Margaret May Blackwell Travel & Study Fellowship Report

Proactive Nursing Practice and Research to Address Improvement of Health Care Needs of Vulnerable Children and their Families

2013/2014

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Table of Contents

Section One: Epidermolysis Bullosa

Section Two: Pressure Injuries

Section 3: Burn Care in New Zealand

Photos

Appendices

Acknowledgements

Firstly I wish to thank the Margaret May Blackwell Trustees, The Margaret May Consultative Committee, Nursing Education Research Foundation and New Zealand Nurses Organisation for the fantastic opportunity to travel and study whilst looking for answers, to fulfil my objectives. This was a wonderful experience which has certainly helped to increase my profile in National and International circles respectively.

I wish to acknowledge my employers & nursing colleagues from the Canterbury District Health Board and DEBRA NZ for nominating me for this prestigious scholarship and supporting my leave.

A huge thank you must go to the dedicated Health Professionals that I had the privilege to meet throughout my journey. It was wonderful to work with you all. Thank you for opportunities you gave me and for sharing your wisdom.

Of course, there would be no purpose of this award without the client/patients. I wish to acknowledge all the vulnerable children and supportive families that I met and thank them most sincerely, for the trust that they held in me.

Lastly, thank you to my husband, family and friends, who supported me particularly around the time of writing this report.

Application

The topic for 2013/2014 was;

1. Proactive nursing practice to address the health care needs of vulnerable children and their families
2. Contribution of technology and/or research to improving child health.

The award was open to Registered Nurses who were practicing in the public and private sectors of early childhood health or who were teaching in a tertiary level in the subject. The nurse must have been nominated by her employer/s indicating their support. I believed the objectives that I wanted to explore would cover both these topics. My objectives were;

1. To observe best practices caring for the new born baby with Epidermolysis Bullosa.
2. To observe other centres and see how they biopsy their baby/child who has suspected Epidermolysis Bullosa (EB).
3. To observe the range of EB services and activities undertaken at existing clinical centres and see what we can adopt for our New Zealand (NZ) families.
4. To gather as much information as I can to help advance the EB Nursing role in NZ
5. To learn up to date best wound management information of baby/children with excessive skin loss to avoid possible risks of infection. Eg. EB and Burn patients.
6. To review current pressure injury programmes around the world and see how else we can improve in New Zealand.
7. To gather up to date information on the latest treatments for Eczema care.

Within my application I wrote of the various 'hats' I wear in my working roles.
At Christchurch Hospital I work one day a week as a senior Staff Nurse in the surgical paediatric ward and another day as Clinical Nurse Specialist for the Child Health Outreach Nursing Service caring for eight children who have the rare skin condition Epidermolysis Bullosa. I am also the Wound Resource Nurse for the Child Health division and sit on several committees' within the hospital, such as the Wound Care, Clinical Nurse Specialists and Pressure Injury Group committees.

Outside of the hospital I run my own community nursing business called SOS Nursing (www.sosnursing.co.nz). I see clients in a clinic within my home or visit people in their

homes. I am registered with ACC and my main sub-contracts are with DEBRA NZ and Keraplast.

DEBRA NZ is a charitable trust organisation whom I work for two days a week in a National role as EB Nurse Specialist. I am one of three nurses covering New Zealand and care for babies through to adults who have a rare skin condition called Epidermolysis Bullosa.

Keraplast develop products made with Keratin protein. I work in a Nurse advisory role regarding the use of their wound care products and am also involved with some of their clinical trials.

All skin conditions are of interest to me. It is always good to benchmark against what others do around the world. In 2013/14 there was to be the opportunity to attend many relevant clinical meetings and meet leaders in the field for not only EB care, but all types of skin and wound care. Principles of wound care underpin all my wound care roles and I believed gaining the travel study fellowship would help to enable me opportunities to attend conferences/meetings or clinics overseas. With this I hoped to gain further knowledge that would improve and enhance care of some vulnerable children within New Zealand.

Introduction

This report will cover the meeting, conferences & clinic's I attended while traveling. The best practice learning opportunities I gained from experts in clinical centres of excellence and the strong networks of specialised professionals I have built relationships with.

I will highlight how New Zealand healthcare is perceived to other healthcare professionals within the industry and discuss some of the gaps in our current service delivery. I will then identify ways in which we could improve the service that we offer our clients.
The report will focus on three key areas, Epidermolysis Bullosa, Pressure Injuries and Burns.

1. **Epidermolysis Bullosa (EB)**

   This section will cover the related conferences (EB CLINET, DEBRA International and the International Paediatric Dermatology) I attended in Europe 2013 and 2014 and the clinics I visited in Austria and the Netherlands. It will include latest research and the new technology that has been developed to improve the care and treatment for children with EB. There will be an in-depth review of New Zealand's current practice of taking a punch biopsy to diagnosis EB. The review will look at what might be the likely cause for receiving non-definitive results and explore some recommendations for improvement.

2. **Pressure Injuries**

   This section will look at what risk assessment tools are used within New Zealand hospitals and what has brought about a change in practice for the Child Health service at Christchurch Hospital.

3. **Burns:**

   The 'burn' section will discuss a trial using a Keratin protein dressing on superficial and partial thickness burn injuries at Christchurch Hospital and the outcomes from this trial.

Getting started

Once I was informed that I had gained the prestigious Margaret May Blackwell (MMB) travel and study fellowship award it was time to start exploring my options. I investigated institutes and areas that could be of interest. It was of utmost importance to me to make the right decisions in order to gain the most knowledge and to utilise this opportunity to its full extent.

My first step was to reach out to other healthcare professionals both in New Zealand and abroad. I contacted nursing colleagues at Great Ormond Street Hospital (UK) & Groningen University Hospital (Netherlands) as these are considered leading centres of excellence as their practice is very innovative. Both countries have long standing EB services and manage very large populations of clients with EB. Both nursing colleagues replied giving advice on conferences and meetings I could/should look at attending. I also contacted two Professors of Dermatology, one in the Netherlands and the other in Germany. From these contacts I was invited to visit their clinics and observe how they 'do things'. However, because of time constraints I only attended the Netherlands clinic, which I will talk about later in my report.

I then consulted with my New Zealand work colleagues who had nominated me for the award from DEBRA NZ and the Canterbury District Health Board (CDHB). It was useful to touch base with them during the decision making process as they had a lot of insight to offer. After doing extensive research and discussing suitable options/ideas it was time to book flights and to explore economical accommodation options and what would be feasible.

Section One: Epidermolysis Bullosa

Background Information

To give an overview of Epidermolysis Bullosa (EB) DEBRA NZ explains in a brochure for clinicians that EB is a group of genetic conditions caused by a “genetic change or mutation, in one of the genes that code for the proteins which "glue" the skin together. The particular protein affected is then reduced or missing in a specific layer of the skin, causing areas of structural weakness” leading to skin fragility with blister formation. Blisters can occur spontaneously or following minor trauma, which sometimes involves the mucous membranes inside the mouth and follows right through the gastro intestinal tract to the anal area.

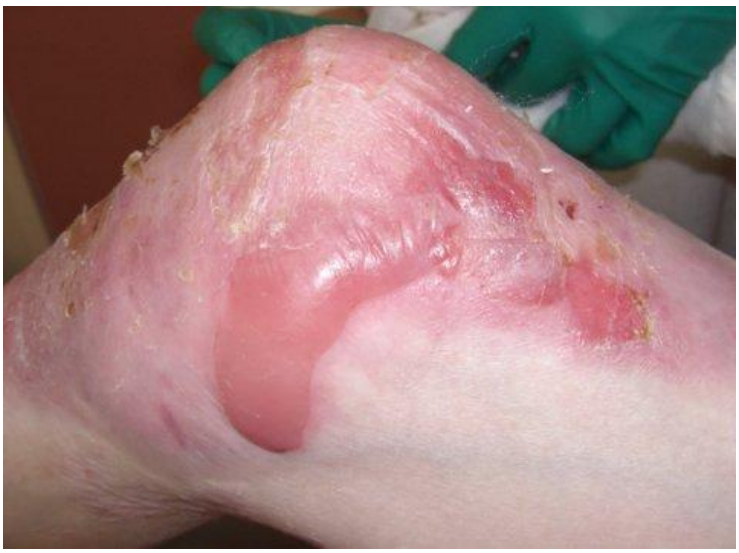

Photo 1: EB Blister (source; personal photo library)

It is also recognised that pressure, friction and heat also contribute to blister formation. EB can be very painful and can make daily living difficult. Currently this condition is incurable, but much research is currently taking place around the world to find a cure.

Babies and children with EB are often called ‘butterfly’ children because their skin is as fragile as butterfly wings. For people with the most severe type of EB they can have a short life expectancy due to complications or be threatened by an aggressive skin cancer. The DEBRA organisation supports people affected by EB and their families.

Who is DEBRA?

DEBRA stands for Dystrophic Epidermolysis Bullosa Research Association. DEBRA is registered as a charitable trust and is a support group for clients/families living with EB. DEBRA is an International organisation with national groups in over 50 countries around the world. EB is extremely rare and many medical practitioners have never heard of this condition and most have never treated a baby/child with this condition.

DEBRA International estimates that “approximately 1 in 17,000 live births can be affected and thought that 500,000 people worldwide are living with EB. Severe forms can be life threatening and fatal in infancy, but 70% of people who have EB will have the less severe types”.

Chronic wounds of EB can result in decreased mobility owing to pain and the extensive scar tissue that forms. Blisters in the severe forms of DEBRA NZ explains that “EB blisters are not confined to the outer skin, but may develop on the soft tissues (mucous membranes) inside the body such as the linings of the mouth, oesophagus, stomach, intestines, lungs, airway, eyes and bladder”. Nutrition can be compromised, resulting in osteoporosis, and general failure to thrive. Some may need a gastrostomy or require highly specialised diets.

The skin cancer, squamous cell carcinoma (SCC), is a major cause of death for teenagers and young adults with Recessive Dystrophic (RDEB). SCC is particularly aggressive and invasive in patients with EB and the need is to prevent development or slow the spread. DEBRA International estimate that the “incidence for severe EB is 1 in 300,000”.

DEBRA New Zealand

DEBRA NZ employ’s three part-time EB Nurse Specialists. The importance of this role was recognised by the Ministry of Health in 2010 when the role was made national and funding was allocated for the nursing service.

Two nursing colleagues cover care for clients in the Central and Upper part of the North Island and I cover the lower third of the North and all of the South Islands. We are available to visit and advise medical, nursing, multi-disciplinary teams and families on the recommended best management of the person with this condition.

Proactive nursing practice is the key to successful outcomes for very vulnerable children with EB. It is important that we profile the condition as much as possible and stress the importance that with normal handling like any other infant would cause permanent severe damage to a fragile baby born with EB or even be life threatening. Recognising EB in a new baby and being able to diagnose the particular subtype correctly is vital to ensure the best health outcomes for the baby and their family.

The DEBRA NZ EB Nurse Specialist uses a preventative model of care and gives education that will help the local multidisciplinary teams who care for baby/child. This helps facilitate early discharge from hospital and for appropriate interventions to be put into place to support the family who care for the complex child at home. The model is also designed to prevent hospital re-admissions, which will incur extra costs for the District Health Boards (DHB's).

New Zealand currently sends biopsies for the probable diagnosis of EB to a laboratory (lab) in Australia. This is because we do not have resources for this type of diagnostic testing in New Zealand. Biopsy results take some time to be processed in Australia, so support systems need to be put in place to help the family cope, while they are waiting for these results. The DEBRA NZ EB Nurse Specialist not only help support the family, but can put the family, if they wish, in touch with other parents who also have a child with EB.

The DEBRA NZ EB Nurse Specialists recognise there are gaps with the current New Zealand service delivery for clients with EB and some of these gaps will discussed within this report. It is hoped that a New Zealand National multidisciplinary service can be established in the near future to bridge these gaps.

Types of Epidermolysis Bullosa (EB)

EB ranges from mild to severe. The extent of tissue involvement experienced by an individual and the complications they may have is usually determined by the severity of the condition and the subtype present. Researchers over the past 15-20 years have identified approximately 13 major genes being responsible for the majority of EB cases and over 30 subtypes or variants. Subtypes are based on inheritance and clinical features and cannot change from one type of EB to another (cited on DEBRA International website).

DEBRA International recognises that there are three main types of the condition which are defined by how deeply into the skin the blistering occurs". Each type then has multiple

subtypes (see box below). Over the years as knowledge has increased, classification of types and subtypes has been refined. Kindler syndrome is now considered to be a fourth type of EB and is part of the broader EB classification.

Type	Number of subtypes	Inheritance of subtypes	Key genes affected
EBS	~ 12 subtypes	dominant or recessive	Keratins 5, 14, Plectin
JEB	~ 6 subtypes	recessive	Collagen XVII, Integrin, Laminin
DEB	~ 13 subtypes	dominant or recessive	Collagen VII

To explain where in the skin structure the problem lays it can be simplified by saying:

EB Simplex (EBS) occurs in the epidermal layer of the skin
Junctional EB (JEB), occurs within the dermal-epidermal junction
Dystrophic EB (DEB), is below the basement membrane in the dermis.
Kindler Syndrome, may involve in multiple layers of the skin

These four types are the major EB types, but the latest consensus report now has a new approach to classifying which is called “onion skinning” (as cited in fine et al, 2014, p.1105).This classifying takes into account not only the major EB type but also specific features such as mode of inheritance, targeted protein etc.

How is EB inherited?

EB can be of autosomal dominant or recessive inheritance.
DEBRA NZ states, “an autosomal dominant disorder is where only one parent needs to have the condition to pass the skin condition on to their child. The one gene for the condition expresses (dominant) itself in an individual. A parent with this dominant form of EB then has a 50:50 chance with each pregnancy of transmitting the abnormal gene to their offspring. A child who does not inherit the gene for EB from an affected parent will not have the condition and cannot pass it on”.

“An autosomal recessive disorder is one where the gene is not expressed (recessive) in either parent. Two recessive genes then paired together will cause the disorder to be expressed in the child. If both parents are carriers, they may not be aware that they carry this gene (cited in DEBRA NZ brochure).

If a person has one recessive EB gene and is paired with a normal gene, the person is "a carrier", but does not have the disorder".

If parents are each carriers of an autosomal recessive gene, there is a 25 percent chance with each pregnancy that their children will have the condition. An individual with a recessive form of EB will be at risk of having an affected child only if he or she has a child with a carrier or another person with recessive EB. Once, the genetic mutation is identified in a family, prenatal diagnosis of future pregnancies maybe possible.

