<td>Identifying definitions to guide each theme &amp; naming</td>
</tr>
</tbody>
</table>
producing the report

Relating each theme identified back to the literature, theory and practice.

Table 3. Six phases of thematic analysis.

**Ethical Considerations**

Given the small sample size ethical considerations were paramount and strictly adhered to. Ethical approval for this research was obtained from the Faculty of Education and Health Sciences Research Ethics committee, University of Limerick.

Rensik (2011) noted that it is the responsibility of the researcher to strive for honesty and avoid misrepresentations of findings. Steps were taken to ensure the trustworthiness of the data obtained. These steps included reflexivity and stakeholder checks. Reflexivity is the deliberate process of self-reflection allowing the researcher to reflect on all behaviours and thoughts experienced throughout the research process. Self-reflection will by no means eliminate bias but it will allow for it to be identified and addressed accordingly so as not influencing any emerging interpretations. (Kielhofner 2006; Watt 2007)

Stakeholder checks, also known as member checking, were also implemented. This is the process of returning all cleaned data to the original stakeholders for review. This allowed the researcher to check any assumptions or emerging themes with the original participants to ensure the information gathered was accurate and factual. (Kielhofner 2006, p353)

Given the nature of the community participating in this study it was decided to represent them as a team of people instead of specific individual professions. Although each profession was acknowledged in Table 2., they will not be represented individually to ensure anonymity.

**Findings**

From the results it became apparent that working in the area of EB highlighted many different issues for professionals. Some of these issues had commonalities with working with other conditions while some were specific to EB. The experiences had by professionals can be broken into three main themes and are outlined in Table 4. These three themes are shaped and connected by numerous sub-themes that best represent the experiences had by health professionals working in hospital based services for EB.
| **Time as a Tool**          | • Building relationships over time  

|                     | • Having enough time  

| **Challenges** | • Financial & Bureaucratic Structures  

|                     | • Emotional Challenges  

| **Room for Change** | • Inequality  

|                     | • Development of Community Services  

|                     | • Availability of Hospital Services  

Table 4. Break down of Findings.

**Time as a Tool**

The nature of EB being a lifelong condition ensures that, provided staff consistency, time can be seen as a therapeutic tool for relationships to be built. Building therapeutic rapport with their patients was seen as an essential part of the care that a hospital service would provide.

> From my point of view I suppose it’s the kind of the continuity of care that they have, somebody who is there for them from the very beginning and watches them grow and they know that they can trust me an I can trust them, it’s a relationship that’s been developed over a long period of time.

(Transcript H, 2012, p5)

Building therapeutic rapport with a client and/or family who will be in their care possibly throughout the clients lifespan brings with it it’s own set of risks.

> You’re looking after them for so long that you get to know them really well and while it’s still very much a professional relationship and that can be quite challenging to not overstep the line of personal versus professional relationship.

(Transcript D, 2012, p3)

Naturally when forging relationships, be they personal or professional, a bond will form. This was identified, as a negative aspect of working with EB patients as inevitably there will be a tragic outcome.

> Well the tragedy part of EB is that you see them through to when they die . . . the sad part of that is you’re managing them from babyhood until they grow up and then you have to see the slow deterioration.

(Transcript A, 2012, p2)

Although the nature of EB was discussed in terms of time as a therapeutic tool, time was also identified as a tool not being utilized appropriately to enhance the therapist client relationship. Similarly time was mentioned as directly influencing how priorities were made.

> So yeah we don’t get a lot of time with them to be honest.
I can’t always see those patients who have a milder form of the condition so I have to pole my time to the ones who are the more severe type.

In saying this it was also identified that developments had been made in the area of EB clinics, and this was a direct result of time allocation. As mentioned previously, it was felt that patients were not receiving the time they required, which is still the case in some areas of the service. To address this EB patients were moved from general dermatology clinics to specific EB clinics.

This person needs a lot more time than you can give them so that motivated me yes . . .
I just like having the time for them because we’ve got them out of general clinics.

Financial, Legislative & Emotional Challenges

When discussing the challenges experienced working in a service for EB, participants unknowingly discussed them under the headings of financial, bureaucratic and emotional challenges. As expected financial and bureaucratic challenges were discussed hand in hand and shared similar commonalities.

Financial, Bureaucratic & Emotional Challenges

Financial and bureaucratic challenges can be seen across all areas of health care delivery, however participants identified some aspects specific to EB. For example, a fall in client numbers due to adult deaths within the service resulted in the cutting of posts, opposed to the distribution of more time to fewer patients.

