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Title: Exploring the experiences and satisfaction with hospital and support services for people living with Epidermolysis Bullosa in Ireland.

Abstract:

Epidermolysis bullosa (EB) refers to a collection of rare inherited connective tissue diseases in which minimal contact with the skin can result in painful blisters and wounds. This survey is part of a larger research project between EB charity Debra Ireland and the University of Limerick titled: “Developing a Support Service Strategy for DEBRA Ireland through Participatory Action”.

Objectives: To explore the experiences and satisfaction with hospital and support services among people living with EB in Ireland. This survey enriches the qualitative aspect of the larger research project which aims to develop a strategy for support services for people with EB in Ireland.

Methods: A postal survey was used to gather the views of participants. 43 members of Debra Ireland were recruited and 20 surveys (46.5%) were returned. Data was analysed using SPSS and qualitative comments were analysed separately to enrich the numerical data.

Findings: The majority of participants were satisfied with the standard of hospital care but felt the direct provision of a medical card for those diagnosed with EB would alleviate the expense associated with acquiring essential provisions such as wound care.

Conclusion: Participants risk reduced health outcomes if provisions central to their survival are not provided within their financial means. Resultant poor occupational participation from unmet healthcare needs is an infringement of their human rights. Occupational Therapists are well placed to advocate that the unique needs of this population be reflected in future developments of the Irish health system.
Introduction

This survey is part of a larger participatory action research project between Debra Ireland and the University of Limerick, which hopes to develop a strategy for support services for people with Epidermolysis Bullosa (EB) in Ireland. The purpose of the overall study is to review the support services available to people with EB by inviting key stakeholders to partake by means of individual interviews and a series of workshops. The rationale for this survey is to enrich the qualitative aspect of an ongoing research collaboration between EB advocacy organisation Debra Ireland and The Occupational Therapy Department in the University of Limerick, titled: Developing a Support Service Strategy for DEBRA Ireland through Participatory Action.

Stakeholders included:

(a) Group 1 Individuals (age>18) with EB or their representatives (parent/guardian)
(b) Group 2 Hospital Based support services
(c) Group 3 Community Based Support Services
(d) Group 4 Policy Development and Administration

This research aims to explore the experiences and satisfaction with hospital and support services for people living with EB in Ireland. The following research objectives have guided the execution of this aim.

(1) To distribute a survey to participant members of DEBRA Ireland.

(2) To generate information concerning the service provision experiences of EB sufferers in the Republic of Ireland.

(3) To identify areas of potential future support service development for individuals with EB

LITERATURE REVIEW

A review of literature will describe life with Epidermolysis Bullosa (EB) for individuals and their families followed by an account of available health and social support services in the Republic of Ireland. Reference will be made to the international efforts to provide adequate health and social care services in the management of EB. Finally, recognition of EB from an occupational therapy and human rights perspective will justify the importance of conducting this survey at this moment in Irish history.
**Epidermolysis bullosa**

Epidermolysis Bullosa (EB) refers to a group of inherited connective tissue diseases. Minimal physical contact can result in blistering and wounds to the skin and mucous membranes (Eady, 1992). Hereditary subtypes of the disease are categorized by three groups; EB Simplex, Junctional EB and Dystrophic EB. Within these three groups there are at least 18 different types of EB (Finklstein and Vincent, 2004). Their severity ranges from mild to lethal with an estimated prevalence of 56.8 per one million individuals worldwide (Horn and Tidman, 2002). In Ireland 1 in every 18,000 new-borns are born with a subtype of the condition (DEBRA UK, 2012).

**Life with Epidermolysis Bullosa**

Physical difficulties can include; “blistering and erosion of the cornea and mucosal tissues, enamel hypoplasia, stenosis or strictures of respiratory, gastrointestinal, and urogenital tracts,muscular dystrophy and skin cancer” (Lanschuetzer 2009, p.3). Individuals tend to have unique podiatric difficulties due to the prevalence of EB symptoms on the lower limbs ranging from blistering or hardening of the feet (hyperkeratosis) in addition to major deformities in the hands and feet requiring orthopaedic surgery to separate fused fingers and toes(Pope et al, 2012, Mellerio 2010, Murat-Sušić et al 2011).

EB care usually requires some degree of wound care as blistering can predispose them to open wounds and life threatening infections (Pope et al, 2012). Recommendations were recently published for practitioners in the management of wound care for this population. Effective wound care encourages participation in activities of daily living as it reduces foul odour, infection and pain which hinder school and work attendance and lead to social isolation (Pope et al, 2012).