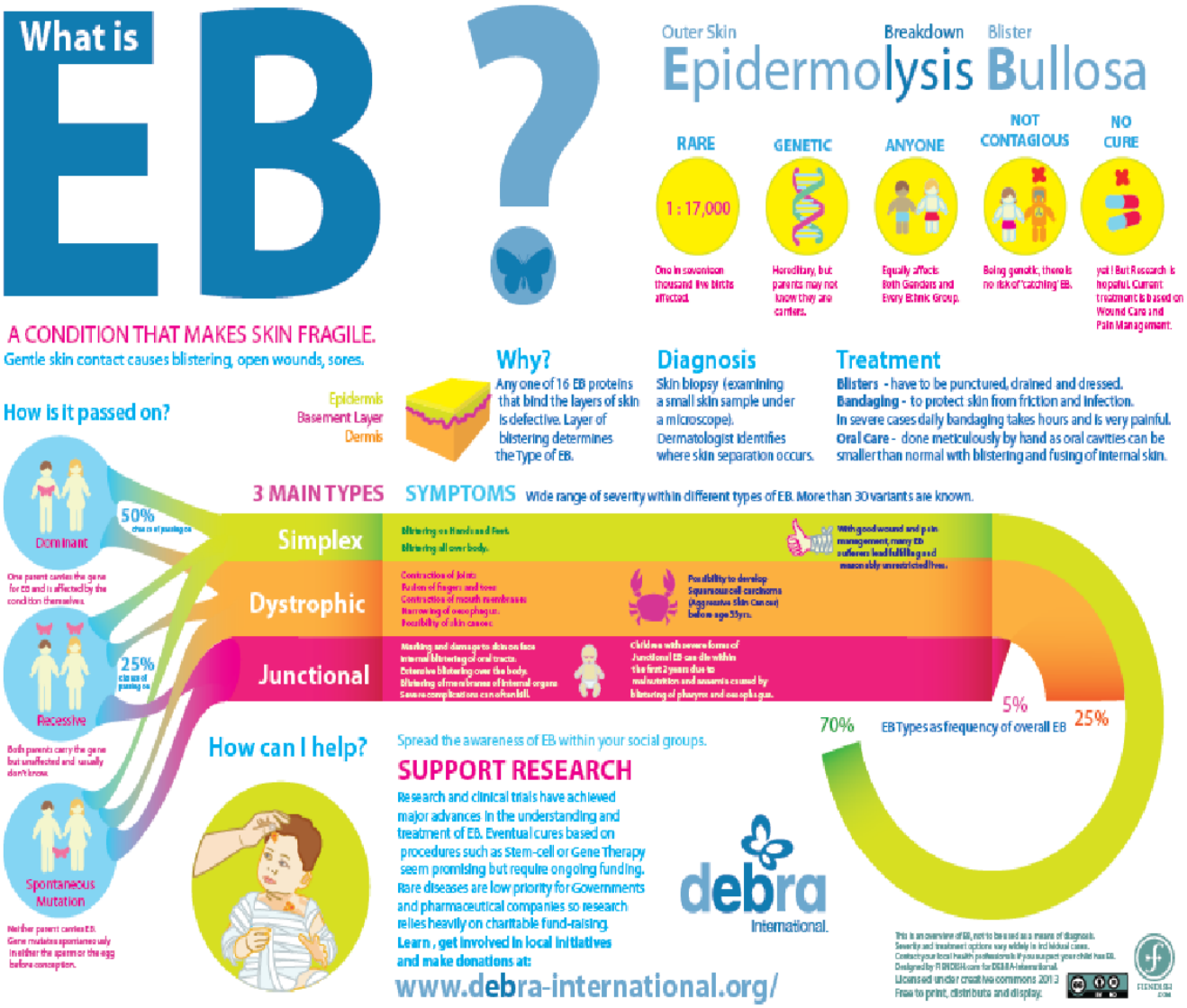

Photo 2: (DEBRA International, 2015)

Diagnosis

A diagnosis of EB is first dependant on the patient's clinical presentation and family history. EB can occur in all racial and ethnic groups and affects males and females equally. With milder forms of EB it is not always evident at birth, but may become apparent when a child crawls, walks, runs or when a young adult becomes more physically active. Information from immunofluorescence mapping and electron microscopy from a skin biopsy is required to make the diagnosis.

Immunofluorescence Mapping "involves using a fresh skin sample and a panel of antibodies tagged with a fluorescent marker to detect the presence, or degree of binding, of a panel of antibodies to the skin proteins affected in EB. This may provide an indication as to the specific protein involved in the structural weakness of the skin" (cited in DEBRA NZ brochure).

Electron Microscopy "involves the use of a highly powered microscope that evaluates the skin sample by looking at the level of skin separation present and also noting the number and appearance of specific structures, such as anchoring fibrils or hemidesmosomes, located within the skin. This will assist in diagnosing the correct subtype of EB" (cited in DEBRA NZ brochure).

How is EB Treated?

EB involves many parts of the body. To help care for a client with EB the health professional need take a multidisciplinary approach to the treatment, particularly young children as some can have very complex needs. Care varies and is dependent on the type of EB a client has and no two cases are the same. We must remember that each person with EB needs their own individualise care plan to suit their needs. Prevention of injury and good principles of hand washing and wound care need to be taught and practiced for all, regardless. For children, management of this condition is often shared jointly by a dermatologist and paediatrician and referrals made to other specialists as required. As DEBRA NZ state "focus should be on prevention of infection, protection of the skin against trauma, attention to nutritional deficiencies and dietary complications, minimisation of deformities and contractures, and the need of support for the entire family".

“The severe forms of EB require meticulous nursing care, in regards to dressing changes and wound care”. Much of the care is often provided by the parents, however, health professionals need to be mindful that we offer support for them, so the emotional load is shared. It is important that we allow the parent, to be the ‘parent’, to show love and protection and not be known by the child, as the person who will hurt them! Any person having contact with the child will need education on the child’s particular needs. This includes not only the health professionals, but teachers, relatives and others. At present there is no cure for EB, but significant research is taking place internationally looking at gene, protein, cell therapy etc. Until a cure is found, the focus remains with managing the symptoms.

New Zealand History

In New Zealand the DEBRA NZ EB Nurse Specialists help over one hundred and fifty people (children and adults) who suffer with Epidermolysis Bullosa. Approximately sixty children have varying types of this rare genetic skin condition. We say approximately because these are the children we know of, but it is believed that there will be many others that have milder forms and who have not yet been identified as having EB. Some parents seek medical advice for their children for years trying to get a diagnosis. This was highlighted in 2014, when a further four children/young adults aged 10, 14, 17 and 22 where added to my caseload.

There are fifteen children in New Zealand who have the most severe type of EB and over the last four and half years five out of six babies born in the North Island have died prematurely as a result of the condition. The last baby died in January 2015.

Even though the numbers of people with EB in New Zealand seem low, these babies/children can still have very complex needs and require a lot of input from a variety of health care professionals. Providing effective care in the early years is essential to reducing the impact of long term complications and costs for the families and the District Health Board’s (DHB). The Canterbury District Health Board (CDHB) recognised this back in 2009 when I was employed as a Clinical Nurse Specialist four hours a week to care for one child. Working as an Outreach Nurse in the Child Health service I mainly deliver care at home. The main brief of my role is to coordinate care for the child & family and keep this child infection free and “out of hospital”. This person has since transitioned to adult services, but eight more children have since been diagnosed with EB within the CDHB area. I continue to care and coordinate for their needs eight hours a week.

DEBRA NZ EB Nurse Specialists have recognised over the years that there are challenges getting definitive diagnosis results when sending biopsy specimens to Australia for analysing. This has led to much anxiety and distress for families. I have questioned in the past, if there is a fault in our processes here in New Zealand and this has lead me explore further as an objective. I was hopeful that a review of our biopsy guidelines and the opportunity to benchmark our processes against other centres of excellence, would give us some of the answers we need to refine our practice.

The purpose of this report is not to point the finger, but merely to advocate for our New Zealand families and see what changes could be made to improve the current situation for more positive outcomes.

Families naturally get upset without having a definitive diagnosis and sometimes it is difficult to get resources such as wound care consumables funded without a diagnosis. The clients with EB require use of advanced wound care consumables as conventional products, will damage their fragile skin. Advanced consumables are very costly and for a client with a severe type of EB it can cost as high as three thousand dollars per week. The Ministry of Health (MOH) fund advanced consumables for clients with EB under special authority, but not before there is a diagnosis. There is also more difficulties if you are an adult client diagnosed and not in the hospital 'system'.

Obtaining a Diagnosis?

Currently in New Zealand we follow a biopsy protocol written by a team at Dermatology services in St Georges Hospital, Sydney, Australia. I am unsure how long our biopsies have been going to Australia and who made this decision for them to be sent there in the first instance. From what I gather from DEBRA members it was well over 30 years ago.

Most of our biopsies in New Zealand are taken by a Dermatologist. Last year one Dermatologist from Wellington did suggest that the Dentist or the Paediatrician take the biopsies from a child while they were under anaesthetic, but neither was willing to do this. This is something I would have been happy to perform, but unfortunately this was outside my scope of practice.

Sometimes the EB Nurse Specialist is unaware that a baby/child is under-going a biopsy, particularly if they are not known to DEBRA NZ. If this is the case, we loss the opportunity to assist with the correct paper work, use of the correct protocol for taking the biopsy and offering support for the family.

The EB Nurse Specialists' have tried over the last few years to make their role more visible. They have presented at many conferences to different health care providers such as Midwives, Dermatology nurses, Wound care consultants/nurses etc. This was to raise awareness of the condition, profile the role of the DEBRA NZ EB Nurse Specialist, and to highlight that EB should also be considered as a differential diagnosis, when a baby is born with a blistering skin condition.

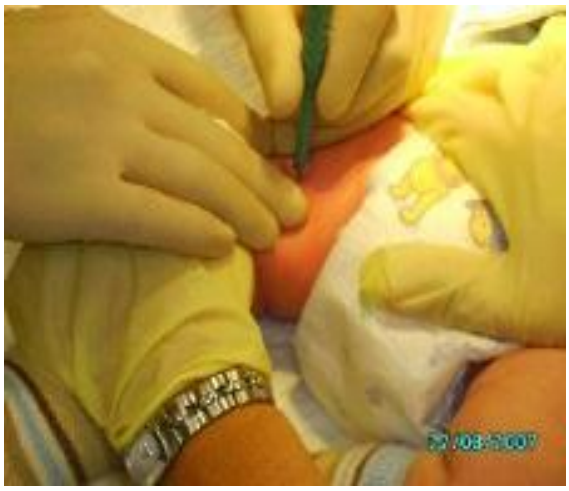

Photo 3: Punch Biopsy (source; DEBRA NZ library)

It is only considered necessary to biopsy a baby when there is no family history of EB and it is thought that the baby might have a recessive form of EB or a new mutation.

The DHB currently funds the cost of this biopsy unless a biopsy is taken in private practice and then the cost is passed on to the client.

Genetic testing may also be suggested and in New Zealand current practice, is to take 20 cc EDTA serum, extracting DNA and then, send the bloods to Molecular Biology Laboratory, Royal Brisbane Women's Hospital, Queensland, Australia.

What is the Current Practice of taking a Biopsy in New Zealand?

The protocol we follow is located on the Australian Blistering Foundation (2015) website suggests;

- A 3 mm punch biopsy from the rubbed area and placed in Michel's solution (transport media used for immunofluorescence specimens).

- Another 2mm punch biopsy is taken again from the (same) rubbed area and placed in 4% glutaraldehyde solution for electron microscopy.

- If possible, it is also useful to take a 3 mm punch biopsy from an unaffected, (NON rubbed area), usually the inner upper arm. The blistered area can identify the layer of blistering but the reduction of protein staining, if present this can be more easily assessed on skin that has not actually blistered. This is then to be transported as for the other IF specimen, in a separate Michel's media container, labelled as normal non-rubbed skin and the site.

The specimens for immunofluorescence (IF) testing are performed at St Georges, but the 2mm punch biopsy is sent to a laboratory in Melbourne for the electron microscopy (EM) test. Each laboratory then reports their own findings.

An International View - What do Other Countries do?

Prior to looking at objective 2, I had travelled to London where I visited two centres of excellence, the Great Ormond Street Children's Hospital and St Thomas's Hospital, where adult clients with EB are seen. I also travelled to Birmingham where I visited the Birmingham Children's Hospital. At this time I did not observe any of the health professionals taking a biopsy, but I was informed that their method of the taking a biopsy was a shave biopsy.

DEBRA UK established the first EB Nursing service at The Great Ormond Street Hospital (GOSH) and New Zealand EB Nurse Specialists' and medical staff benchmark with GOSH often. It is interesting to note that we don't take our biopsies in the same way though. As I have said before I am not sure who in New Zealand decided that our biopsies go to the laboratory in Australia, but I assume this was the closest country and laboratory that was set up to perform testing for the EB at the time of the decision and that travel distance and costs were part of the determining factor.

Great Ormond Street Hospital (London)

To show a comparison of how a shave biopsy is different I will explain the guidelines that Great Ormond Street follow. A biopsy site is taken from uninvolved skin on an unexposed site, e.g. buttock.

“The area to be biopsied may be gently rubbed with a finger (this is to induce micro-splits at the dermal-epidermal junction which can then be visualised by microscopy).
Local anaesthetic is then infiltrated into the skin, e.g. 2% lignocaine with adrenaline.
Once anaesthetised, a blue needle is inserted into the biopsy site, running parallel to the surface of the skin a few mm deep for around 5-10mm. A scalpel blade is then used to slice the skin from the surface of the blue needle. This will leave a defect in the skin around 2-5mm x 4-7mm in size which does not generally require suturing. The skin biopsy can be divided in two on a suitable surface (such as the lid of a plastic petri dish) using a scalpel blade with a rocking action (avoid shearing forces). Alternatively, if the biopsy size is small, a further biopsy may be taken. The samples should then be placed in the tubes of fixative provided for immunofluorescence and electron microscopy. It is important to transfer samples into these solutions immediately and they should not be allowed to dry out at all plus do not cross-contaminate the solutions” (DEBRA UK, 2011)

Bench Marking

Bench Marking with other countries, I found;

- **America (Cincinnati Children Hospital)** - Take a shave biopsy and this can be taken by a nurse.

- **Australia** - Take 2mm & 3 mm punch biopsies.
  They follow the same protocol as New Zealand. They also find that they don’t always get definitive results.

- **Austria (EB Haus)** - Take 4mm & 6mm punch biopsies. .

