



Identifying the Optimum Role and Function of an Epidermolysis Bullosa (EB) Outreach Nurse

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Study Overview

Study Aim

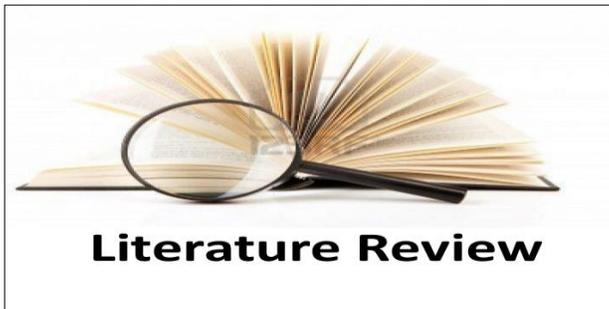
To determine how the role of the EB outreach nurse could be developed to meet the healthcare needs of people with EB in Ireland.



Literature review

While a relatively comprehensive range of specialist services are available in Ireland, additional supports were required.

An EB outreach nurse service had the potential to function at the interface between the various service requirements.



Methodology

Participatory action research

Research steering group

Qualitative approach using semi structured interviews

Sample; Adults with EB and parents of children with EB





Findings

Participants

- 10 Parents
- 6 Adults

1. Support managing physical healthcare issues
 2. Access to community/home based services
 3. EB specific information and support
 4. Effective interaction with healthcare professionals
 5. Advice regarding benefits and entitlements
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Findings

Theme 1: Support Managing **Physical** Healthcare Issues

Support with bandage changes & wound care – priority for both cohorts

“.....so your child suffers through the dressings, screaming in pain, you didn’t feel like you were absorbing the whole impact maybe the other person was absorbing, so if you wanted to walk away out of the room to get yourself together, when you just probably couldn’t go any further, at least there was somebody else there, a knowledgeable person...” Parent Participant

“.....she’s here (at home) in her own environment and she’s comfortable so she’ll let us do her bandaging but even to go to the doctor she walks in the door and starts screaming so if they’re here (EB Outreach nurse) they can see everything that’s going on....Just have them here.” Parent Participant



Findings

Theme 2: Access to Community/Home-based Services



“by the time I’d park the car and walk in that far my feet would be blistered, do you know and generally my rationale is just to come home and stay off my feet”
Adult Participant.

“Not getting, I think occupational therapy. It’s very much like, kind’ve an acceptance, oh a child with EB that their hands are going to contract, their feet are going to contract and they’ll probably end up in a wheelchair. I kinda tapped into stuff outside that I pay for privately.....” Parent Participant

Findings

Theme 3: EB Specific Information and Support

Practical information regarding the management of wound care, infections & bandages

Services for the emotional & social effects of having EB

“And the thing is it’s all **practical stuff I need to know**, you know like **what shoes cause the least blisters, brands of clothing**, things like that and they don’t have any of that information there, so that’s more stuff that you work out for yourself or hear through the grapevine.” Parent Participant

“Like you **don’t ever stop thinking about it** like, like **it’s constantly on your mind**. Like, we do nothing outside of EB because we don’t have time. Our day is just **completely consumed by bandaging** or soaking or whatever it is that needs to be done that day but we just **don’t have a life outside of EB**.” Parent Participant

Findings

- Theme 4: Effective Interaction with Healthcare Professionals

1) Positive Experiences

“Our GP, he didn’t know about it but the minute she was born and he heard it, he went away and researched it and everything so now we can trust him, you know, he knows how to handle her and, you know for injections now or for any normal sicknesses or anything like that, he’s great. Parent Participant

“... The hospital is my sanctuary, it’s where I receive my knowledge, it’s where I know the best practice that’s going on...” Parent Participant

1) Negative Experiences

“She had to get a drip and they wanted to put plasters on her and we were, no way, we have our own stuff we’ll use it, “Sure it’ll just be on for a second like, is she allergic to it or something?” We’re like, “It will rip her skin off like, you just can’t” Parent Participant

“I have to explain in the A&E, when they put those little things on to do ECGs and stuff, they tend to want to pull them off and I have to explain don’t pull them off because then, because it actually does take the skin off with them, yeah and it’s just constantly explaining.” Adult Participant

Findings

- Theme 5: Advice Regarding Benefits and Entitlements

Difficulties
accessing free
medical care

Problems with
bureaucratic
nature of
health service

“Then it went up to 120 euro, then it went up to 140 euro, so like at the point when we would’ve been doing a lot of care of blisters, we would’ve always been spending the maximum amount you needed to spend on the drugs payment” Parent Participant

“Can I say the process was worth it? Yes, if I was to go back to that time, I don’t know how I did it. I don’t know how I went through it, the stress that it created, the lack of support, fighting every, month in month out, it took so much out of me that you know, it was just such an emotional time, it was like, you know, I knew we weren’t going to survive as a family or I wasn’t going to get through it if I didn’t get some type of support.” Parent Participant

“They’re looking at a piece of paper and saying why is this tiny person costing this much money, you know. They didn’t, they didn’t kind’ve want to see what the problem was or why they needed all this bandaging and then when they realized that it’s for life, they kind’ve panicked, it’s between fifteen and twenty thousand a month.....” Parent Participant

The role of the EB outreach nurse

1) Physical Care

- Consultant led **multidisciplinary team**, in a specialist EB center.
- **Specific educational preparation** in a specialist EB center.
- **A point of contact.**

2) Community services

- Provide **home visits** at pivotal periods.
- Act as a **co-ordinator of care.**

3) Information & Support

- Direct patients/families towards **key information services.**
- Referral to a range of community based **psychosocial supports.**

The role of the EB outreach nurse

4) Interaction with HCPs

- Play a key role in the educational provision and support of **non-specialist HCPs**.
- Be actively involved in staff **CPD** and **research development**.

5) Benefits & Entitlements

- Provide additional support in relation to **benefits and entitlements**.
- Act as a **strategic advocate** to secure adequate funding/resources while articulating the healthcare needs of EB patients both nationally and internationally.

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Questions



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