Psycho-social challenges associated with EB can include; learning to live with disfigurement and pain across the lifespan, the unpredictable progression of EB, coping with disability and loneliness and low self-esteem (Dures et al 2011, Moss 2008, Tabolli et al., 2009, Andreoli 2009). Impact on family and caregivers can include mental illness, high levels of anxiety irrespective of the subtype and high levels of disease burden regardless of financial status (Tabolli et al, 2010). Parental stress and marital difficulties have been documented among
parent and spouse caregivers due to the financial and emotional demands of the care (Fine et al 2005).

Research documenting coping behaviours of individuals with EB have described some individuals living “uncomplainingly”(Magari et al 2010) with physical pain and psychological stress in order to cope with the disabling nature of the disease (Moss 2008, Andreoli et al 2002, Magari et al 2010). These coping methods along with the stress of caring for a chronically ill person imply that the ability to advocate for the individual may be restricted. In this country specialised EB care is provided by two hospitals and the national EB charity Debra Ireland.

**EB care in Ireland**

Our Lady’s Children’s Hospital Crumlin and St James Hospital, situated in Dublin specialise in the care of EB in Ireland. Proximity to the United Kingdom and Scotland afford clients access to other quality centres of care particularly for complex health needs (Watson, 2010). The centralised nature of the care centres potentially impedes hospital service access for those living outside of the capital (Debra Ireland, 2012). Both hospitals have a dedicated EB unit, lead by Dr. Rosemarie Watson. They have a community support facility and a drop-in service with a purpose built treatment room. In collaboration with national EB charity Debra Ireland, the hospitals are developing a patient registry to ensure that suitable patients are available for treatment or clinical trials (Watson, 2010).

Debra Ireland is a national EB charity which provides various services to support individuals with EB, their families. They partially fund the EB Liaison Nurse at Our Lady’s Hospital, Dublin and the EB Medical service in both hospitals. They offer support groups, a family support worker, a bereavement group and respite grants to families experiencing hardship. They also fund research initiatives to advance the development of curative treatments (Debra Ireland, 2013). Access hospital services can be facilitated by the Medical Card scheme and private health insurance.

**The Irish Medical Card Scheme & Long Term Illness Scheme**

The medical card scheme is mainly a means tested service permitting free outpatient hospital visits, inpatient stays, free GP visits and medical prescriptions. It must be renewed by the individual regardless of health status (Citizen Information, 2012). Under Section 59 of the Health Act individuals with a ‘long term illness’ (LTI) but ineligible for the medical card on
financial grounds may avail of free prescription drugs, non-prescription drugs and doctors’ visits under the LTI Scheme. Diabetes Mellitus and Spina Bifida are examples of conditions covered by the scheme (Citizens Information, 2013).

At government level, Senator Colm Burke recently sought recognition for EB as a long term illness and proposed the automatic provision of the medical card to families and individuals with EB regardless of financial means (Burke, 2012). Deputy Roisin Shorthall rejected this request (Shorthall, 2012) and described government plans to support individuals with rare diseases through Ireland’s partnership with Europlan (Europlan, 2013). Europlan is a European initiative which plans to develop a National Strategy for Rare Diseases by 2013 among all EU Member States. These actions show the emerging recognition of EB in the Republic of Ireland and the efforts of individuals and policy makers to consider the support needs of this population.

A comprehensive understanding of EB from policy makers is crucial for resources and funding to be allocated to EB to provide supportive social structures and advance curative treatments (Pagliarello and Tabolli, 2010). Resource allocation is fundamental in improving healthcare outcomes which often depend on the extent to which communities and policy makers perceive the benefits of social action (Calman, 1994). It also depends on the practical ability of effected individuals to demand adequate services (Kronenberg and Pollard, 2005).

**EB care internationally**

Internationally efforts have been made to manage the disease and reduce complications for sufferers (Castiglia and Zambruno, 2010, Bodemer, 2010, Brukner Tuderman, 2010). The EB Haus in Austria (EB Haus, 2013) has created a purpose built research and treatment facility to cater for the needs of both patient and caregiver. In Australia the Government has pledged AUS$16.4m over four years to set up the National EB Dressing Scheme to improve access to wound care and reduce infection and hospitalisations (NEBDS, 2013).