- **Chile** - Take 3mm & 4mm
  F. Palisson, (personal communication, March 3rd, 2014) lead Dermatologist for EB in Chile stated in an email communication with me, “Our experience is that only one person makes the antigen mapping and the Electron Microscopy to combine both information and make the diagnosis”.
- **Netherlands (Groningen University Hospital) -** Take 1.5mm & 4mm punch biopsies.

Similarities

Current practice in all centres is to biopsy for diagnosis

Differences

1. America & Great Ormond Street take shave biopsies and these can be taken by a nurse.

2. New Zealand, Austria, Australia, Chile and Netherlands take punch biopsies and these are not taken by a nurse.

3. Austria & Chile take 4mm & 6mm punch biopsies.

4. New Zealand and Australia take 2mm & 3mm biopsies.

5. Netherlands take 1.5mm & 4mm biopsies

6. All countries except New Zealand and Australia have their IF and EM testing in the same hospital. Results of both tests are placed side by side and one person then compares these results, which facilitates the process of making a final diagnosis.

Why are our results in New Zealand not definitive?

As I previously mentioned our biopsies are sent to different laboratories in Australia for Immunofluorescence (IF) mapping and the Electron Microscopy (EM) testing. I am not sure why this is, though I do know that all states have different limitations and are governed differently. It may also be an expense or resource issue.

I have asked the receiving laboratory on several occasions why we are not always receiving a definitive diagnosis and questioned “could the problem lie within New Zealand with the way the biopsies are taken?” When liaising with the Dermatologist and the Nurse Consultant at St Georges Hospital I have been told “not to numb the biopsy area with Emla cream first, as this may taint the results and that we must always rub the skin to induce a blister, but wait

until the blister appears before we biopsy and that this could mean waiting several hours after rubbing" (personal communication 2013). Often it is also suggested that we may need to re-biopsy the person and this has led to much frustration from DEBRA NZ families and EB Nurse Specialists.

How could we improve Care in New Zealand?

In February 2014 I met with my DEBRA NZ EB Nurse Specialist colleagues to discuss how we might be able to improve care for the EB clients and families in New Zealand when biopsies were taken. We considered the possibility of undertaking training to learn how to take a punch biopsy. Concerns were raised around the skills we would need and if we would need prescribing rights to prescribe Lignocaine that is used to numb the biopsy site and who would authorise the administration of this Lignocaine.

Earlier in 2013, on behalf of the NZ EB Nurse Specialists, I put a submission forward, to the New Zealand Nursing Council (NZNC) outlining our thoughts on the consultation proposal for registered nurse prescribing (NZNC 2013). In the submission I highlighted, if we were able to prescribe wound care consumables (which are already on special authority, but some families are asked for a script from a GP before they can order through a pharmacy) and simple medications we would be able to help reduce stress/anxiety and costs for the New Zealand families with EB & DHB's. We knew this was still a little way off becoming a reality, but something we might be able to work towards. We also had the offer from a paediatric dermatologist at Starship Children's Health to help train the DEBRA EB Nurse Specialists' with the procedure of biopsy taking, if this was given approval. It was decided that, I would approach Nursing Council to see if this could be something that might be approved if we perused this venture.

I phoned a representative at the at New Zealand Nurses Organisation (NZNO) office and explained that one of my objectives for the MMB travel and study fellowship was to improve the process of taking biopsies to aid the diagnosis of babies/children with suspected EB in New Zealand. I explained that the NZ EB Nurse Specialists' were thinking it may be beneficial to learn this skill, so that then there could be some consistency of biopsy taking for the EB patient in New Zealand. We had thought that this could lead to more definitive results and better patient satisfaction.

I was advised by an NZNO Representative that I needed to look and see if this would be within the RN scope of practice. She thought it could come under the general scope and that

we would need to adapt some training and education to support this. She said we also needed to ask the following questions;

1. Does doing this procedure keep within our scope?
2. How would we as an RN remain within our scope of practice and maintain our competency?
3. What would we have to show if asked about knowledge around it?

The NZNO representative went on to say, that because a biopsy is not a diagnosis, but a procedure that this should fit within our scope, as long as we were not to diagnose with the results ourselves. She did however think that we would need to have an endorsed education package around this and we would need to support this with references which were evidence based. She suggested we also look overseas for support.

As EB Nurse Specialists we are very aware of our professional and ethical accountabilities and the competencies as determined by Nursing Council. We are currently looking at the 'Guideline: Expanded Practice for Registered Nurses (2011) and the Education Policy Framework (2013) that NZNO have written. It is hoped that these policies will also reflect the College of Child and Youth Nurses' (2014) mission to assist the "development of specialty knowledge and skills to meet the unique health needs of all children within New Zealand". We believe an expanded practice role would help us practice within the protection, partnership and participation principles of Te Tiriti o Waitangi.

I went on to contact this council office to ask again, if an RN wanted to be trained to take biopsies, what would she need to do to formalise some training and does Nursing Council need to be involved?

It was suggested that I look at the education package that Nursing Council had developed as Nursing Council did not have a list of what we can or cannot do, but the decisions were more around scope and competencies. Questions that might be asked around the competency are;

1. Is it safe?
2. Is it appropriate?
3. Has there been education for this and what was the preparation?
4. Who will evaluate the expanded practice?

It was explained to me by the Nursing Council Representative, that the education package should talk us through the steps of what is required to expand our practice and then I would be able to see if we fitted into this criteria. The final decision however would still lie with our employer. For the EB Nurse Specialists' it would be a matter of deciding who would be the right body to take this responsibility – DEBRA NZ who employ us or MOH who fund the position.

All three NZ DEBRA EB Nurse Specialists have an expert level PDRP, and this was suggested to be a good place to show where our evidence lies for expanded practice. We could document our training and ongoing evidence of professional development, which would show relevance to our expanded practice. With maintaining our PDRP we would not be audited, but there may be another time that evidence was asked for by Nursing Council, so this is why it was important to keep this documentation. The Nursing Council representative then went on to say that we had identified a gap and this is what an expanded practice framework is for, plus we have the knowledge and expertise so it makes sense to look at doing this.

After further consultation with my nursing colleagues in 2014, it was thought that perhaps we would not have enough babies born in New Zealand annually to keep our competency skills up, this could be said for other competency such as CPR. We will continue to debate the need for this in 2015. In the meantime the NZ EB Nurse Specialists' will continue to support the health professionals who take the biopsies.

We do agree however, that an advantage of having the EB Nurse Specialists gain this competency would save costs to DHB's as some babies/children in rural or smaller towns are often referred to Starship Children's Health in Auckland. They are often flown there or wait for a visiting Dermatologist to visit their centre. There is usually a delay to get this organised, which then leads to more anxiety and stress for the families, leaving their homes and not having continued support. If the EB Nurse Specialist was already flying to the local area, then it seemed sensible that they also take the biopsy. This is highlighted in the case study below.

Case Study

Baby X was born in a small New Zealand city in November 2014. The locum dermatologist working in this area had never performed a biopsy on a baby before and was not keen to do so, on baby X who had a suspected diagnosis of EB. At the request of the staff from the Special Baby Care Unit, I flew to visit the baby, family and health professionals to offer

support, advice and education, which then enabled the family to be discharged home the next day.

The local dermatologist had been in touch with a Paediatric Consultant/Dermatologist at Starship Children's Health and it was thought that since the baby did not have extensive skin loss that there was no urgency to biopsy this baby and it could wait until the visiting Consultant ran a clinic there in March. The family were very disappointed as they wanted answers now, but were anxious to also get their baby home.

After being discharged home the homecare nurses visited regularly and when baby X started to show more signs of skin loss and nutritional deficits, they communicated their concerns to the Paediatrian. It was then thought that baby X had more internal problems that were not apparent at birth and a biopsy sooner than later would be preferable. After further consultation the baby was biopsied in the local hospital by the locum dermatologist five weeks later. The specimens were then flown from New Zealand on the 16th December to Australia as per protocol. I had asked one of our New Zealand consultants who oversees EB in NZ, if on this occasion they could consider a change in our practice and send these biopsies to a new research Laboratory in Singapore. I was keen to see if we could get definitive results from this facility, but it was not considered on this occasion. As baby X continued to deteriorate a request was made to the Australian laboratory asking for the results as soon as possible. These were received one month after they had been taken, though the Christmas holiday period probably had some impact on this delay. Two days after the provisional results were available baby X died.

There has been much learning from this case but all too late to be of help for this family. We *are* unsure why the results took so long to get from Australia when other overseas laboratories can give results within 24-48 hours, particularly if they urgent. Earlier diagnosis is unlikely to have changed the outcome for baby X as the type of EB was extremely severe, but it would have provided more time for preparing the family for an evident loss.

International Collaboration - a further opportunity to compare and evaluate other treatment methods for EB care.

1. EB CLINET - Salzburg

In October 2013 I was fortunate to attend the 2nd Conference of EB CLINET held in Salzburg, Austria, which saw 91 delegates from 29 countries.

EB CLINET is the name for Clinical Network of EB Centres and Experts. The aim of EB CLINET is to strengthen collaboration between medical institutions worldwide that already provide specialised medical care for clients with EB. The purpose is to share expert knowledge through networking and to provide a basis for clinical trials to help accelerate finding a cure for this condition.

EB CLINET is an initiative of EB Academy. At the Academy, training and education programmes are run for doctors, therapists and scientists and evidence-based peer reviewed clinical practice guidelines for EB care are also developed. They hold the International EB registry for clinical studies and treatment and have the directory of all the centres of expertise, laboratories and bio-banks in the field of EB. One reason for the global registry is help identify and recruit patients for clinical practice trials

At this conference there was an opportunity to discuss in workshops, what happens in our own countries in relation to the clinical practice guidelines that we saw as being important to be developed, through to ideas to be written in a patient handbook on how to manage EB and living with EB. In addition to the workshops there was a series of clinical complex case presentations and case studies.

Three representatives from New Zealand attended the conference – a Consultant Paediatrian/Dermatologist who has an interest in EB, DEBRA NZ Director and me as the NZ EB Nurse Specialist. We were separated into different 'working groups' to brain storm on many different topics. The international group that I worked in consisted of researchers, a dermatologist, a psychologist, nurses, and others with genetics and pharmaceutical backgrounds. Each group at the end of each the working session would choose a leader to present back their ideas to the larger audience. At one stage the 3 NZ representatives found themselves doing this at the same time. Several delegates commented that New Zealand were very much active contributing members regardless on the size of their country and population base that they treat. This was pleasing to hear and gave us a true sense of value.

Photo 4: My 'Working Group'

Photo 5: Three Representatives from New Zealand

I found this meeting very thought provoking and was pleased that sufficient time was provided to make valuable connections for future networking with so many experts working within the field of EB.

EB Haus

During this conference we had the opportunity to visit EB Haus. The Paediatric Dermatologist Consultant and I had already had a private tour, but on this day we got to meet many of the staff who worked in the facility and to visit the research laboratory where they are investigating a cure for EB. This is where their biopsies are also processed. EB Haus was set up by DEBRA Austria by using donations and a one off subsidy granted by their Federal Government to set up this special medical centre. It is set up in the grounds of Salzburg Hospital and forms part of the department of Dermatology. Since opening in 2005 it has become known as a centre of expertise. The centre not only gives medical care in their outpatient unit for people with EB but runs educational training for health professionals to access all over the world. EB Haus continues to run with private donations and the use of the centre is supervised by DEBRA Austria.

2. DEBRA International Conference - Rome

From Salzburg, I travelled on to the DEBRA International 23rd Conference. This has grown in size since the first DEBRA International Congress, which was held in Salzburg in 1992. Only eight countries attended the inaugural DEBRA International conference while over forty countries were represented in 2013.

DEBRA International is the main point of contact with the worldwide research community. It has encouraged the development of centres of clinical excellence and continues to link professionals worldwide. DEBRA International is also recognised as a major player in the international rare disease world and has significant influence in policy development at a World Union level (DEBRA International website).

This conference is very much patient focused and we heard from the patients themselves what it is like to live with EB. It is important that they and their parents have a voice at these events. After all, this is our main focus.

A new International Consensus document titled “Best Practice Guidelines for Skin and Wound Care in Epidermolysis Bullosa” was released in 2012 by UK nurses. DEBRA NZ EB Nurse Specialists where among a few countries asked to peer re-view these prior to the launch. These guidelines were a great topic of conversation at this conference. Families have found these practical and easy to follow and delighted to have something written to give their treating health professionals who often do not have a high level of knowledge or expertise of their condition.

Just prior to leaving New Zealand, the EB Nurse Consultant from the UK emailed me to say she would be facilitating the Nurses Forum at the DEBRA International conference. She asked if I would present my clinical case study findings on a new wound care product that I had trialled in New Zealand for our clients. Though I would not be gaining any knowledge myself, I felt it was important to share my experience with my International Nursing colleagues, as this is how we all learn. It was also a good opportunity to showcase how a New Zealand Nurse working autonomously and thinking ‘outside the square’ is able to improve client outcomes. It was pleasing to present on a product that not only showed promise, but was also made in New Zealand.

I started my presentation by saying, while there is currently no cure for EB, nurses are always on the lookout for new products that could be of benefit for our clients/patients. I explained how I first came across the Keratin range of dressings at a New Zealand Wound Care Society branch meeting when the products were first introduced as “new to the market”. Because our clients with EB have a defect with the Keratin gene, I wondered if these products would be useful, if applied topically. I approached the company about trailing their products and they were happy to support me with free samples.

During the trial some of the clients articulated that Keragel® was a little thick and took too long to dry, so the company went on to make a thinner version called KeragelT®, especially for the client with EB. Clients or parents (youngest child was 6 months old) felt that this product helped heal wounds more quickly and make the skin more robust. Many were able to reduce the amount of dressings they used, which in turn went on to become a cost saving for the DHB’s. I went on to present the findings at the Australian Wound Care conference (Appendix1) and the results were published (Than, M, et al. (2013) & (Kirsner, R, et al. (2012).

The basis of this trial recognised the potential of a product and KeragelT® is now used by many other EB suffers around the world. My presentation at this conference gave others insight into a product that they had not been exposed to before. It helped me to strengthen my international ties as I continued to answer many emails with questions, once I returned back home to New Zealand. Since this trial I now sub-contract to Keraplast as a Nursing

Advisor on the use of their Keratin products and help with other clinical trials/case studies as requested.

Conferences are a great way for networking opportunities and to gain ideas from others. One idea I particularly liked was an EB simulation baby. I think this would be a useful resource for the DEBRA NZ nursing team to have when teaching not only in the hospital environment to health professionals, but also in the community with families.