We used to have our nurse full time but because we’ve had some deaths in the adult service her time has been cut by 50% (Transcript A, 2012, p2)

Dealing with the HSE and funding were identified as barriers to delivering an equitable service and were difficult to overcome. Each participant made reference to the fact that this is “a constant fight for services” (Transcript A, 2012, p3), whether you are a service provider or a service user. From a service provider perspective one of the main frustrations is the act if dealing with the HSE.

Dealing with, preparing business plans and submitting business plans, that has frustrated me. Dealing with the HSE. (Transcript A, 2012, p4)
This frustration extended on to the fact that a service had approval for additional staff members but was unable to fill these posts due to legislation. It was seen by many as a basic need to provide a full cohort of staff in order to provide a favourable service.

Well I’d like to see all of our staff appointed that we have approval for and that hasn’t happened in the paediatric hospital because of the capping of posts.

(Transcript A, 2012, p4)

The limitation of staffing in an area that requires such expertise makes it difficult to provide a consistent comprehensive service. Currently there is no ‘back up plan’ or replacement expertise in the event that an EB staff member would no longer be available to work. This limitation was not only seen in hospital services but was also discussed by participants as being apparent in community services, largely due to the limitation in funding. Nationally the lack of knowledge in the area of EB poses a tremendous risk for clients in search of services outside of the centers of excellence.

Somebody who is dedicated to EB knows and realizes the necessity of the multidisciplinary team and that no one profession has all the answers so that we actually all have to integrate.

(Transcript H, 2012 p4)

Some limitations in community services however were identified as “therapists locally change a lot”, (Transcript D, 2012, p5) and therefore the patient misses out on the IDEA of continuity of care. Also patients when referred on to community services may not be seen to as promptly as needed.

We refer them on, they don’t always get seen as quickly as we like, they don’t always get seen as frequently as we’d like and a lot of that is just resource limitations locally.

(Transcript D, 2012, p5)

Funding was also identified as a contributing factor to the challenge of working in the area of EB and it was highlighted that “Financing for outreach is not where it should be at.” (Transcript D, 2012, p3)

Emotional Challenge

The emotional challenge was identified by all participants as the discrepancies and inequalities across the spectrum of EB, and dealing with the different emotions such a severe condition evoked in people personally.

The discrepancies and inequalities identified were generally in relation to medical card applications and obtaining bandages. These were described by one participant as “a post code lottery.” (Transcript I, 2012, p6) The idea that the distribution of services and materials was based on random selection evoked anger and frustration among participants and made evident just how broad the range of inequality was.
Some kids have medical cards some kids haven’t.  
(Transcript C, 2012, p3)

If they do get a medical card it doesn’t guarantee them the range of specialized dressings that they need because the availability of dressings on medical cards is very limited.  
(Transcript E, 2012, p2)

Debra Ireland, who were identified by all participants as being a major support in a bid to providing services to all EB patients, are currently trying to address the medical card issue with hospital based services.

We’re going through a process with Debra where we’re trying to get the medical card situation sorted out but . . . dealing with the HSE like it’s unreal, I mean I don’t need to say anymore.  
(Transcript C, 2012, p3)

In conjunction with dealing with the emotions of inequality within the same condition participants also identified having to deal with the emotions EB can evoke in a person as a practitioner and also as a human being.

Dislikes is just the severity the very severe patients, that it’s not always comfortable to watch or to attend and sometimes it’s just human nature really.  
(Transcript F, 2012, p2)

The positive aspect of this was that the reward of working with such a rare condition, unique set of people and an extremely supportive team out-weighed the emotional challenge.

It’s very challenging, no day is the same, everyday is different, but it’s very rewarding so I suppose I try to do my best for the families and to make things a little bit easier for them.  
(Transcript E, 2012, p2)

And again the team is there as a kind of peer support as well.  
(Transcript I, 2012, p4)

**Room for Change**

Each participant also identified different areas they felt there was room to improve and change from currently. These changes included medical card & bandages availability and inequality, community services, and hospital service availability.

**Medical card & bandages availability and inequality**

Participants felt that inequality was very evident across the spectrum of EB, and at times they felt at the core of this inequality. It was felt that there was a need to address the issue of inequality in EB and by doing this enhancing the recognition the condition currently holds.
They should be automatically entitled to it with an add on that they are entitled to X, Y and Z dressings.  
(Transcript E, 2012, p3)

Something more streamlined across the board, and that there’s better medical recognition of the condition.  
(Transcript I & H, 2012, p 3 & p3)

Community services

It was felt by participants that although they provided a very comprehensive service within the hospital setting clients could benefit from more support from the community.