**Occupational Therapy Perspective**

Occupational therapists view humans as occupational beings developing into themselves through engagement in occupations of meaning and necessity (Clarke et al, 1996, p.374, Wilcock, 1993) and that such engagement is imperative to health and wellness (Townsend and Whiteford, p.110). They advocate for the rights of the most vulnerable achieving their occupational potential (Kronenberg and Pollard, 2005). Occupational potential is “the future
capability, to engage in occupation towards needs goals and dreams” (Wilcock, 1998, p.256). Access occupations may be hindered by inadequate provisions for people with a disability (Kronenberg and Pollard, 2005) however the concept of occupational justice defends the right to experience the occupations we desire regardless of our health status (Wilcock, 2004).

Access to occupations may depend on the coordinated effort of interrelated systems such as social care, health care institutions and government (Townsend, 2002). The World Federation of Occupational Therapists position on Human Rights outlines how attitudinal barriers, institutional practices and national legislation can obstruct the individual’s right to occupation leading to occupational deprivation (WFOT, 2010). Occupational deprivation is “A prolonged preclusion from engagement in occupations of necessity and or meaning due to factors that stand outside the control of the individual” (Whiteford, 2000).

The relevance of this research

Due to exhaustive health care needs that can characterise the lives of EB sufferers (DEBRA Ireland, 2012) social action for expedient and efficient services may be hindered by physical and psychosocial challenges outlined in this literature review. During periods of economic uncertainty such as the current financial crisis, the allocation of resources to the most vulnerable is paramount to our society. This research is therefore particularly timely given the current flux in health and social care service provision in the Republic of Ireland in wake of the global economic recession.

METHODS

A participatory action paradigm of inquiry was chosen to guide this research. This paradigm aims to promote personal and social change by encouraging the stakeholders in a particular experience to generate practical knowledge about issues impacting them (Schneider, 2010). This paradigm of inquiry suited the researcher’s aim of gaining insight into the experiences of EB sufferers and their families, when navigating the Irish health services (Heron and Reason, 1997).

The survey was the method used to gather the views of participants. A survey is a restricted gathering of information used to estimate the results that a comprehensive gathering may describe (Couper and Bosnjak, 2010). This researcher used a postal survey. Postal surveys are filled in by the participant at their own pace (Ayidia and McClendon 1990). Hall (1999) found that respondents were likely to respond to sensitive topics when anonymity was offered.
as was the case with this survey. Postal surveys however, are generally more expensive to
develop and distribute than internet surveys (Cole 2005) and there are higher response rates
generally among educated individuals, females and older participants (Dholakia, 2006)
meaning that other groups may not be well represented (Green 1996).

The survey was divided into four main sections: demographics, hospital and community
services available, funding available and vision for the future of EB care in Ireland. Another
researcher examined the community aspect of this survey while this researcher focused on the
hospital care aspect. The survey process was supervised by the primary investigator in the
larger study in collaboration with DEBRA Ireland. It was not piloted as the researchers were
unable to access the population prior to the study; therefore the survey was reviewed by the
staff at Debra Ireland to ensure issues covered were relevant, appropriately phrased and in
line with their professional ethos.

Failure to understand the participant’s world might jeopardise the validity of findings
(Balnaves and Caputi 2001, p.103). Phrasing the questions clearly and without bias involved
contextualising the experience of living with EB from international research and exploring
potential issues of concern in this country in supervision with the primary investigator and
Debra Ireland.

**Recruitment Strategy**

The inclusion criteria for this project were parents with at least one child under 18 with EB
and adults with E.B who were members of DEBRA Ireland. DEBRA Ireland recruited the
participants in line with this. Forty-three members of the organisation were invited to take
part in the survey. DEBRA Ireland distributed the surveys from their Irish headquarters in
August 2012. The primary investigator of the larger study was the main point of contact for
participants.

**Data Collection**

Surveys were returned directly to the primary investigator using a pre-stamped addressed
envelope. Following an initial return of 14 surveys by the deadline, the researchers decided to
telephone the remaining individuals who had not returned a survey. This yielded a surplus 5
surveys. An incentive of inclusion in a draw for a 200 euro ‘One for All’ voucher was used to
encourage participation.
Data Analysis

The survey contained the essential quantitative components of Likert scales and closed answered questions to describe the frequency of attitudes or behaviours such as hospital visits and satisfaction levels with services. Data analysis of the quantitative components was undertaken using the Statistical Package for the Social Sciences software (SPSS Version 20). SPSS is computer software used for the analysis of statistical data (Boslaugh, 2005). A Pearson Chi-Square was used to measure associations between normally distributed variables. However this resulted in weak correlations on account of the small sample (n=20) and an insufficient cell count. For this reason simple cross tabulations were produced to observe emerging trends in the data.