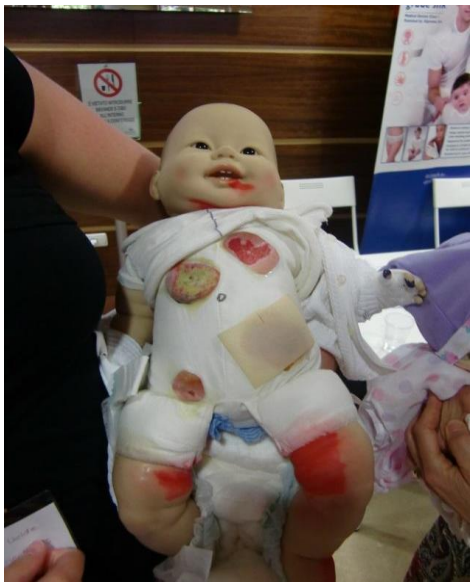

Photo 6: EB Simulation Baby

I have since put a request forward to the Medical Physic & Bioengineering department at CDHB to see if they can make this resource for the NZ EB Nurse Specialists' and suggested that though I would like our simulation baby to be similar to the baby pictured, we would need one with a washable body, so it complied with our NZ infection control standards.

DEBRA International also has another 'arm' called **EB Without Borders** (EBWB). The focus of this group is to help patients, families and doctors in countries where there is no or little support and to also help establish national DEBRA groups.

3. Further Opportunities - Turkey

After the DEBRA International conference was finished I had two free days before the next conference in Madrid. As I was close to Turkey, the company Keraplast (who developed the Keratin products) asked if they could fly me to Istanbul to give education to approximately 50

health professionals there who were caring for people with EB and who had been using the Keratin products for several months.

Once again I was happy to share my knowledge, but to also see how others were practising Health Care in Turkey. This was quite a different model of care to New Zealand. Basically you have to be an inpatient in Turkey to receive any funded dressings. All the children being treated with funded products had to return to the hospital for their dressing changes. They do not have community nursing services as we do in New Zealand. Many of the health professionals had not had a lot of experience caring for people with EB and many children with a severe form EB already had mitten deformity. Mitten deformity is where fingers contract and skin cocoons the hand. One plastic surgeon asked what he could do for these patients. I explained that surgery was an option, but they would need to focus on a preventive model of care afterwards. With careful positioning and wrapping of the fingers/hand this can prevent or slow down at the very least, further contractures and stop the mitten re-developing in a very short time.

Photo 7: Mitten Deformity

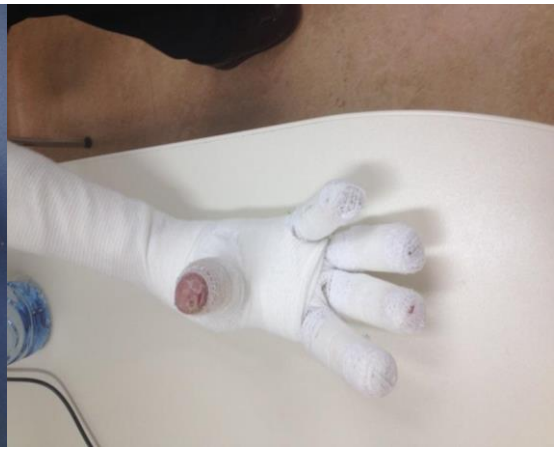

Photo 8: ABC Wrap Technique

In New Zealand we put these preventive measures into place and use a technique called ABC wrapping. I was able to teach this technique to the nurses at this training day.

Having just returned from the EB CLIENT meeting, I knew of the training that could and should be offered to the health professionals, so once I returned to New Zealand I connected the doctors from Turkey with the doctors at EB Academy at EB Haus (personal communication with Dr G,Pohla-Gubo & R,Ried October 2013).This travel opportunity showed me that such international exposure not only benefited children and families in New Zealand, but it can also be of benefit to patients in other less fortunate countries.

5.

6. 12th World Congress of Pediatric Dermatology Conference – Madrid

From Istanbul I travelled to Madrid for the 12th World Dermatology conference. There were only two representatives from New Zealand, myself and a Consultant Paediatric Dermatologist from Starship Children's Health. A small proportion of the meeting covered one of my objectives looking at childhood eczema. This conference highlighted that New Zealand not only keep up with best practice care, but we also lead the way. It was mentioned in several presentations that New Zealand has the best Dermatology website to gain information from called, Dermnet.

Other topics which were also of interest to me were neonatal dermatology, nails disorders of the new born and pathophysiology of pruritus which is a constant problem for our children with EB and eczema. There were also further presentations from UK & Australia consultants on EB who had not attended the previous two meetings that I had attended.

Since returning from this conference Consultant Dermatologist Dr Diana Purvis from Starship Children's Health has released 'Bleach Guidelines' (Appendix 1), for prevention of infection issues relating particularly to eczema and I initiated that DEBRA NZ formalise their 'Normal Saline' bathing guidelines (Appendix 2).

'Normal Saline guidelines are useful for people who suffer with painful skin conditions when bathing. Anecdotally over the last 30 years, DEBRA NZ clients have found that bathing in saline can reduce the pain experienced. A paper by Petersen.B (2015) to support bathing in saline has since been published in America. I use both the 'bleach' and 'normal saline' guidelines in my everyday practice and have shared these resources with many health professionals nationally and internationally.

After this conference I returned home to New Zealand for a few days and the following week flew to Perth to attend the Australia and New Zealand Burn Association conference. I will cover this in more detail in section 3 of this report.

5. Malaysia

In 2014 one of the DEBRA New Zealand's adult clients asked if a NZ EB Nurse Specialist could travel to her home country, Malaysia. This was to give support and education to health care professionals who were looking after children with EB and their families, as they set up DEBRA Malaysia. One of my colleagues was not available and the other did not feel she had

enough experience particularly in Paediatric care. I was happy to go, but explained it would be dependent on timing because of my other travel/study commitments for the year.

Early August I flew to Malaysia for what they called a ‘road trip’. Even though this visit had nothing to do with my MMB study I have decided to include some findings because as a dedicated nurse, we help people in need and I knew that with every experience there is always something new to learn. I was invited as a health professional to give presentations on EB to other health professionals & families in Kuala Lumpur, Ipoh, Penang, Kota Baru and Kuching. After each presentation I attended their Dermatology clinic where I was able to offer advice on wound care and give demonstrations on practical aspects of care.

Photo 9: Delivering Education in Malaysia

This trip highlighted many things we take for granted in New Zealand; clean water, a funded dressing scheme, access to many advanced wound care products and good community nursing services.

I had to think quickly on my feet at times and this experience certainly taught me to pull from my library of knowledge and to transfer this knowledge in ways that could be useful for the people in this country.

I found the way the health professionals dealt with the children within their culture quite different to how we would in New Zealand. We have access to specialised play therapy teams who teach us many good ways to help the child when procedures are taking place. It didn’t appear the nurses had been taught the same skills and would lay the baby/child flat

down on their back to undress them, while many adults towered over top of them. The children understandably felt frightened, vulnerable, stressed and upset. I had taken several bottles of ‘bubbles’ with me to give to the children as a thank you gift, so each time I saw this happen I brought the bubbles out and asked someone to blow them, to help distract the child. I also suggested to parents to pick their baby/child up, put them on their knee or stand them on the bed and cuddle them and that I would work around them. This comfort positioning appeared to alleviate some stress and anxiety for the children and they were very happy to try and catch the bubbles to ‘pop’ them. The older children also felt very exposed being asked to take all their clothing off with many strange faces looking on. Again, I made a suggestion that perhaps I just look at one area at a time and that there was no need to totally undress their child. By the end of my interaction with families they appeared to leave feeling quite happy. One little girl even ran back to give me the biggest cuddle and said “thank you, thank you for making my skin feel better”.

I left each child with a gift of a book called ‘Going to Hospital’- A book for children (Fernando et al; 2003). This was a book that I was a co-author of in 2003. A Nursing colleague and I updated this book for re-publication in 2014. A trustee from Rainbow Children’s Trust, who funded the book, had given permission for me to distribute the older copies overseas. I hoped leaving this resource might help alleviate some of the anxiety around a hospital visit in the future as it had for many children in New Zealand. I also knew that children like to see pictures of other children.

Photo 10: Photo of Family at Clinic – Malaysia

Photo 11: Helping with Wound Care in Malaysia

Due to the lack of clean water supply many do not bath in Malaysia. I was told that one young girl was constantly on antibiotics because her wounds were always infected. I left copies of the New Zealand ‘bleach’ and ‘normal saline’ guidelines for them to consider using.

Wearing many dressings was not always practical because of the temperatures in Malaysia. I introduced them to a variety of suitable dressings (and techniques) to use including KeragelT. As mentioned previously, from case studies, this dressing had been effective for healing the EB wounds quickly and helped to strengthen the skin.

DEBRA Malaysia was keen to adopt a lot of the same practices that we deliver in New Zealand. I was able to share many of our DEBRA NZ resources including a list of the contents that we have in our ‘baby box’. This box has the dressings required if a new baby is born with EB. In NZ our initial boxes were funded by Molnlycke Health Care and these are kept in 4 main city centres around New Zealand. Molnlycke Health Care in Malaysia funded my visit and also the baby boxes for their country and delivered them to each neonatal unit in each of the hospitals that I visited.

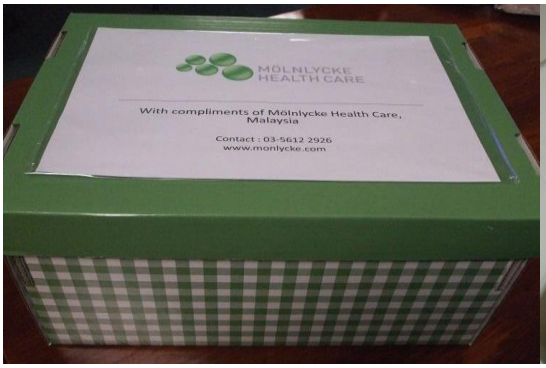

Photo 12: EB baby box

Photo 13: Contents in baby box

6. Singapore

Early 2013 a free research laboratory in Singapore was set up. They provide a diagnostic service of Immunofluorescence mapping. The Lab agreed for me to visit but asked if I could in return speak with some health professionals and families about EB while I was there. They had heard I had given clinical education in Malaysia and Singapore was also in the midst of setting up a DEBRA group. I spoke to Dermatology/Paediatric Nurses & other health professional, plus some families giving some practical tips on care. This teaching was videoed by a DEBRA Singapore (2014) and is now available for anyone to view via U Tube. This is something that other health professionals in New Zealand may find useful to watch.

The afternoon was spent in the Laboratory watching how they prepare their punch biopsies. DEBRA Singapore (2014) has since posted the education they gave me online for others to see also see - titled 'Histology processing'. The researchers at this lab believe that the biopsies should be of 3 & 4mm in diameter and not 2 & 3mm which are taken in New Zealand.

This lab is keen to genetically screen patients with EB of all types to help identify subtypes for clinicians and families, but also identify new mutations and genes to progress research. I asked the question around costs and favourably was told it would only be the cost of transport.

They are also able to run blood panel testing on nine genes. It is believed that this will be the way of diagnosis in the future and perhaps another avenue for us to explore in New Zealand. This is a less invasive and less painful procedure than a biopsy and only requires 20mls of blood to test. Such a visit helped me to question what is; "best practice for the diagnosis of EB. I hope by passing this information on will stimulate health professionals involved with EB to discuss the diagnosis methods in New Zealand and develop some guidelines around this.

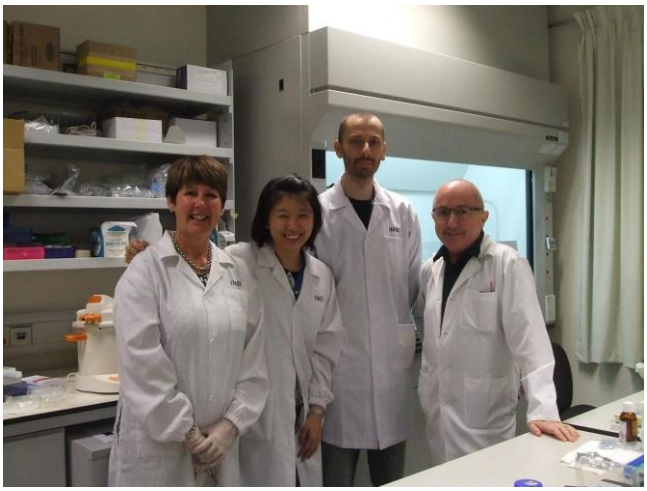

Photo 14: Lab Team in Singapore

7. Groningen Hospital - Netherlands (EB Centre of Excellence)

When visiting the Netherlands, I spent two days observing the work of Dermatology/Nurse Practitioner at Groningen University hospital. Groningen Dermatology department, care for approximately three hundred and fifty patients with EB.

I had the opportunity to talk again with their Genetic Service Researcher whom I had met the year previous at EB CLINET. He had been working on a series of blood testing panels and was able to confirm that from the following week (1st October 2014) they would be able to offer a blood testing panel for 27 genes. He said they would be happy to accept blood for testing from New Zealand, but the cost would be approximately three thousand dollars. This was exciting news to hear and something I plan to pass on to the Geneticists in New Zealand, who has expressed an interest in compiling a database of New Zealand EB clients.

The day continued with the Nurse Practitioner and me visiting a new family in the neonatal unit who had a baby born two days prior with EB. The parents were keen to have hands on experience changing their baby's dressings with the nurses giving guidance where necessary.

The Nurse Practitioner was also keen to benchmark with what we are doing in New Zealand, so after she had given her advice to the family, she asked if we would do anything differently and invited me to offer further advice. It was a real privilege to work alongside this nurse. Once again, this offered an opportunity to discuss best practice and improve practice throughout the world. I confirmed that the method of treatment that she was using was the same as ours and this highlighted that New Zealand are working in accordance with other international areas.

Photo 15: New baby born with EB

After the dressing change we all met with Professor Jonkman, He gave the family their child's biopsy results and was able to discuss the future for the child & family. What was of significant difference from care in New Zealand was the biopsy results were available within 48 hours. This enabled early conversations about the infant's diagnosis, which helped when discussing future outcomes.

The next day I attended the laboratory to observe how they also prepare their biopsies. The process appeared the same as I had seen in Singapore, so again it led me to think the problem could lie either in the way we take the biopsies, the diameter of biopsy we take or in the lack of consistency with different people reading both IF and EM results.

I then spent some time with Professor Jonkman and he showed me how he would look at making his diagnosis looking at both reports/slides side by side. This was good to see, but did highlight to me why he is considered an expert in his field as the process still appeared very complicated.