They might benefit from more input from OT, physiotherapy in the community and maybe more input from community nursing, health care, public health care nurses and stuff.  
(Transcript E, 2012, p2)

I’m thinking more community based because obviously a hospital can only do so much.  
(Transcript G, 2012, p3)

Hospital service availability

Generally participants spoke highly of the services provided in the hospital settings however it was noted that some key specialist areas were not available. Participants felt that when a client did not have access too all needed services it had a knock on impact on all services provided.

Podiatry they could also do with, like what they do with the elderly population they get three visits to a podiatrist per year, EB the milder forms of EB they do have podiatry issues and there isn’t currently a service for that.  
(Transcript H, 2012, p4)

Discussion

This study focused on the current experiences being had by health care professionals working in hospital services for people living with EB. The results from the interviews showed that working with a life long condition such as EB evoked unique challenges for professionals. The three themes identified depict the current experiences had by professionals working in the Irish health care system and will be discussed in terms of their sub-themes.

Time as a Tool

All participants discussed time as a tool in the deliverance of services. It was discussed under two broad headings, ‘Building relationships over time’ and ‘having enough time’.
Care of the EB patient is a specialist service that can facilitate the growth of therapeutic relationships over time. Each participant acknowledged their emotions when working with a life-long condition, but they also highlighted the reward and privilege of working with a condition that allowed for the development of a therapeutic relationship. The development of a therapeutic relationship is not an intrinsic occurrence and requires great competence and consistency. (Moyle 2003) There are a number of factors and skills required by an individual to optimize the possibility of a therapeutic relationship being formed. Some of these include having understanding and empathy; being able to acknowledge the patient as an individual beyond their illness; provide support and being available for such; be authentic; promote equality; and demonstrate respect, boundaries and self-awareness. (Dziopa and Ahern 2009) As professionals the participants of the study felt emotionally equipped to build such therapeutic relationships but identified difficulties in relation to the structure of the service they were working in.

Western culture has a very economic view of time and a perception that time is a “commodity that should be invested wisely.” (Pierce 2003, p179) This translated directly to the participants’ experiences of working in a system where the therapeutic use of time was not valued as a vital component to patient outcomes. (Dziopa and Ahern 2009) The way in which services are delivered is a direct result of management of the system and highlights the lack of knowledge and understanding of policy makers.

**Financial, Bureaucratic & Emotional Challenges**

The lack of knowledge and understanding within the health care system has lead to financial and bureaucratic structures that effect both service providers and service users in a negative manner. These were discussed in terms of service deliverance in both hospital and community based facilities. When looking at service availability in a cultural context Ireland can be seen to be lacking when compared to countries such as Austria and Australia. This is a direct result of a lack of knowledge and understanding from the health service of the care required by EB patients. Balcazar (1999) spoke of a process involving a person transferring from ‘naïve awareness’ to ‘critical awareness’. Critical awareness encourages the transformation of individuals, societies and organisations and facilitates the exploration of problems and the implementation of new ideas. (Abelenda et al 2005) Participants spoke of the challenges associated with dealing with financial and bureaucratic structures and the need for flexibility in the deliverance of services. It must be highlighted that although
financial challenges were identified, these were generally accepted due to the current economic climate Ireland finds itself in. The biggest frustration and challenge lay in the structure of the healthcare system and the restrictions on staff to implement change to enhance service deliverance for patients.

When discussing service deliverance in hospital and community settings it was generally with regard to staffing. As discussed by one participant the systems lack of understanding in relation to the cutting of posts due to deaths in the service had an overall negative impact on the maintenance of therapeutic relationships and service deliverance in general. If the system had a true understanding of the needs associated with this condition the post would have remained and patients would have benefited from increased time allocation and interaction with this particular professional.

Emotional challenges were discussed in terms of the financial and bureaucratic structures that were in place but also in terms of the pathology of the condition. Emotional control was identified as being an important aspect of the participants’ occupational identity. (Bar-on et al 2000) Participants identified an emotional challenge when having to deal with discrepancies and inequalities across the spectrum of EB with regard to patient care. They also highlighted the emotional challenge of working with such a debilitating lifelong condition. Gardner (1983) and Steiner (1984) both suggested that in order to manage emotional reactions and use them as a guide to our behaviour we first need to be capable of identifying what it is we are feeling and what is the cause of such feelings. It is believed that ones feelings, thoughts and processes can impact on professional thoughts and reasoning (Reed and Nelson Sanderson 1999) which in this situation could have the potential to impact on the way a health professional could deliver a service.