The survey provided opportunities for qualitative comments to enrich the numerical data. This qualitative content was later analysed manually by the researchers. Due to the small sample the researchers were able to write each comment and count how many references were made to certain issues such as the medical cards. This qualitative information is referred to throughout the discussion of results.

Ethical considerations

This research project acquired ethical approval from the Ethics Committee in the University of Limerick. An information letter outlining the key ethical considerations e.g. voluntary consent, no harm to participant, anonymity, confidentiality and privacy (De Vaus 2002, p.59) was enclosed with the survey.

An ethical tension unique to this project was the issue of anonymity due to the small number of members affiliated with DEBRA Ireland. Anonymity may not be guaranteed if the sample population is small and controversial social change is the focus (Manzo & Brightbill 2006) which is true of this research. Measures taken to ensure the anonymity of participants have been to refer broadly to their location using region rather than county in addition to using citations from comments which do not disclose identifying information.

Reliability and Validity

The integrity of a survey relies on its validity and reliability. Reliability is the extent to which the results are consistent and repeatable. The responses should be similar if retested on the same participants or if administered by another researcher (Myers and Hansen 2012, p.116).
Validity refers to the extent of which the survey measures what it intended to measure (Litwin 1995, p.33). Measures taken to bolster validity in this survey have included engagement in supervision with the primary investigator, presenting the survey to DEBRA Ireland prior to an ethics review, engaging in an ethics review and ensuring that all relevant topics have been included (Fink, 2006, pps.39-40).

FINDINGS

Forty three individuals were invited to take part in this survey. Twenty surveys (46.5%) were returned. One individual answered on behalf of themselves and their child. This posed a unique dilemma to the researchers as to whether to accept both perspectives or to discard it completely. After much deliberation with the primary investigator it was decided to treat this one survey two due to the clear distinction in the answers. This allowed the researcher to input both sets of responses. Three other respondents were individuals with EB and had a child with the condition. These respondents answered the survey about themselves only therefore they were not subdivided. The characteristics of the participants are reported in Table 1a.

Table 1a

<table>
<thead>
<tr>
<th>Participant</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Person with EB Subtype</td>
<td>6 (30%)</td>
</tr>
<tr>
<td>Parent of child with EB subtype</td>
<td>11 (55%)</td>
</tr>
<tr>
<td>Both</td>
<td>3 (15%)</td>
</tr>
<tr>
<td>Total</td>
<td>20 (100%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>EB Subtype</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Epidermolysis Bullosa Simplex</td>
<td>10(50%)</td>
</tr>
<tr>
<td>Dystrophic Epidermolysis Bullosa</td>
<td>7(35%)</td>
</tr>
<tr>
<td>Other subtype</td>
<td>3 (15%)</td>
</tr>
<tr>
<td>Total</td>
<td>20/100%</td>
</tr>
</tbody>
</table>
### Age of participants

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-5</td>
<td>3</td>
<td>15%</td>
</tr>
<tr>
<td>6-12</td>
<td>7</td>
<td>35%</td>
</tr>
<tr>
<td>13-20</td>
<td>4</td>
<td>20%</td>
</tr>
<tr>
<td>21-30</td>
<td>1</td>
<td>5%</td>
</tr>
<tr>
<td>31-45</td>
<td>2</td>
<td>10%</td>
</tr>
<tr>
<td>46-60</td>
<td>2</td>
<td>10%</td>
</tr>
<tr>
<td>60+</td>
<td>1</td>
<td>5%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>20</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

Sixty percent of participants (n=12) attended Our Ladys Childrens Hospital while 30% (n=6) attended St James Hospital. One participant availed of both hospitals and one did not report their centre of care though they proceeded to comment on their hospital experience.

The majority of participants (n=15) were from the Leinster area and represented the majority of hospital visitations among the sample. Table 1b describes to residence of participants. Hospital frequency was cross-tabulated with EB subtype to identify if certain subtypes required more hospitalisation. Individuals with EBS (n=10) required the least amount of hospital appointments while DEB (n=7), the more severe subtype frequented hospital the most. See table 2.