In the afternoon I was an observer at what they call their 'carousel' multidisciplinary clinic, which is held every two months. It was suggested that I stay with one child in one room, so I could see how this worked. All health teams consult with an individual patient/family and rotate in 30 minute time slots. This included, a Dermatologist, Nurse Practitioner Paediatrian, Dentist, Plastic Surgeon, Physiotherapist, OT, Dietician, Psychologist and Social worker.

Photo 16: Patient I Observed in Multidisciplinary Clinic

After the clinic in a team meeting, future needs of all the cases were discussed one by one and the relevant referrals were made. This type of clinic is certainly something the DEBRA NZ EB Nurse Specialists would like to see available for New Zealand families.

Following this team meeting the Professor gave a presentation on his latest research. This was also what he would be presenting at the up & coming DEBRA 2014 Conference (two days later). His presentation was on Revertant Mosaicism.

Revertant Mosaicism (RM)

The Professor discussed that normal skin for patients with EB is viable skin and called Revertant. He had been taking a skin biopsy from 'normal skin', to grow the cells and then graft these cells onto the patient. He has found that grafting the biopsy straight into the wound has helped. This is called transplantation or mini grafting. The Professor explained that if a patient had a mutation then they wouldn't produce the protein, but they can have Revertant spots on their body. Pigmentation does require Collagen Vll, so this is a possible place to start looking. He talked of rubbing the skin first to make sure it doesn't blister; otherwise it will be a waste of time taking the biopsy. He explained that Revertant skin is not seen at birth, but after 4 weeks of life and it can grow up to 8 years and then cease growing. The professor believes everyone has RM cells, but you can't always see them and all you need is a 1cm patch.

He advised us to ask our patients if they have normal skin anywhere on their body. Can they wear jewellery? Is there pigmentation, and does the skin feel normal? He then suggests that the health professional check the skin by pushing a ball point pen to see if the area blisters or not. If the skin doesn't blister, then the skin is appropriate to biopsy. Once the biopsy is taken it is then 'transplanted' straight onto another non-healed area of the body. I know talking with nurses in the UK they are able to perform this procedure for their clients. Something else for us to look at in New Zealand, but as Nursing Council have explained it would need and educational framework to support this.

Another promising research trial the Professor and his team are working on is Allogenic Bone Marrow Transportation. On the 10th September 2014 (just a week prior to my arrival) the first child was given this treatment. This is what they call a phase two trial which is a safety trial. It is hoped that the transplant will increase Collagen Vll and improve blistering.

These trials have been happening in Minnesota for a few years now, but two out of twelve cases have died from associated complications. Groningen has been collaborating with Minnesota, but is doing things slightly different. They have chosen not to give full chemotherapy to reduce toxicity of stem cells and are using unrelated

cord blood as the stem cell source called a ‘wild’ type donor (where the person doesn’t have EB). Cells are to be given 3 times in 2 months and care monitoring continues to take place.

This programme will last 5 years and they are only enrolling patients who have Recessive Dystrophic EB (RDEB) at present. They are allowing Junctional EB Herlitz (JEBH) patients who suffer another severe type of EB, which is life shortening, to be enrolled on the trial also. This is for comfort and compassionate reasons and to have them ‘buy’ some more time. We have three children in NZ with RDEB and 5 out of 6 of our babies that have died in the last few years have had JEBH. The professor is hopeful to have funding for stem cell treatment in 2016 and there is already one NZ family thinking about this as a treatment option for their child.

After a busy day the Professor treated his team all to dinner and I was invited also as their ‘guest’. This was for not only team building, but also celebrate a retirement. The photo as you will see shows their dynamic team. It was a truly inspiring day/evening.

Photo 17: EB Multidisciplinary Team – Netherlands

Unfortunately we do not operate this type of service for our patients in New Zealand. There are many challenges in New Zealand’s health care services including some differences and inequalities across DHB’s around access of dressings through the hospital system. I will not

be focusing on this further in this report, but I did highlight frustrations around this at the 2013 National Clinical Nurse Specialist conference.

As Christopher Lanschuetzer (2009) states “although the initial concern of Pediatric Dermatologists and Neonatologists is to establish an accurate diagnosis and implement appropriate care for the skin, treatment of extracutaneous complications becomes increasingly important over time, in order to ensure the best quality of life for these patients. Given the rather protean manifestations that arise in hereditary EB, optimal care is performed in a specialised multidisciplinary centre, staffed by physicians and therapists of all medical disciplines who are well familiar with this disease”.

It is hoped in the near future that a National multidisciplinary service can be established like Groningen offer. This could see ‘tagged’ experts visiting the patients who have EB either in their local Paediatric clinic, to support the local health professionals or for the patients to be funded to travel to one nominated centre, just like the model of care I witnessed in Groningen. Seeing this model used overseas has helped me to understand how valuable this could be for the NZ EB client. This is the **‘gold standard’** that we are also striving for and an exciting goal for the future.

8. DEBRA International Conference - Paris

After leaving Groningen I travelled through to Paris to attend the 2014 DEBRA International conference. It was lovely to meet up with old acquaintances from the previous year and a large group of Nurse’s & Dietician’s from the UK whom I liaise with regularly, by email.

 P

Photo 18: UK Team

This conference was quite different from the 2013 conference. There were many more presentations on research that was taking place internationally to try and find a cure for EB. It was also explained that because of the rarity of different forms of EB, clinical trials require clients to be recruited from different countries. Sometimes more than one country will collaborate and combine their trials. Recently there have only been a handful of clients from NZ who have assisted with research. These have been adults and the trials have been through St George's Laboratory in Australia. The three main therapeutic approaches to EB at present are: Gene Therapy, Protein Therapy and Cell Therapy.

A review from DEBRA International (2013) recognised that funding continues to be a challenge, so external partners are sort that are willing to invest. New Zealand certainly does not have the expertise, the funding or patient numbers to run large trials. We do however make some small contributions as I have previously mentioned with the case study series of trials that I ran in New Zealand with the Keratin products. This trial highlighted advancement of wound healing by activating Keratinocyte activity. The Keratin products are seen as an adjunct to treatment at the current time, until a cure is found.

Again I go back to one of my main objectives which are for New Zealand to be able to obtain definitive results when taking a biopsy for the diagnosis of EB. There are concerns by nurses that although the management of all types of EB is similar, it is important to be clear about the diagnosis so that families can be given accurate information regarding the prognosis especially in the newborn.

Clinical Guidelines

Currently there are no International Guidelines for taking of a biopsy to diagnose EB, but EB CLIENT has identified diagnosis of EB as a **high priority.** In March 2014 DEBRA International were calling for EB clinical experts to get involved with clinical practice guidelines to help improve the medical care of the EB patients across the globe. I responded to the call (personal communication March 14) explaining I had attended the EB CLINET & DEBRA International meetings where it was made clear we should all be working together to develop one consensus document for each area of EB care. I explained that current practice is in NZ was that a medical doctor took a punch biopsy, but that NZ DEBRA EB Nurse Specialists were exploring if this could be an advanced role on their practicing certificate. I offered to help in anyway, but did not feel I would have the necessary knowledge or expertise to lead or develop a guideline.

A reply letter from DEBRA International council explained that "Dr.Gabriela Pohla-Gubo, Dermatologist from the Department of Dermatology & EB House in Austria would be the

leader of the EB Diagnosis and Antigen mapping Clinical Guidelines, but I was welcome to collaborate with her work". I was also told that the "idea to develop a video with the explanation of how to take a skin biopsy for a patient with suspected EB was an excellent idea". It was suggested that we apply to DEBRA International small grants for funding.

I had met with Gabriela on several occasions, at EB Haus and the EB Clinet meeting in Salzburg in 2013 plus DEBRA International conferences 2013 & 2014. I emailed her to offer my assistance. She replied saying "I´ve just started with some preliminary steps, e.g. methodologies to prepare a diagnostic guideline, and therefore it is not the time to act at the moment". "I´m glad to have the opportunity to come back to you, as soon as we have more information and a structure. Any collaboration is highly welcome". This will be something I can follow up on in the future.

Photo 19: Networking with Dr.Gabriela Pohla-Gubo

In a discussion with my DEBRA EB Nurse Specialist colleagues it was thought a good way to capture information on how biopsies' are taken for the diagnosis of EB would be to ask other countries what they did via a survey. Talking with the DEBRA NZ Director she suggested that perhaps a video had already been made of the biopsy taking procedure that could be shared. It was thought this could be a question put into the survey. Since this discussion our Director has been contacted from a health professional in Singapore asking if there is such an educational tool to guide them.

Around the same time I was assisting our New Zealand Consultant Paediatric Dermatologist take a biopsy of a child with suspected EB. I asked if I could arrange for the procedure to be professionally videoed as this would be a helpful resource for others less confident in the procedure and also help with consistency of biopsy taking. It was felt at this time that the best place to arrange for this was with the receiving laboratory in Sydney. I have currently put this

idea on hold, but I would still be keen to pursue this once we decide the future of biopsy taking in New Zealand. It had been suggested by Dr Francis Palisson (personal communication March 14) that DEBRA International small grants might be able to help fund this. Again, this is something to follow up in the future.

Further Questions

I still have many questions that need to be discussed with the relevant parties for future advancement to be made;

- Would there be a funding issue if we want to send our biopsies further afield overseas?
- Who would make the decision if we were to change the laboratory we send our biopsies to?
- Would the laboratory in Singapore be seen as authentic, if it is a research laboratory?
- Should the person taking the biopsy have prior experience with taking biopsies for an EB diagnosis?

Recommendations to be considered for future improvements

- Prepare a New Zealand guideline on procedure for taking a biopsy.
- Video a step by step approach of how to take a biopsy.
- Consider the EB Nurse developing the skill of taking a biopsy.
- Consider reviewing the mm of the biopsies we take. Perhaps take two, 3mm biopsies, or 3 & 4mm biopsies.
- Consider sending biopsies from NZ to a laboratory where both tests are performed in the same place and results are read by one person to make the final diagnosis.
- Consider sending bloods only, for blood panel testing instead of taking biopsies.

Conclusion

It is known that organisations benefit when the care we provide is based on best practice and this therefore reduces the risk of untoward events. Margaret May Travel & Study Fellowship has enabled me the opportunity to observe in clinics of excellence (EB Haus and Groningen University Hospital), attend three of the most important EB related conferences/meetings (EB Clinet, DEBRA International and the World Dermatology) and provided me to opportunity to look at how we work in New Zealand in relation to International best practice. With this travel opportunity I have not only enhanced my knowledge to bring back to share in New Zealand, but I also participated in discussions offering the New Zealand perspective. What was also pleasing, though not planned, was as a New Zealand nurse, I could contribute to others gaining knowledge in the care of children with EB in Turkey, Malaysia and Singapore.

My knowledge and skills have been developed through experience and training. With the relatively small number of children with Epidermolysis Bullosa in New Zealand, for any specialist training or to learn about best practice from experts, it has been essential for me to travel overseas where clinical centres of excellence and strong networks of expert professionals are established or being developed.

Looking at the frustrations of the length of time and lack of definitive results for the biopsies we send to Australia was one of my main objectives. I have been able to establish that that we are asked to take 2 & 3mm punch biopsies in New Zealand, but Austria, Chile, Singapore and the Netherland ask for 4mm biopsies or larger .
Our biopsies for Immunofluorescence Mapping and Electron Microscopy testing is performed in separate laboratories and reported on by two different people hence not always giving us definitive results. This can also be a lengthy process weeks/months rather than days as in other countries. Even though a diagnosis would not change an outcome, it could still provide more time to prepare a family if loss was evident. I had wondered if it was a New Zealand "user error", but experts from Chile and the Netherlands in personal communication told me that they believe only "one person should make the 'antigen mapping' and the 'electron microscopy' to combine both information and make the diagnosis. Observing how a biopsy is prepared in two laboratories (Singapore & Groningen University Hospital) and being shown by Professor Jonkman how he would look to make his diagnosis was good to watch. I could see why he is considered an expert in his field as the process still appeared very complicated to me.

EB ClINET have identified diagnosis of EB as a high priority and early 2014 DEBRA International called for EB clinical experts to get involved to write clinical practice guidelines to help improve the medical care of the EB patients across the globe. I have offered to help in any way, such as taking a video of the procedure.
The New Zealand EB Nurse Specialist is exploring the possibility of undertaking training to learn how to take a punch biopsy and there have been discussions with the New Zealand Nursing Council and New Zealand Nurses Organisation around scope of practice and the educational framework needed to support this expanded practice. On behalf of the New Zealand EB Specialists I had put a submission forward for registered nurse prescribing which could benefit our role.

Observing how a 'carousel' multidisciplinary clinic works and the benefits for the child and family who see many health professionals was also good to see. It is hoped New Zealand may be able to establish a National service for the EB clients in the near future, either where clients are flown to one main nominated centre or 'tagged' experts are flown to other clinics to support the local health professionals.

Hearing first-hand about the research and the development of new technologies in the Singapore and the Netherlands such as blood panel tests and how these may reduce the need for biopsies in the future and assist with a more accurate diagnosis in a quicker timeframe, was truly encouraging.

This travel and study opportunity has helped strengthen my international networks, so ensured that I and my EB Nurse Specialist colleagues are not working in isolation. I will continue advance the knowledge I have gained from this travel opportunity and work on further improving care for people with EB within New Zealand.

Section Two: Pressure Injuries

Introduction

Early 2014, I made plans for further travel that would enable me to expand my knowledge and expertise, and assist with achieving my objectives. These included reviewing current pressure injury programmes around the world and using this experience to improve care in New Zealand.

My intention was to attend the 2nd International Paediatric Wound Care Symposium (ISPEW). This conference got re-deferred to September 2014 in Paris, so I worked to tailor my travel plans around this date. First I sought permission from the trustee's to extend my travel and study time, then to plan and attend this Symposium. The added advantage was the 2014 DEBRA International conference was also going to be held in Paris, around the same time. My interest in attending the 2nd ISPEW, stemmed from attending the inaugural Symposium in 2011 as the sole New Zealand delegate. This symposium provided the opportunity for all multidisciplinary team members to present their latest clinical and research efforts and to network with colleagues from around the world. The meeting was the best I had ever attended in terms of relevant content to my work. Pressure injuries papers were of great interest to me, as I was the Child Health Representative for the Canterbury District Health Board (CDHB) on the 'Pressure Injury Group' (PIG). Many presenters spoke of the risk assessment tools available to utilise in practice when assessing a baby/child for the risk of developing a pressure injury and changes that they were looking to make. After gaining permission from the Margaret May Blackwell trustees, I took advantage of booking early bird flights and continued on to make other appointments with places I was keen to visit.