Room for Change

Room for change was discussed under three headings Inequality; Development of Community Services; Availability of Hospital Services.

Inequality

Inequality in EB services in Ireland is very apparent with regard to medical card application and the availability of specialist bandages. As highlighted in the Australian context specialist bandages are delivered to a patient’s home monthly for a concession price through the National EB Dressing Scheme regardless of the subtype of EB. (BrightSky Australia 2012) Currently in Ireland support for EB services is
dependent on acquisition of a medical card, which is not an automatic process for EB patients and is based on means testing. (Debra Ireland 2012) As highlighted by participants this creates a social injustice among patients of the same condition and at times can leave the professional feeling trapped and responsible. As described by the Commission on Social Justice (AOTA 2008, p675) social justice is the “ethical distribution and sharing of resources, rights and responsibilities between people recognizing their equal status as citizens”. Although patients fall under the same umbrella term of EB currently in Ireland they are faced with inequalities and social injustice.

**Development of Community Services and Availability of Hospital Services**

These headings can be discussed in conjunction with each other as they relate to the same concept of developing and maintaining needed services for EB patients whether they are outreach or hospital based. A fundamental change identified is the availability and accessibility of the medical card and specialist bandages across the spectrum of EB, which was highlighted as being a primary need for any EB patient. As highlighted in the literature review currently the healthcare system in Ireland is promoting inequality across the spectrum of EB and is enhancing the challenges being experienced by professionals in the area.

**Methodological Limitations and Areas of Future Work**

Some limitations to this study included the small sample size of participants that did not represent a full multidisciplinary team of either adult or children services; and also the lack of previous evidence and knowledge regarding this topic.

To address the issues identified it is recommended that professionals working with EB be given an international forum for discussion regarding others experience of EB and service provision. As the larger study endeavours to, it is important to work towards a pathway for change in conjunction with Debra Ireland. In terms of future research there is room for the development a Participatory Action Research project to identify key issues and develop a strategy plan.

**Conclusion**

This study endeavoured to explore the occupational perspectives of hospital based professionals working with people with EB, identify their views on current services available and highlight areas for possible change. The study identified three main themes with numerous interlinking sub-themes. Themes were discussed under the
headings of *Time as a Tool; Challenges;* and *Room for Change.* The discussion highlighted the main outcomes identified from the findings. On a group level participants identified issues regarding their own health and well being when working with this condition. They strongly acknowledged their passion for working in such an area but discussed the feeling of powerlessness and lacking a voice when it came to the need for changes in service provision.
Bibliography


Kildare Education Centre (2010). Participatory Action Research Workshop. [online], available: www.ideaonline.ie/content/participatory-action-research-workshop.ie/content/participatory-action-research-workshop [accessed 14th April 2012].


Rare Diseases Task Force (2006) *Centres of Reference for Rare Disease in Europe: State-of-the-art in 2006 and recommendations of the Rare Diseases Task Force* [online], available: www.eucerd.eu/%3Fpost_type%3Ddocument%26p%3D1334+&hl=en&gl=ie&pid=b1&srcid=ADGEESguljz5BWL_5kwyE2SsKa9G8TKfwK24aUHI5Le7HwI7fPLJB1JHR-CASYTI9Glw5W19DWQcAJSg97KIVjEiqlWnJS7ZGXwEs9DfCwKeOjpK7yWYsIg47_4NrrN-VK7rl7ly4JxDHd&sig=AHIEtbR7seuXoz5imUO3D1tPiJ0pBGB1Ng [accessed 20 April 2013]


Reid, B. (1993) ‘But we’re doing it already! Exploring a response to the concept of reflective practice in order to improve its facilitation’, *Nursing Education Today*, 13, 305-309.


Appendix A

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
PARTICIPANT INFORMATION SHEET

Study Title
Examine the occupational perspectives of hospital based support services for people living with epidermolysis bullosa (EB).

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, it is important to be aware that questions may generate immediate or delayed emotional responses.
- 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

Rosie Gowran
Department of Occupational Therapy
Faculty of Education and Health Science
University of Limerick
e-mail: rosie.gowran@ul.ie
Appendix C.

CONSENT FORM

STUDY TITLE:

Examine the occupational perspectives of hospital based support services for people living with epidermolysis bullosa (EB).

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    Date
(Staff/Family/Friend)