### Table 1b

#### Residence

<table>
<thead>
<tr>
<th>Region</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Connaught</td>
<td>1</td>
<td>5%</td>
</tr>
<tr>
<td>Leinster</td>
<td>15</td>
<td>75%</td>
</tr>
<tr>
<td>Munster</td>
<td>3</td>
<td>15%</td>
</tr>
<tr>
<td>Ulster</td>
<td>1</td>
<td>5%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>20</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>
The most visited healthcare professional was the dermatologist; this was followed by nursing 85% and dietetics 55%. Table 3 below describes the professionals involved in the inpatient service.
Table 3: Hospital staff frequented at outpatient hospital appointments:

<table>
<thead>
<tr>
<th>Health care professionals</th>
<th>%</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dermatologist</td>
<td>20</td>
<td>100%</td>
</tr>
<tr>
<td>Podiatrist</td>
<td>3</td>
<td>15%</td>
</tr>
<tr>
<td>Nurse</td>
<td>17</td>
<td>85%</td>
</tr>
<tr>
<td>Dentist</td>
<td>8</td>
<td>40%</td>
</tr>
<tr>
<td>Dietician</td>
<td>11</td>
<td>55%</td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>10</td>
<td>50%</td>
</tr>
<tr>
<td>Social worker</td>
<td>6</td>
<td>30%</td>
</tr>
<tr>
<td>Psychologist</td>
<td>3</td>
<td>15%</td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td>5</td>
<td>25%</td>
</tr>
<tr>
<td>Others</td>
<td>1</td>
<td>5%</td>
</tr>
<tr>
<td>Total</td>
<td>84 vists</td>
<td>420%</td>
</tr>
</tbody>
</table>

Podiatry

Podiatrists ranked among the least visited health care professionals with only 3 participants attending regularly. Access to a podiatrist emerged as a theme in the content analysis. Six participants reported a desire to see the podiatrist more frequently during hospital appointments. They viewed this service as specialist and required it regularly.

“I would like to see a properly trained podiatrist in EB dressings and padding for feet”

Comment from Participant

Satisfaction with hospital services

Nineteen individuals used the hospital services. The majority of them were (n=11) “very satisfied” with hospital services and most (n=7) rated the services as “very important” to them. The single participant who was dissatisfied with the hospitals services rated them as “unimportant”. See Table 4 provides a visual representation of this data.
Participants also provided qualitative comments regarding their satisfaction with the hospital services reflecting a commitment to their care: “Our Lady’s’ Hospital is our life line” – Comment from Participant

Levels of hospital service dissatisfaction were very low however comments describing a future vision for hospital services were reported in the survey by the majority of participants (n= 12). Comments included desired reductions in waiting lists for allied health professionals such as physiotherapy, increased funding for EB services in Ireland and EB services in their own county to reduce the burden of travelling to Dublin for appointments

“More inclusive holistic clinics with multidisciplinary team involvement, physio, SLT, Dietician, social support, psychology, consultant, specialist nurse etc on an ongoing basis” (Comment from participant)

Wound care

12 participants were concerned about the expense associated with purchasing the correct dressings for their own or their children’s EB to manage wound care. They described wound care as critical to avoid hospitalisation. One participant queried if Ireland was up to date on the best practice of wound care while other participants expressed general dissatisfaction in the qualitative comments about the process of getting essential dressings.
“Once diagnosed with EB, a person should have guaranteed easy access to essential bandages and dressings. It shouldn’t be an ordeal to get them when required” (Comment from participant.)

Medical Card Services
Thirty five percent (n=7) of participants were medical card holders. The frequency of renewal varied among this group. Ten percent of participants renewed the medical card yearly, 5% every two years, 10% every eighteen months and 10% every three years. Table 5 describes satisfaction levels with funding healthcare needs via the medical card, one individual did not respond to this question.

Table 5:

<table>
<thead>
<tr>
<th>Satisfied with funding healthcare needs via the medical card system?</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>very satisfied</td>
<td>1</td>
</tr>
<tr>
<td>satisfied</td>
<td>2</td>
</tr>
<tr>
<td>neither</td>
<td>1</td>
</tr>
<tr>
<td>dissatisfied</td>
<td>2</td>
</tr>
</tbody>
</table>

Medical card holders were: one individual with EBS, four individuals with DEB and two medical card holders had a different subtype. 3 participants received the medical card on the basis of means testing, 2 on account of hardship and 2 on account of both.