Several months later I was notified by the ISPEW conference organiser to say they were again shifting the conference venue, but this time to Rome and changing the date to early December 2014. I emailed my travel agent asking if it was possible to change my flight back via Rome, but because I had booked an early bird flight it was very expensive change. Unfortunately I had already accounted for all the money I had been allocated and was extremely disappointed that I could not attend the conference that I had set my sights on. However, I was still working towards improvements for pressure injury care in my own work place at Christchurch Hospital, so in this section of my report I will now describe how I have contributed to a change in practice for Paediatric pressure injury care, which did stem from the first ISPEW conference I attended.

Background

As I have said my interest in attending the 2nd ISPEW conference stemmed from attending the inaugural International Paediatric Wound Care Symposium held in Rome in 2011.

This meeting was one of the best I had ever attended in terms of relevant content to my work. Pressure injuries papers were of great interest to me as I was the Child Health representative for Canterbury District Health Board (CDHB) on the 'Pressure Injury Group' (PIG). Many presenters spoke of the risk assessment tools available to utilise in practice when assessing a baby/child for the risk of developing a pressure injury and some spoke of changes that they were looking to make.

The International National Pressure Ulcer Advisory Panel (NPUAP) & European Pressure Ulcer Advisory Panel (EPUAP) (2007), define a pressure injury/ulcer a "A pressure ulcer is localized injury to the skin and/or underlying tissue usually over a bony prominence, as a result of pressure, or pressure in combination with shear. A number of contributing or confounding factors are also associated with pressure ulcers; the significance of these factors is yet to be elucidated".

There is a misconception that baby/children do not get pressure injuries, but in fact this is not true. The Royal Children's Hospital in Melbourne developed a fact sheet around this, which the Child Health Division (2014) at Christchurch hospital tailored to fit their patient care needs. The leaflet is to help families understand the importance of regular checks and position chances for any 'at risk' child. It states that "a pressure injury is an area of skin that has been damaged due to unrelieved pressure, poor blood flow or chafing and rubbing of the skin".

Everyone is at risk of getting a pressure injury, particularly if;

- they have reduced activity
- unable to move themselves normally
- have reduced skin sensation
- have loss of bowel/bladder control
- have poor nutrition or fluid intake
- has pressure or friction to one area of the body
- has medical equipment attached to them that could cause friction or pressure

Pressure Injuries are staged according to the depth of the tissue damaged and are known to pose a huge financial burden to health care services. It is well documented that pressure injuries are preventable and can be avoided with careful management.

Sandy Quigley and Martha Curley adapted the Braden Scale (adult risk assessment tool) to develop the Braden Q scale (Appendix 3) for Paediatric use, announced at the 1st ISPEW symposium that they would be updating their tool to incorporate risk assessment on devices and would then rename their scale the Braden Q & D scale. Their rationale for this was that they found that approx. 50% of pressure injuries for the neonates and children were from devices.

Jane Wilcock, from the UK, strongly advocated for the use of the 'Glamorgan Risk Assessment Scale', which she was involved in developing. She explained that this scale could be used from birth through to 18 years and already included assessment for risk of devices. She explained that it was point scoring system and the higher the number scored, the higher the risk of a child developing a pressure injury. She went on to say that other known reasons that contribute to skin break down, are a child's mobility, equipment being used to nurse a child, anaemia, persistent pyrexia, poor peripheral perfusion, inadequate nutrition, low serum albumin levels and incontinence.

The development of the 'Glamorgan Paediatric Pressure Ulcer Risk Assessment Scale' was first accepted for publication in the Journal for Children's and Young People's Nursing, 2007 (cited New Zealand Wound Care Society Inc. (n.d). In the article the authors highlight that "most paediatric pressure ulcer risk assessment scales have been derived either from adult risk assessment scales, clinical observation or literature review" They believed that developing a risk assessment tools for Paediatric population would be preferable to modifying existing adult tools. They go on to explain that the Glamorgan Scale was developed from using data collected from reviewing inpatients (336 children) in 11 hospitals in England and Wales. They found that pressure ulceration included: difficult to position, anaemia, equipment pressing or rubbing against skin, reduced mobility for age, prolonged surgery and persistent pyrexia.

PHARMAC

In October 2013, Pharmac asked for submissions regarding their "consultation document on hospital medical devices". With my many nursing 'hats', I wrote asking Pharmac to consider what they purchase in the way of medical devices that might have the potential to be harmful to our children in New Zealand. Working as the Clinical Nurse/Wound Resource Nurse at CDHB and EB Nurse Specialist for DEBRA NZ, I felt it was of critical importance to have a voice regarding policy changes. I went on to say that pressure, friction and heat can affect the baby/child's skin with Epidermolysis Bullosa (EB), but medical devices also pose a high

risk, not only to the child with EB, but to all neonates and children. Many in this population group cannot verbalise their pain with devices such as nasal prongs, continuous positive airway pressure (CPAP) machines, plaster casts, IV luer etc. thus making this group extremely vulnerable.

Pressure Injury Group (PIG)

The Pressure Injury Group (PIG) at Christchurch Hospital was formed in early 2011. We initially worked to establish a CDHB Policy which included standard terminology and tools. We then went on to work with other DHB's and providers in the South Island to establish a joint contract for pressure relieving mattresses.

The PIG group adopted a zero tolerance of pressure injuries acquired during a hospital stay and felt the most effective evidence-based approach to pressure injury prevention and management would be to implement;

- Timely risk assessment to identify risk factors both clinical and environmental
- Use of validated risk assessment tools to guide clinical decision making to identify pressure injury risk
- Engage patients and their family/whanau with clinicians
- Develop and implementation of an individualised, multi factorial and multidisciplinary plan of care
- Having systems in place such as audits and prevalence studies to monitor and analyse pressure injury data and to review and implement quality improvement activities

These interventions are to prevent patients from developing pressure injuries and effectively manage pressure injuries if they did occur.

The Pan Pacific guidelines (2012, p33) point out however that "there is minimal-to-no evidence on the effectiveness of PI risk assessment scales in reducing PI incidence. Indirect evidence suggests that implementing preventative management interventions reduces PI incidence" so in 2011 the group audited the prevalence of pressure injuries throughout CDHB. Prior to this, prevalence for pressure injuries within CDHB was unknown and led the CDHB Pressure Injury Group to undertake an annual sample point prevalence study. This

was to provide a more accurate picture of pressure injury prevalence, to raise staff awareness and monitor the effect of pressure injury strategies that were being implemented, such as an e-learning package, changes in practice and use of resources such as pressure relieving mattresses.

Prevalence studies are known to provide a snapshot view of the number of patients with pressure injuries present on a specific day, including old and new cases. The first prevalence study at CDHB did not include Child Health and took place prior to my attendance at the ISPEW symposium. At this time, I was unaware if the Braden Q scale was meeting CDHB Child Health needs.

After returning from the ISPEW symposium I discussed with my Director of Nursing the work that was taking place internationally around pressure injuries and he suggested I meet with one of our 'Quality' team members. Having learnt that medical devices are the biggest risk for children, I felt it was important right now, to review our usage and so, I proposed to the PIG group, that Child Health be included in the 2012 prevalence study.

Change in Practice

The 2012 prevalence study revealed that the overall prevalence rate for Child Health was at zero percent, but the potential for device related pressure injuries still remained evident. Enteral/parental feeding was identified as the primary contributing factor, which included the high usage of Comfeel, being placed under tubing as a preventative measure. It highlighted that the Braden Q scale did not include assessment for the potential impact of devices. The conclusion from this study showed that the Braden Q scale was not fitting our paediatric populations' needs and that the tool was mainly geared towards the immobile patient.

I contacted the authors of the Braden Q scale, enquiring when their update would be available. M. Curley (personal communication, 2013) replied saying, "we're about to start a pilot study with five hospitals within the USA, so it could be some time away".

It was then suggested at a Child Health Quality meeting that we either, do nothing and wait for the new Braden Q & D assessment guidelines to be released, or look to see if another resource, such as the 'Glamorgan Pressure Injury Risk Assessment Scale', could be implemented. Our Quality Team had already researched other leading Paediatric hospitals, such as Starship Children's Health and The Royal Children's Hospital in Australia. Both hospitals were using an adapted version of the 'Glamorgan Pressure Injury Risk Assessment Scale. However, the Royal Children's Hospital in Queensland had released a report in 2011,

looking at the reliability and validity of two paediatric pressure ulcer risk assessment scales, the Braden Q & Glamorgan Scales. Their report concluded that both these pressure injury risk assessment scales were worth consideration, and that there was no difference between the two, but highlighted that the Glamorgan scale was easier to use. However, medical devices were not mentioned in this report.

I was supportive of a change and voiced my concern that the introduction of a new guideline should not take place without proper documentation, education & training for the staff that would be using the tool. I adapted our current 'CDHB Pressure Relieving Product Guideline' tool (Appendix 4), simultaneously incorporating the new scoring of the 'Adapted Glamorgan Pressure Injury Risk Assessment Scale' (Appendix 5).

The 'Pressure Relieving Product Guideline' tool was first developed by the PIG group. It used a traffic light colour approach of green, yellow and red as an easy way to help indicate risk. The colour green indicated the patient was not risk, orange indicated the patient was at risk or high risk and red that the patient was at very high risk. Depending on the risk category, this would indicate the action to be taken. This gave consistency with a traffic light indicator report that had also been introduced at CDHB to raise awareness for early detection of pressure injuries. This was a visual tool, to show at a glance, the number of pressure injuries over the month for all areas of the hospitals. The data was to help show staff where improvements were needed, so changes could be made. It was not intended to be used as judgement. Again using these colours, Green = no pressure injuries reported for the month, Orange = grade one or two pressure injury's reported for the month, Red = any grade three or four pressure injury's reported for the month.

I am aware how hard it is to keep up with the many changes that happen at ward level. Already a Clinical Nurse Specialist in two positions I also choose to work one day a week, as a Staff Nurse/Wound Resource nurse on a busy surgical ward to keep my clinical skills up to date. There are many assessments required when a child is admitted to the hospital, so I suggested that it would be helpful if all our assessments could be put together in a flip chart for ease of access. Something similar had been introduced in the adult medical/surgical division at CDHB and this appeared to be a good way to keep up to date assessments in one place.

The Child Health Nurse Educator introduced to nurses the new 'flip chart' at the Child Health mandatory study days. This included the both new pressure prevention tools and a 'Pressure Injury Prevention Care Plan' (Appendix 6). This was for immediate use and staff, were also encouraged to complete the new CDHB on-line learning package for prevention of pressure injuries.

November 2014 CDHB performed another pressure Injury prevalence study and also looked at incidence rates. I requested that Child Health take part once again. For added awareness, this study was conducted on the week of “International Stop Pressure Injury Prevention Day”.

Photo 20: Raising awareness

This day was first profiled in 2012 to increase awareness of pressure injuries amongst the public, medical professionals and politicians. The European Pressure Ulcer Advisory Panel (EPUAP), encouraged countries internationally to participate and The New Zealand Wound Care Society (NZWCS) local area groups organise events to raise awareness of pressure injuries for prevention and management. Even though not all of the Paediatric staff had yet attended the 2014 mandatory study day my thought was that the process of being involved again would give us a basis of using the newly introduced ‘Adapted Glamorgan Pressure Injury Risk Assessment Scale’ going forward. This information could help us to make comparisons in years to follow on our performance. It was also thought that regardless of not all staff having completed the mandatory study day they should still have been using and documenting some form of preventive practice to reduce the incidence of pressure injuries.

The neonatal unit, paediatric surgical, medical and oncology wards were assessed. Teams of three undertook the assessments in each area. Two in each group were required to be senior clinical nurse assessors, with wound care expertise and the other was the scriber. As a pre-requisite, the clinical assessors were required to have in the last year, completed the online ‘Pressure Injury’ package.

Result

2014 results showed that the overall prevalence rate for Child Health was three percent, with a zero percent incidence rate. However, assessors found limited evidence of assessment and reassessment of pressure injury risk documented and this area needs attention for future improvement.

At the 2014 CDHB Innovation Awards, the PIG group presented their working and findings of the last 3 years under the category of Improved Health and Equity for all Populations. Our group was awarded the runner up prize, collecting two thousand dollars for our efforts.

Photo 21: Improved Health and Equity for all Population

What Pressure Risk Assessment Scale's Do Other DHB's Use in New Zealand?

I was keen to see what other Child Health areas in other DHB's around New Zealand were using as their tools for pressure injury assessment. Out of interest, I phoned the remaining 19 to make enquiries. I had mixed responses from the nurses I spoke with;

- 6 - Adapted Glamorgan Risk Assessment Scale,
- 2 - Braden Q Scale
- 1 - Ministry of Health answer phone
- 1 - Braden scale (used for adults)
- 2 - No assessment used. "but good old fashioned observations and assessment skills".
- 3 – no assessment used, but we are smaller based hospitals
- 4 - unable to tell me

Many now acknowledge that it is important that we take an active role in learning how to improve care for our patients and not cause them further harm. The first, 'Do No Harm' (2012) patient safety campaign was launched in New Zealand. This was coordinated across the Northern Region. Four DHBs – Northland, Waitemata, Auckland and Counties Manukau all collaborated as one to set some shared objectives around patient safety and improvements. One of the five key areas they targeted in primary care through to age care was pressure injuries and this has now resulted in consistently across their region. This seemed a very good initiative and I hope their findings can be mirrored now around the country along with other tools that the CDHB 'PIG' group have working on since 2011. Shared resources will then give us a more consistent approach for prevention of pressure injuries for the vulnerable children that we care for.

Conclusion

My goal was to attend the Second International Pediatric Wound Care Symposium (ISPEW) to further extend the knowledge on pressure injury care that I had gained at the inaugural symposium. However, due to date and venue changes I was unable to fulfil this objective.

I was, in other ways, able to build on what I had learnt at this meeting and follow through to fruition for a change in practice.

Sandy Quigley, Martha Curley & Jane Wilcock had all reported on Paediatric pressure risk assessments scales that they had developed. I had been involved with a prevalence study at Christchurch Hospital prior to going to this conference, but Child Health had not been involved. When I returned to New Zealand I spoke to my nursing director about what I had learnt and he suggested I meet with a member from our Quality team.

As a member of the Pressure Injury Group (PIG) at Christchurch Hospital I advocated for the Child Health division to be involved with future Prevalence studies, and wrote submissions to Pharmac regarding the consultation document on medical devices. I expressed concerns that medical devices posed a high risk to all neonates and children. Many in this population group could not verbalise if something was causing them pain, such as nasal prongs, continuous positive airway pressure (CPAP) machines, plaster casts, IV luers etc. and this made them a vulnerable group. The intention was to prevent patients from developing pressure injuries and effectively manage pressure injuries when they do occur.

