The Psychosocial Implications of Patients Living with Epidermolysis Bullosa

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PRESENTATION OUTLINE

- SickKids EB Clinic – Toronto, Canada

- Psychosocial Research
  - Purpose/Method (brief)
  - Themes
  - Strategies for Psychosocial Care

- Questions/Comments
EB CLINIC - History

PRIOR TO 2004

- No consistent follow-up in Dermatology
- Scattered visits to other services (not allowing for coordination of appointments)
- No care plan in case of admission
EB CLINIC – Family Perspective

- Frustrated with medical system
- Few doctors aware of the diagnosis and its complications
- Discrepancy of opinion regarding care when admitted
EB CLINIC – Staff Perspective

- Complicated medical condition
- Unable to provide comprehensive care
- Unable to coordinate urgent care or appointments with other services
- Patient dissatisfaction/Frequent cancellations
- Minimal psychosocial focus (.1 social work FTE)
EB CLINIC

- First Clinic – January 2004
- Monthly – Last Thursday of the month
- 10 Clinics/year
- 35-40 patients with severe EB (birth to 18 years/special permission over 18 years)

GOALS

- To provide better patient care
- To allow coordination of services
- To allow a dialogue with other services
- To educate residents/fellows/students/community
EB CLINIC

STRUCTURE OF THE DAY

- Morning – Coordinated appointments with other services
- Lunch Break (Debra Canada)
- Afternoon – EB Multidisciplinary Clinic
**EB CLINIC**

**EB MULTIDISCIPLINARY CLINIC**

- Dermatology
- Wound Care
- Plastic Surgery
- Paediatrics
- Dermatology Nursing
- Social Work
- Occupational Therapy
- Physiotherapy
- Dietetics
- Residents/Fellows/other students
EB CLINIC – What Has Changed?

- Coordinated same day appointments
- Improved clinical assessment of chronic wounds and their management
- Developed standard forms for data collection
- Mandatory psychosocial assessment
- Improved patient satisfaction
EB CLINIC - Goals

- Continue to develop guidelines for care
- Ongoing assessment of clinic structure and relevance to patient needs
- Develop a transition phase to adult care
- Help to establish similar clinics in other Canadian centres
- Generate and test more research ideas
- Continue to expand national/international collaboration
- Increase psychosocial focus
**TITLE:** “The Psychosocial Implications of Patients Living with Epidermolysis Bullosa”

**PURPOSE:** To study the psychosocial impact of epidermolysis bullosa (EB) on a population of affected patients affiliated with the EB Clinic at The Hospital for Sick Children. We hoped to gain insight into EB patients’ challenges, perceptions and beliefs. Our thought was, that health care professionals would be better able to serve their patients by gaining a better understanding of the issues faced by this population and as a result of this understanding, tailoring appropriate treatment plans.

**METHOD:** Debra Canada – Family Education Day (September 2006)
- 8 patients (12 to 22 years)
- focus group
PSYCHOSOCIAL RESEARCH - Themes

1. **SCHOOL** – avoidance/physical disability equals cognitive disability

2. **FAMILY INTERACTIONS** – caregivers being overprotective/feeling like a burden to caregivers

3. **MEDICAL INTERACTIONS** – being treated like an object/not being part of the treatment plan

4. **SOCIETAL INTERACTIONS** – being treated differently/ignorance
PSYCHOSOCIAL RESEARCH – Themes

SCHOOL

Avoidance
- Avoided by peers because they appear physically different
- Less opportunities to develop friendships among their peer group
- Treated differently from the other children by school staff

Physical Disability Equals Cognitive Disability
- Automatically assumed that they are not intellectually capable
- Assumption not limited to elementary level but up to and including university level
- Many underwent unnecessary psycho-educational testing for non-existent learning disabilities

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PSYCHOSOCIAL RESEARCH - Themes

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PSYCHOSOCIAL RESEARCH - Themes

FAMILY INTERACTIONS

Caregivers Being Overprotective
- Being treated younger than their age
- Missing out on key age-appropriate experiences
- Inability to achieve independence

Being a Burden
- Feelings of guilt for care required by parents ($, quality of life)
- Siblings neglected (to varying degrees) by parents
PSYCHOSOCIAL RESEARCH - Themes

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PSYCHOSOCIAL RESEARCH - Themes

MEDICAL INTERACTIONS

*Treated Like an Object*
- Patients excluded from intellectual collaboration during assessment

*Not Being Part of the Treatment Plan*
- Inability to develop independence
- Cycle of exclusion
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PSYCHOSOCIAL RESEARCH - Themes

SOCIETAL INTERACTIONS

_Treated Differently_
- Being stared at

_Ignorance_
- comments (assumptions)/questions
- unsolicited advice on skin care
PSYCHOSOCIAL RESEARCH - Strategies

SCHOOL
- meeting with parents
- letter to school
- dEBra school package
- meeting with school/parents

FAMILY INTERACTIONS
- ongoing counselling/discussions with families/siblings
- networking between parents
- developmental checklist for parents/teens

MEDICAL INTERACTIONS
- team education
- teen/adult clinics
- clinic structure
- self-assessment tool
- positive focus

SOCIETAL INTERACTIONS
- role playing
- networking/buddy program
PSYCHOSOCIAL RESEARCH - QUOTES

“Just because you’re slow on the outside, you’re not slow on the inside.”

“They’re all taking notes on clipboards, saying manifested at birth. I feel like I’m in a zoo.”

“I remember this activity in kindergarten that we used to do. We used to talk about our day, like what we did during the day. Other kids used to say, I woke up, I ate breakfast, I watched cartoons, I played, I went to school, I came home and all that stuff and I was like, why aren’t they talking about dressing changes.”

“I’m human, just like you and don’t treat me different, don’t look down at me. I’m the same person inside. Everyone has something to deal with and this is just our obstacle.”

“...sometimes I wish that everyone could sort of have it for a week or a day or whatever, and then they would know, then they would understand.”
QUESTIONS/COMMENTS