One of the seven medical card holders was “very satisfied” with the process of funding their needs via the medical card system, two were “satisfied” and two individuals were dissatisfied with this process. 85.7% (n=6) of medical card holders felt the medical card adequately funded their hospital, community and medical supply needs and 14.3% (n=1) said it did not cover this adequately. Thirteen participants were in favour of automatic medical card
provision upon diagnosis with EB due to the associated healthcare costs incurred by the disease.

“Children with EB should automatically qualify for medical card to enable access to hospital and pharmacy for dressings regardless of parental means” Comment from participant.

**Private Health Insurance**

Sixty percent of participants (n= 12) had private health insurance. Fifty percent (n=6) felt it adequately covered hospital community and medical supply needs. Forty five percent (n=5) felt it did not provide sufficient cover. One individual did not respond to this question. The following bar chart describes the satisfaction with health insurance cover for medical needs.

![Bar Chart](chart.png)

**Self Funding**

11 individuals reported that they were self funding their care. 10 of these individuals had either the medical card or health insurance. These participants may perceive that they are
indeed financing their healthcare despite access to insurance or medical cards as some services must be paid privately for example; ointments, creams and bandages.

Thirty one percent of self funders (n=4) were satisfied with their ability to fund their own healthcare needs, five participants (38.5%) while one person was very dissatisfied and one did not comment. Concerns about self funding hospital care emerged when discussing podiatry access and funding essential bandages and dressing to avoid hospitalisation.

“The podiatrist is the most important person to us- not having to pay would be a great help we only go when the feet are in a chronic condition” Comment from participant

Discussion

This is the first study in Ireland that explores the experience of EB sufferers with the current hospital service and available social care provision. Dr. Rosemarie Watson has described this provision for individuals with EB in Ireland (Watson, 2012) however there is a scarcity of research documenting the perspective of the various stakeholders such as patients and families navigating these services in Ireland. Internationally there is also a dearth of literature exploring this area.

The quantitative data in this survey revealed good satisfaction levels with the hospital system generally and the ability to manage healthcare needs with the medical care and insurance. If taken alone this would imply there were very few difficulties in the current system. Yet the qualitative comments richly described how the current health care system is not fully meeting their needs and participants had clear opinions on how it should evolve in the future. These results will be discussed under the following headings

1. Funding hospital and EB associated care
2. Wound care and Podiatry

Funding healthcare needs and family life

These results show that the majority of participants perceived they were they were funding their own and /or child’s care even when they had the medical card or health insurance. Most medical card holders were satisfied (87.8%) with their ability to fund their healthcare. One participant relies on this to provide appropriate care for her child “Without the medical card we probably wouldn’t give him the proper care he deserves” (Comment from participant). Forty five percent (n=5) of health insurance holder’s were dissatisfied perceiving that
healthcare needs were not adequately covered. Insurance holder’s dissatisfaction may be due to the cost of GP visits and prescriptions which are not covered by the health insurance scheme. The majority of all participants were health insurance holders (n=12). Therefore it is not surprising that so many participants were in favour of the direct provision of medical cards given that the majority did not have one. They sought medical cards for all EB families hoping it would make life easier when managing the condition. One participant referred to the distress of not being able to afford some of the care needs for their child describing “neglect of the child with EB” (comment from participant) when a family is not awarded the medical card.

The literature shows that the financial hard ship of EB care can have a detrimental impact on the family unit. This can lead to high levels of stress and high separation levels (Fine et al 2005). In one study the majority of parents caring for the most serious EB subtype attributed their separation to the financial and emotional pressure of managing the condition (Fine et al, 2005). In line with the literature, one participant in this study disclosed there were difficulties for the family when managing EB: “E.B plays havoc with a family physically and emotionally. Families should be supported and they are not” (comment from participant). It is thus important to recognise that the financial burden can impact the families in Ireland.