I assisted with the audit of the prevalence of pressure injuries at CDHB who had adopted a zero tolerance policy of pressure injuries acquired during a hospital stay. It was revealed from this study that the 'Braden Q scale', which was currently in use, was not fitting our paediatric populations' needs as the tool was mainly geared towards the immobile patient. This led to a change in practice and the introduction and use of the 'Adapted Glamorgan Pressure Injury Risk Assessment Scale'.

I adapted a tool for Child Health use that the 'PIG' had first developed to help identify the correct pressure relieving mattress to order in accordance with the guidelines if a patient was at risk of getting a pressure area. I then suggested that all assessment forms along with the 'Adapted Glamorgan Pressure Injury Risk Assessment Scale' be put into a flip chart for easy access for staff and this was actioned by one of the Child Health educators.

After the introduction of the new tools, another prevalence study was conducted on the week of Stop Pressure Injury Prevention Day, which included the neonatal unit, paediatric surgical,

medical and oncology wards. This information will help going forward and to make comparisons and improvements in 2015. The results showed a 3% prevalence, with a 0% incidence rate, however it was also found that the documentation of assessment and reassessment of pressure injury risk needed further attention.

Many now acknowledge that it is important that we take an active role in learning how to improve care for our patients and not cause them further harm. At the 2014 CDHB Innovation awards, PIG group at CDHB were awarded the runner up prize, for their efforts.

The first, ‘Do No Harm’ patient safety campaign was launched in New Zealand at the beginning of 2012. This was coordinated across the Northern Region, and four DHBs; Northland, Waitemata, Auckland and Counties Manukau, took part. It is hoped that this initiative along with the tools and prevalence studies of CDHB ‘PIG’ group can be mirrored around the country. Shared resources will then enable us to have a more consistent approach for prevention of pressure injuries, and provide the best care for the vulnerable children that we care for.

Section 3: Burn Care in New Zealand

Introduction

The Safe Kids website reports (2010) that each week on average 5.5 children are hospitalised due to a burn injury. Preschool children have the highest incidence of all burn types and over half of all children aged 1-2 years are scalded with hot object & hot substances such as tea & coffee and other liquids like soup and noodles. The majority of burn injuries happen at home in places like the bathroom and kitchen

In 1976 the Australian and New Zealand Burns Associations (ANZBA) was formed to help improve the quality of care for 'burn' patients. It comprises of a multidisciplinary group of health professionals whose interests lie in teaching, care, research and prevention of burn related problems. Health professionals in both countries work closely together following the same emergency management of severe burns (EMSB) guidelines, so care is standardised particularly for the patient that is severely burnt.

A common goal for all types of burn injuries, even the smallest, is to start with the;

1. Airway Breathing Circulation (assessment and management)
2. Stop the burning and cool the burn for 20 minutes
3. Assess the depth & percentage of the burn
4. Manage the pain
5. Prevent infection

Children with burn injuries are expected to be referred to a regional burn unit if they have greater than 5% total body surface area (TBSA) affected or if their burn is an inhalation injury, or burn to special areas – such as to their face, genitalia, hands (Referral criteria EMSB Australian and New Zealand Course Manual, 17th ed, 2014).

If possible it is recognised that the family are kept together for everyone's emotional wellbeing, but of course this is weighed depending on the treating facility and what they can offer.

Background

With a background in burns and plastic surgery I was eager to explore an alternative option for treating superficial and partial thickness burn injuries which would give improved patient outcomes and additionally, reduce associated hospital admissions and costs.

The purpose of this report is to only look at how superficial and partial thickness burn injuries are treated and not the cause of the burn injury. 'SafeKids' website state;

"A **superficial** burn affects the top layer of skin. The skin is red and will hurt when you touch it. Healing takes approximately seven days and usually heals without scarring".

"A **partial thickness** or mid dermal burn affects the top and middle layers of skin.
The skin often has blisters. It may look pink or red. It is often painful to touch. Healing may take 10 days to three weeks. Scarring may occur with burns that take longer to heal".

The aim is to get the burn to heal as quickly as possible and the 'rule of thumb' is anything that hasn't healed within two weeks will scar!

As the Wound Resource Nurse for the Child Health division at Christchurch Hospital I am always mindful of wound care dressing costs within today's economic constraints. Working as a Paediatric nurse my main objective though is foremost for the best options of care for the child and family.

As mentioned previously in 2008 I attended the New Zealand Wound Care Society branch meeting and was introduced to some new keratin wound care products. I had previously conducted case studies using keratin products with children/adults who have epidermolysis bullosa (EB). Since the completion of the EB trial, I now sub-contract some time to the manufacturing company, Keraplast, through my own community nursing service, SOS Nursing. I act as a nursing advisor and also assist with clinical trials as needed. Working in my various roles allows me to transfer knowledge from one wound care role that I work in to another whilst managing any conflict of interest.

Keratin Products

Keratin products are made in New Zealand and manufactured in rural Christchurch (Lincoln) by the company Keraplast. Keraplast make a range of dressings called Keragel®, KeragelT®, Keramatrix® and Kerasorb®. Choosing the correct dressing to use is dependent on the type of wound you are treating.

Keraplast report that, Keragel™ is an aqueous gel product which is rich in keratin protein and has been designed as an easy to apply and fast drying low viscosity gel. The keratin protein used has been exacted from sheep's wool. Keratin protein is a major component of the outermost layer of the skin and is an essential component of the structure put in place by the healing wounds. It has been shown to activate keratinocyte cells and dries as a strong film (like a second stratum corneum).

Keratin protein has fundamental importance to the structure of the healing wound, but has not until recently been exploited as a component of wound dressings. Keratin, incorporated into dressings is a relatively new technology and has shown in trials to improve rates of healing and scarring outcomes.

Photo 22: Keratin Product Range

After completing a trial for clients with Epidermolysis Bullosa I expressed a desire to trial keratin products on burn injuries, as this is another area I specialise in and which I see has some similarities to EB. I believed that even though modern dressings help with moist wound healing, most don't actively donate anything to the wound to accelerate wound closure or assist with skin remodelling. Professor Geoff Sussman (2013) is also of the same opinion and talks about this in his paper titled 'Advances in wound dressing technology. I was keen to see if the Keratin products could advance burns to heal more quickly, which could then reduce the risk of infection and eliminate the escalated costs for Accident Compensation Corporation (ACC) and the District Health Boards (DHB).

Current Practice

When a child presents with a 'burn' at Christchurch Hospital the current practice is to make an assessment of the injury in the Emergency Department. Once their burn has have been assessed by the Plastic Surgery Registrar they are either sent home and followed up with their General Practitioner (GP) or admitted to one of the Paediatric inpatient wards. Management of dressing burn injuries can vary. For a facial burn, olive oil is applied to keep the face/nerve endings moist and/or Chlorsig cream is used to prevent infection

Some children with superficial burn injuries are admitted and taken to the operating theatre for a 'rub down' and to have a dressing called Biobrane™ applied. Biobrane "is biosynthetic wound dressing constructed of a silicone film bonded to a collagen cross-linked nylon fabric" It is said to "provide a bacteriologic barrier, prevents fluid and protein loss, reduces pain, and allows for undisturbed healing" (Smith & Nephew Wound Management Product Guide. (n.d). Edition 1, Biobrane, page 31)

The dressing is designed to separate and lift away from the skin as the wound re-epithelialises (heals). This is good to see when this happens, but it is the extra care needed and anxiety caused prior to that is what I had concerns with.

The children treated with Biobrane usually had an antimicrobial dressing applied on top of Biobrane to prevent any infection problems that might happen, though the education committee of the Australian and New Zealand Burn Association (2012. p.93) state "that any area of burn judged to be deep dermal or full thickness should be treated with a topical antimicrobial" dressing and the company that manufacture Biobrane state that it "provides a bacteriologic barrier". My concerns were that we were not using the product as specified and I was seeing an overuse of antimicrobials in my workplace. This was a key reason why I was keen to trial another dressing that might offer an alternative treatment.

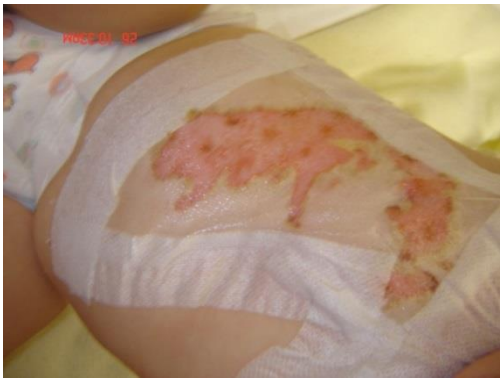

Photo 23: Biobrane applied to the trunk of a child

When Biobrane is the chosen dressing, a child is NBM for at least six hours, or longer depending on what has gone before them. The child is given a general anaesthetic and is required to stay at least one or more nights in hospital. After discharge, follow up treatment is back in the hospital environment with some children needing oral sedation of Ketamine and Midazolam for their dressing to be reviewed.

Some hospital interventions can cause much anxiety and stress to the child and family. If they are necessary, then it is hoped anxiety can be alleviated with resources such the 'Going to Hospital' a book for children and a video resource 'Having an Operation at Christchurch Hospital' that I was one involved in producing. In 2014 a Nursing colleague and I re-shoot the 'Having an Operation' video with professionals at Whitebait TV. This video featured well known TV actors from 'What Now'. When there is the opportunity to give preparation to a child prior to going for an operation, both these resources are utilized. They can be located on the CDHB Child Health website which my Nursing colleague and I initiated back in 2003.

Aside from these resources a hospital stay and many procedures can cause much upheaval for families. It can affect time off pre-school/school for children, time off work for the parent/s, stress around who will look after other family members and the extra costs incurred for petrol, parking, bus/taxi fares and sometimes even loss of income etc.

If a child is admitted with a partial thickness burn the standard treatment of care is to fully cleanse the burn and use dressings that facilitate moist wound healing, protect the wound from infection and manage any bio burden that could present. This usually includes applying an antimicrobial dressing which in my institution is usually 'Acticoat'™

There have been investigations looking at the use of silver dressings with children that have extensive skin loss. Denyer (2012) suggests that silver dressings could be detrimental and this was highlighted by raised blood plasma silver levels with paediatric patients with Epidermolysis Bullosa. The use of silver dressings has now been removed from their practice. Wounds International consensus document (2012) reports on the appropriate use of silver dressings. They suggest that there is conflicting evidence as to whether silver is toxic and delays healing or promotes healing. However they do report that antimicrobial dressings may be used prophylactically. Both reports agree however, that if silver is to be used with paediatric wounds that caution should be taken and dressings should not be used for a prolonged period.

Burn case study series

In accordance with a protocol and with products that had already been awarded the CE mark approval for use in New Zealand. They were also approved by the Australian TGA and the FDA in USA. There had been no safety concerns with these products in the past and no history of adverse events.

A Plastic Surgery consultant from Christchurch Hospital and one of his Registrars were also interested to see if the Keratin products could show benefits of increased healing rates as they had in the past with donor sites and Sternotomy wound trials.

Keraplast provided their products free of charge and I (SOS Nursing) was sub-contracted as the Community Nursing Provider to provide continuality of care and be the consistent nursing link once the patients left hospital.

The aim of the study was to determine the effectiveness of Keratin-based products in the management of superficial and partial thickness burn injuries by comparing them against current standard care. It was agreed that antimicrobial dressings were not to be used prophylactically in this study.

Ethics approval & trial

Ethical approval was sought from the South Island Ethics committee.

The application stated that, “Keratin dressings had the potential to improve care by reducing healing time and thus risk of infection and other complications and improve cosmetic appearance by reduced scarring and skin colour change effects”. This claim was from results from previous trials by Than, et al. & Jina et al. 2014.

Subjects sought for the study were to have a superficial or partial thickness burn, < 10% of body surface area and present within 24 hours of their injury.

Patients were consented and enrolled by the on-call plastics Registrars from the Plastic Surgery Department at Christchurch Hospital and via the Emergency Department.

The exclusion criteria was any patients with full thickness burns or burns, which appeared to be infected at the time of first treatment or had an existing condition that would compromise their participation and follow-up in the study.

Method

Wounds were cleaned as per standard protocol under the direction of the on-call Plastics Registrar and then the appropriate Keratin dressing was chosen and applied. Patients were then discharged from hospital and visited by the community nurse in their own homes two days later. The nurse continued to treat with products from the Keratin range and changes of dressings were typically every 3~4 days after initial visit and until the wound had healed.

If the burn became infected, then an antimicrobial dressing was used to treat this. Around day 14 either the Principal Investigator or associate followed up with the patient in the outpatients clinic at the Plastic Surgery Department of Christchurch Hospital. After healing was complete, the patient continued to apply KeragelT™ for one month to the wound area to assist with remodelling and scar minimisation.

Digital photographs were taken by the on call plastics registrar at time of enrolment and by the community nurse at each change of dressing. The time until the wound is fully re-epithelialised was measured and recorded along with details of any infection or suspected infections. Patients were treated until the wound epithelialised and were then provided with the thin keratin gel called KeragelT to apply daily for a further month to assist with scar management. Six and twelve months after the injury, the community nurse revisited the patients, took photographs and made a scar assessment using the recognised 'Patient Observer Scar Assessment Score (POSAS)' scale.

The Outcomes and statistical analysis were measured by healing times, infection rates and scar scores.

Case study

A total of 40 were enrolled on the trial with 61 burn injuries in total.
Approximately 50% were adults and 50% children. As the community nursing provider I followed up and attended to patients dressing changes in their own homes until epithelialisation occurred. This was typically between 6-10 days.
The typical time line for the patients was;

- Day 0: Patient presents, is enrolled and first treatment given by Plastics Registrar.
- Day 2: First follow up by community nurse.
- Day 6: Second follow up by community nurse.

- Day 10: Third follow up by community nurse - start post-healing treatment with KeragelT for scar minimisation.
- Day 14: Outpatient clinic assessment (Plastic Outpatients)
- Day 40 (typical timing) end of 1 month post-healing treatment with keragelT.
- 6 months first scar assessment
- 12 months final scar assessment.

Most patients coped well with oral analgesia, simple dressing changes and no antimicrobial cover. It appeared that Keragel helped seal nerve endings, and therefore stopped pain/burning. I was told by many that it *"took the heat out of the burn and that it gave instant* pain relief".

Parents were able to manage care for their children in their familiar environments at home. I followed up care as per the protocol, though the patient below was not seen on day 6, but day 8 and the parent reported that the face was healed in "4-5 days".

Photo 24: Use of KeragelT on Superficial Burn with No Secondary Dressing

Any blisters were debrided to aid faster healing rates and prevent colonization and infection under the skin. Healing rates appeared faster than standard care.

