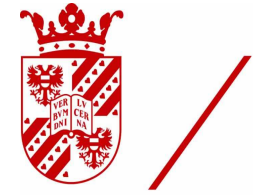


WOUNDCARE AS A SOURCE OF STRESS

‘The impact of wound care on children with Epidermolysis
Bullosa and their parents’



Petra de Graaf-Mauritz
Phd student Dermatology/Health Psychology



university of
groningen

Wound care as a source of stress

Projectleaders: Prof. dr. M.F. Jonkman
Center for Blistering Diseases Groningen
Prof. dr. M. Hagedoorn
Faculty of Health Psychology
Principal Investigator: Petra de Graaf-Mauritz MScN

Study Design

Mixed method, observational research

- Part 1: Qualitative research (interviews)
- Part 2: Quantitative research (questionnaires)

Objective

The overall objective of this study is gaining insight into needs for psychological treatment of children with EB and their parents with regard to problems related to wound care.

Part 1 Objectives Qualitative Research

- To explore how parents and patients experienced wound care from their child or themselves in childhood
- To explore how they dealt with it personally or interacted in relation to their parents or children respectively
- To create an EB-wound care questionnaire based on the outcomes of the interviews

Design Qualitative Research

- One- to-one semi structured interviews
- Interview guide constructed by analysis literature and refined by comments of practioners EB team, some parents and a board member of Debra Netherlands.
- Interview guide contained five themes, respectively (1) personal history, (2) physical impact, (3) psychological impact, (4) support and (5) recommendations

Participants Qualitative Research

Including criteria:

- Patients with a subtype of EB > 25 year
- Parents of patients with a subtype of EB >25 year
- Speak Dutch fluently
- Registered as patient or registered child as patient in the UMCG
- Parent who is most involved with the wound care
- Relevant experience with wound care

Sample Qualitative Research

- 12 persons were approached, 3 persons didn't want participate
- 3 other persons were approached, 1 person spontaneously added
- All parents who participated were mothers

DDEB	Patient (1)	Parent (2)
EBS	Patient (1)	Parent (1)
JEB	Patient (2)	Parent (1)
RDEB	Patient (3)	Parent (2)

Procedure Qualitative Research

- Seen by METC Groningen: non WMO study
- Participation voluntary
- All interviews conducted by principal investigator
- Interviews took place in participants' homes
- Duration varied from 45 minutes to one and half hour

Data analysis Qualitative Research

- Interviews transcribed verbatim by principal investigator
- Analysis done in inductive thematic way
- Interviews were double coded by principal investigator and another person
- A thematic network was also separately created
- After comparison and agreement, principal investigator coded rest of the interviews.

EB wound care list

- EB-Wound Care List I: Children and adolescents (8-25 year)
- EB-Wound Care List II: Parents (own experiences and views on their children)
- Goal: Determine how stressful your wound care has been for parents or patients the past 3 months, both emotionally and physically.
- Subscales:
 - Characteristics of wound care (for example duration)
 - Coping strategies (for example distraction)
 - Outcomes (for example anxiety)

EB wound care list

Epidermolysis Bullosa Wound Care List I (For completion by children and adolescents aged 8-25)

The goal of this questionnaire is to determine how stressful your wound care has been for you the past 3 months, both emotionally and physically.

1. Type EB:

Name:

Sex:

Age:

Below you can find an example.

How much pain do you have before wound care?
Please circle one of the faces.



Example: Items of subscale coping

- | | |
|---|---------------|
| 7. I help perform the wound care. | 0 Very much |
| | 0 Quite a lot |
| | 0 A little |
| | 0 Not at all |
| 8. I decide what happens during wound care. | 0 Very much |
| | 0 Quite a lot |
| | 0 A little |
| | 0 Not at all |
| 9. I distract myself during wound care. | 0 Very much |
| | 0 Quite a lot |
| | 0 A little |
| | 0 Not at all |
| 10. Other people distract me during wound care. | 0 Very much |
| | 0 Quite a lot |
| | 0 A little |
| | 0 Not at all |

Part 2 Objectives Quantitative Research

- To examine wellbeing of parents and children with EB
- To examine their coping strategies with regard to the disease EB
- To examine which coping strategies are associated with reduced stress during wound care

Design quantitative research

- Observational research
- 3 questionnaires for children with EB (8-25 year)
- 4 questionnaires for parents of children with EB

Participants Quantitative Research

Inclusion criteria

- All Parents of a child with EB (EBS, JEB, DEB or Kindler syndrome) registered in the UMCG
- All children / adolescents with EB (EBS, JEB, DEB or Kindler syndrome) between 0-25 years and registered in the UMCG
- The parent whom is most involved with the wound care will be asked to fill in the questionnaires

Methods

Concepts	Instruments
HRQoL Child	PedsQI. (8-25 year)
Experiences related to wound care (Itch, Pain and Anxiety included)	EB Wound Care List I (8-25 year)
Coping strategies	Codi (8-25 year)

Schematic overview of questionnaires for children with EB > 8 years old

Methods

Concepts	Instruments
HRQoL	TAAQOL
HRQoL child	PedsqI (0 - 7 year)
Experiences of parents and children related to wound care	EB Wound Care List II (parents and parents about children 0-25 year)
Coping strategies	Codi

Schematic overview of questionnaires for parents of children with EB

Procedure Quantitative Research

- Proposal seen by METC Groningen: approved in July 2017, study will start as soon as possible
- Participation voluntary
- The questionnaires can be accessed by participants through a safe portal (KLIK) online
- Parents and children fill in separately, once and duration varied from 30 minutes for children to 45 minutes for parents