The implication for EB families who are not entirely satisfied with the EB care for their child or partner is insufficient energy or resources to actually challenge the current system. One participant describes their efforts to acquire adequate healthcare “From the day the child is born it becomes a battle ground fighting for support and proper services” (comment from participant). The literature suggests that the pressure of managing EB care can lead to reduced occupational potential. Occupations such as hobbies or caring for other family members becomes compromised by the dearth of adequate support, the financial strain and intense care needs associated with EB (Tabolli et al 2010). From an OT perspective the health of the entire family is in jeopardy when they cannot take part in the occupations they need or want to do (Kronenberg and Pollard 2005). One participant reflects on the negative impact this has on the occupation of motherhood “Every family should have the input of a public health nurse; mothers should be allowed to mother not nurse”, (comment from participant.)
Wound care and Podiatry

Twelve participants in this study were frustrated at the expense of essential wound care irrespective of whether they had a medical card or not. They felt that access to non-prescriptive ointments and certain dressings was impeded by cost. Participants wished to be alleviated of the staggering costs associated with non-prescriptive necessities. This is in line with literature which acknowledges the practical and financial challenge of accessing appropriate bandages and dressings (Stevens, 2012). The costs associated with podiatry in addition to other factors such as lack of home-visits were seen as impediments to the service in our study. The literature also recognises the challenge of maintaining good podiatric and wound health to avoid a plethora of complications (Khan 2010). Reduced occupational participation was documented by Van Scheppingen et al (2009) when she explored the main problems for children with EB, one of her participant’s spoke of how painful feet impeded the occupation of play: "I would just like to run free for once. I can’t do that anymore because of my feet” Participant comment.

Ireland does not have the adequate infrastructure in place to accommodate the unique needs of this population however the Australian government has taken steps to alleviate the financial burden. Since October 2012 the scheme has pledged to cover wound care costs irrespective of age or financial means with the view to reducing unnecessary hospitalisations and disability (Debra Australia 2013).

From an occupational therapy perspective, the implication to patient’s participation in occupation if wound care or podiatry needs are not met is significant. Potential to access occupations may be hampered by inadequate social provisions (Kronenberg and Pollard, 2005). This in turn violates their human right to participate in work and leisure, a right upheld by the concept of occupational justice (Wilcock, 2004).

The implication for the human rights of this population is of concern to this author in light of their dissatisfaction with aspects of the current system. Occupational deprivation and hindered access to services due to illness or disability are rejected by the UN Convention for Human Rights (UN, 1947) which further supports the goal of this research at this moment in Irish history. However this poses unique challenges for policy makers in this country who are charged with providing ethical and adequate systems (Calman, 1994).

This study also has an implication for the role of Occupational Therapists. OT’s are well
placed to advocate for individuals with EB as they value the interconnectedness of occupational participation with health, well being and survival (Wilcock, 1993).

This study adds to the current literature which recommends considering the health and wellbeing of the individually and their support system when creating systems which impact the EB care of the patient (Tabolli et al 2010, Fine et al 2005). This study also reflects other literature which recognises the impact financial strain from EB care has on the holistic care of the patient (Tabolli et al 2010, Fine et al 2005). In order for the health care system to provide care which meets this populations needs it is imperative that their concerns be recognised at governmental level.

**Limitations of this study and further research**

Due to the small sample size and insufficient cell count it was not possible to make any reliable hypotheses using the Pearson Chi-Square in SPSS. The results of the study cannot be generalised for the greater population of EB sufferers. Limitations in the survey may have been clearer had the survey been piloted however it was not possible to do this. Postal surveys do not represent certain individuals well such as males, people with literacy difficulties and those with low levels of education (Dholakia, 2006) there this must be considered a limitation of this study.

Further exploration of how EB impacts the occupational potential of the family unit in Ireland is recommended. This may reveal how occupational therapists can best support this population in the future. This author could not find any academic study which attempted to capture this unique experience.

**Conclusion**

This study explored the experience of individuals with EB with the hospital and social care system in Ireland. It contextualised the main concerns of participants within a framework of occupational science concepts such as occupational potential and occupational justice. This was done to highlight the importance of supporting this population so they can achieve optimal health and wellness in the current system. Interspersed were references to the role of occupational therapy in advocating for a system which encourages EB sufferers to achieve their occupational potential. The data attained in this survey has offered an insight into the extent to which the current systems support and hinder the health and occupations of participants.
The importance of hospital services in the lives of the participants was unquestionable and they praised the commitment of hospital staff to their condition. Participants also expressed the main areas in current health care provision they would like to see evolve based on their experience navigating this system. It is therefore imperative that the current health care system is challenged to recognise the unique needs associated with EB in order to provide satisfactory care for all of those affected.


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