When a secondary dressing was required on top of the Keratin product it was not obtrusive and always waterproofed if possible, so the child could continue with ‘normal’ activities of daily living.

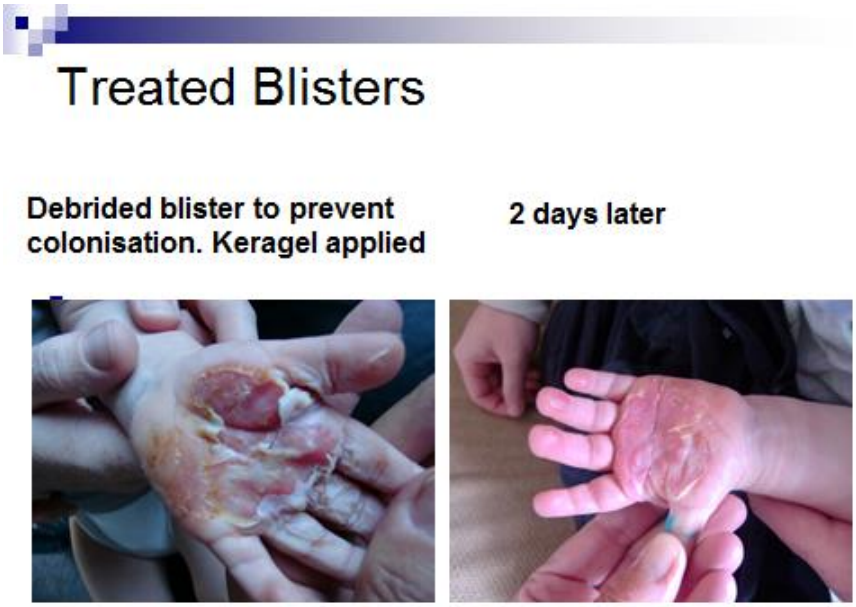

Photo 25: Treated Blisters

Study Results

Of the 40 patients, two burns sites out of 61 burn injuries became infected (adult patients) and at this time a short course of oral antibiotic treatment was prescribed and an antimicrobial dressing used. These trial results are currently being written up for publication, but at this time I can share that 95% of the burns healed, with only 3% infected and one elderly patient went on to have grafting and was excluded from the trial after 14 day, as her burns revealed deeper burn injuries then first assessed and was not eligible for the trial.

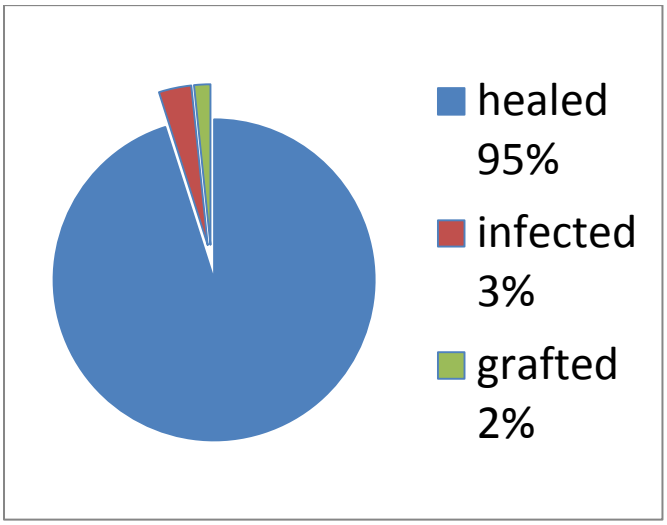

Photo 26: Trial Results

Conclusion of Trial

- Well suited to high contour areas (difficult to dress) e.g. face/neck
- Maintained a moist wound healing environment
- Added a physical barrier & protection
- Gave rapid and comfortable healing response
- Was sticky, but this was manageable
- Good healing rates- effective outcomes - anecdotally faster than standard care.
- Easy to use, well tolerated and minimised pain.
- Allowed activities of daily living.
- There was no need to use antimicrobials prophylactically.
- Only one patient needed operating theatre time, but they were excluded from the trial, as there burns were deeper than the inclusion criteria.
- Most patients did not need an admission.
- Treatment was in the community.
- Follow-up outpatient appointments were not always needed, as nothing to show.
- To date there has been good scar outcomes.
- **Patient satisfaction.**

Outcomes

All babies/children on the trial showed fast or faster healing rates than current standard treatment. Most spent no nights in hospital and required no trips to the operating theatre. If another dressing was required on top of the keratin products it was not obtrusive, which allowed the children to continue with their 'normal' daily living. Many parents were able to cancel their follow up outpatient clinic appointments, as there was no burn injury left to show. The children only required minimal pain relief and families were delighted with the convenience of care for their child. The Keratin-based products showed a reduction in resources used and costs to ACC and the DHB.

Dissemination of findings

The trial results were very positive, for not only the patient, but also the DHB. Since the completion of the trial I have presented the trial results at National and International meetings/conferences hoping to influence others and for them to think about implementing a change into their practice. In 2013/2014 I presented at;

Christchurch Hospital Plastic Surgery Department
New Zealand Wound Care Conference – (Dunedin)
Australian New Zealand Burns Association conference - (Perth)
National Burn's Unit – (Auckland)
Kids Trauma Conference – Auckland
Christchurch Plastic Surgery Consultants
Paediatric Department – Christchurch Hospital

Another author presented the results in poster format at the Symposium on Advanced Wound Care (SAWC) in 2014.

ANZBA

The largest of the meetings I delivered the trial results to was the 37th Annual Scientific meeting of the Australian New Zealand Burn Association (ANZBA) which was held in Fremantle, Perth, Australia. I choose not to take this further afield as there was already much to learn and improve on within these two countries.

On the Burn Registry of Australia (2013) map below you will see where the national/regional burns centres are in New Zealand & Australia.

Photo 27: Designated Burns Units across Australia and New Zealand

My focus at this conference was to network with other like-minded colleagues and to co-present the 'burn' trial results highlighting the positive results from the case study series. A poster was also presented by the Plastic Surgery Registrar.

Similarities

Australian New Zealand Burn Association (ANZBA) is a joint organisation and has a consensus for Emergency Management of Severe Burns. With superficial and partial~~,~~ thickness burn treatment however it seems to come down to personal preference in the treating centre as to how a burn is treated. Regardless of the depth of burn, antimicrobial treatment is used, not for just the mid to deep dermal burn areas as suggested in the Emergency Management of Severe burns handbook.

Standard care for facial burns in both countries seems to be consistent with the use of paraffin or olive oil.

Differences between NZ & Australia

In Australia each state has different rules and the Federal government does not easily allow introductions of new wound care products. Many centres still have their own likes and dislikes and preferences of dressings. Herpes seems to be a problem in Australia for patients with burns, though we do not find that here in New Zealand. There is anecdotal evidence however to suggest that Keragel has been shown to also heal herpes more quickly and slow down the rate of reoccurrence, though up until now there has been no formal trials/case studies to show this.

In New Zealand we are not governed in the same way as Australia and are a smaller country, so we do not as yet have the same restrictions on inducing new wound care products to the market, we do have disparities in our DHB's in what offering patients the same standard of care. Pharmac are currently looking at standardising wound care consumables around New Zealand and having a National procurement contract. As described in section one of this report I am involved with the consultation process of this.

Return Home

On my return home from the ANZBA conference I wrote to the heads of Paediatric and Plastic Surgery departments at Christchurch hospital with some concerns regarding treatment for the paediatric 'burn' patients (personal communication December 2013). Along with my concerns I asked if they would consider the trial results and implement a change in our current practice of care. I explained my involvement in trailing a new wound dressing called Keragel and that since the completion of the trial our admission rate for paediatric 'burn' patients had increased. I explained that the trial highlighted prevention of hospital admission, operating time, extra costs etc.

I went on to say, that I had been awarded the NZNO Margaret May Blackwell travel and study fellowship and that one of my objectives was to look at improvements for the New Zealand paediatric 'burn' patient and their families and would like the opportunity to share the full trial results with them.

In January 2014, I followed up with the head of Plastic Surgery department to see what his thoughts were on implementing Keragel into practice. He explained that he had read my letter out at a recent department meeting and that they would like the trial results presented at a department meeting. Since this presentation, KeragelT has been adopted as standard practice for difficult to dress wound areas such as the face, neck, hands etc.

Current thinking is that there are no suitable dressings available for these areas. I am hopeful in time that the Keratin range of dressings will be considered for further areas of the body and will stop the need for children to have a hospital stay and trip to OT for the application of Biobrane and antimicrobial dressings. My next step is to have this introduction of care for the paediatric 'burn' patient mirrored at the very least around New Zealand.

Since the introduction of KeragelT, I have had dialogue with the Nurse Educator of the Plastic Surgery Department at Christchurch Hospital, regarding some confusion around how to use the product. I feel sure this will be because a new product has been introduced to the adult service without any education around how to use it. I have since gone on to develop an algorithm showing the appropriate steps to take when using Keragel I am hopeful this will eliminate the current confusion (Appendix 7).

One observation made also was that children were presenting back to the outpatient department for dressing changes and had wet dressings and macerated wounds. It was established that the emergency department staff were not lancing (taking fluid out of) the blisters and when they 'popped' the fluid was expressed into the dressing and made this wet. The wet dressing was then in place until the family brought the child back to plastic surgery outpatients for a dressing change. This posed an infection risk to the wound where bacteria can travel through wet dressings to the injury site. It was important to add this step on the algorithm that a blister was to be lanced. I continue to work with the Nurse Educator in plastics and I will also profile the algorithm to the emergency department once we have perfected the steps. I will then proceed to pass this information on further to other 'burn' centres around New Zealand and Australia.

Continuing to promote better outcomes

I strive to continue to promote better outcomes for children with 'burn' injuries. In my private practice I am ACC Registered and deliver assessment and treatment as needed. I recently made a request to a child's ACC case manager for the approval of KeragelT to be used on a child who had surgery for contracture release of an old burn injury. This was not a stock item on their ACC Consumables list at the time, but with requests and rationale for use, this was added in July 2014 and is now available for other ACC providers to order.

I was keen to speak at a General Practitioner meeting to deliver the trial results, but my request was denied because they saw this as promoting an industries product. The extra challenge for me is when others see this as a conflict of interest. I always try to be

transparent in what I am doing and declare the 'hat' I am wearing. I will request this again at a later date, as I believe that primary practice is the best starting point for prevention of admissions to hospital. Some local GP practices, who I offer wound care advice for, have however seen the merit of using the two Keragel products and now purchase this for their clinic use.

Another avenue of spreading the word may be through Health Pathways website, though this is a Canterbury District Health Board (CDHB) initiative and currently only available for health practitioners with CDHB access log in. However, in March 2014 I was contacted by a GP Clinical Contributor who was given the task of putting up to date information on a website for the general public explaining how to deal with a burn injury www.healthinfo.org.nz. The GP asked if I could give advice on the Paediatric perspective and if I would review the site before it went 'live'. As yet the Keratin products are not mentioned on this site, but there will be the opportunity to update this site in the future.

Publication

To disseminate the trial and result further the authors submitted for publication to the Journal of Burns. After our first draft we were asked for more 'control' evidence to support our findings. A control group of patients was then formed comprising of 40 patients who had burn injuries at the time of the trail, but who had not been enrolled on the trial. They all met the inclusion criteria but had for unknown reasons been treated with protocols representing standard care for the Plastics Department. Data and associated treatment costs were collected from hospital clinical data records and then the clinical outcomes were retrospectively analysed and compared. The comparisons very much favoured the use of Keratin products and it we are hopeful that the paper will now be accepted now for publication.

Overall analysis

The Keratin products are ‘home grown’ from our sheep and manufactured in New Zealand. New Zealand has led with this being the first trail in the world using Keratin products for burn injuries. It is the responsibility now of the authors to inform others of the results.

All babies/children on the trial showed fast or faster healing rates than the control group. Most spent no nights in hospital and required no trips to the operating theatre. If any dressing was required on top of the keratin products it was not obtrusive, which allowed the children to continue with their ‘normal’ daily living. Many parents were able to cancel their follow up outpatient clinic appointments, as there was no injury left to show. The children only required minimal pain relief and families were delighted with the convenience of care for their child. The Keratin-based products showed a reduction in resources used and costs for ACC and the DHB.

The control group on the other hand had a significant number of hospital admissions. The majority were treated with an antimicrobial dressing and a high number had Biobrane applied under general anaesthetic. They then required a significantly greater number of outpatient dressing changes which was often under sedation. A significant number of patients in the control group were also prescribed a course of oral antibiotics. This all showed escalated costs associated with the control group, which was well over $2,000 more per patient than the treated group. Complications for the control group were not collected prospectively and therefore not compared. The outcome, favoured facilitating the use of Keratin products and community based management in contrast to the control group.

Conclusion

Safe Kids website reports that many children sustain burn injuries each week and are hospitalised. Much of current standard treatment can mean at least one overnight stay in hospital, and some children also have a trip to the operating theatre drawing on many resources. It can also mean follow up treatment back at the hospital, sometimes with sedation and parents and children having to take time of work/school and loss of income.

I worked in conjunction with the Plastic Surgery department. Ethics approval was sought and 40 patients enrolled into a trial using a Keratin wound products. These were to be used on superficial and partial thickness burns injuries. I was the community nursing provider who followed up these patients in their own home after the initial assessment, enrolment and treatment in the Emergency department at Christchurch Hospital.

Most coped well with oral analgesia and simple dressings changes and with no antimicrobial cover. Providing care in the patient's home meant less anxiety and stress for the child and family.

Antimicrobial dressings were not to be used prophylactically in this study as they usually were in current practice. A control group of 40 patients, who also had burn injuries around the same time as the trial was reviewed and length of treatment, and care compared.

The Keratin dressing range was able to provide comfort, convenience and healing of the wounds in a timely manner, which in turn showed reduced costs to ACC and the DHB. 95% healed, 3% became infected and 2% had to go onto be grafted as this burn injury was deeper than initially accessed.

Since completion of the study, I have presented results at many meetings and conferences. An Oral and poster presentation were given at the 2013 Australian and New Zealand Burns Associations (ANZBA) conference which comprised of a multidisciplinary group of health professionals

There has been a small shift in practice for children and adult 'burn' patients at Christchurch Hospital. Keragel®, KeragelT® are now used for the difficult to dress areas, such as the face, neck and hands.

Working in my various roles allows me to transfer knowledge from all the wound care roles that I work in, but there is the extra challenge that others see this as conflict of interest. The end picture for me is - who will this benefit? In this case, it was the patient, their family, ACC and the DHB.

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