

# **Parenting in the shadow of illness and bereavement**

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# A Tale of Love and Darkness

- The CF team develops an empathy for child with CF and feel responsible for maintenance of family function following his death
- Some parents continue to come to the clinic with their other children's with CF, which enables us to help them
- **Parent coping with child illness may predict coping with his loss.**

# Diagnosing pediatric chronic illness

- The diagnosis of CF, is a stressful event for the child and family
- It is the turning point from a normative healthy child to a child with a disability
- Their lives are altered.
- They experience a physical and emotional burden

Glasscoe, C., & Smith, J. A. (2010). *Clinical Child Psychology and Psychiatry*, 1-20.

Palmor-Haspel, S. (2014). *Doctoral Dissertation, Tel Aviv University, ISRAEL*

# The many aspects of adjusting to illness

Responses to a chronic illness vary.

Most patients adjust well.

## What is successful adjustment?

**The adjustment process includes 3 components:**

- Adherence with medical treatment
- Maintaining regular activities (work, studies)
- A sense of quality of life and wellbeing.

# **Non-adaptive Adjustment: Pathological Grief**

Diagnosis is perceived as an unacceptable threat.

## **Characteristics:**

- feeling that time has stopped, refuses to be comforted.
- Refusal to accept medical information or emotional support

**Adjustment to the child illness may predict the adjustment to his death**

# **Parenting in the shadow of bereavement: The loss**

- **The loss of a child is one of the most difficult losses in a person's life.**
- **Parents often feel guilt (Irrational guilt, Survivor's guilt, Recuperation guilt)**
- **Bereavement is worsened by a feeling of ambivalence toward the child.**
- **The loss changes to routine and roles in the family, A sense of multiple losses**

# Coping with bereavement

- A child death precipitated a severe crisis of meaning.
- **Gender differences**  
Mother experiencing intense grief, But also more growth than fathers.  
Mothers have an active coping
- **Active coping** includes - art as a source of comfort, commemoration, Philanthropic activity in the community.
- Incomplete/ complex mourning-The parent refuses to be comforted.

Riley, L.P. (2007). *Death studies*, 31: 4, 277-299.

Buchi, S. et al., (2007). *Psychotherapy and Psychosomatics*, 76: 2, 106-114.

# Parenting of CF child in the shadow of bereavement

- Few studies have been conducted on bereavement of parents to CF child
- Impact of the death of a CF child similar to another fatal childhood illness.
- High incidence of emotional and medical problem in the parents.
- Half reported incomplete mourning During the first 12 months.
- The family may need mental health services.

Kerner, J., Harvey, B., & Lewinson, N. (1979). *Journal of Chronic Disease*, 32, 221-225.



# **Words Spoken in an Evening Commemorating Netta, who was 13.5 when she died**

**What can we learn from Netta?**

**The importance of mutual giving,  
doing for others.**

**Netta's path encourages us to be  
better, more generous and courteous  
with each other.**

**From this moment, we can all decide to make a change.**

# **Epilogue:**

**Written by the mother of a 12 year old girl,  
Died after a transplant**

**There was a time when a great little angel walked among us.  
There was a time when she shone with true faith.**

**But her journey is over, her story of purity and giving and light is  
over.**

**The sadness and cold has reached our bones,  
For the absence she left in us is great.**

**Our heart is broken in half, she was only twelve – and – a –half,**

**And has not reached her thirteenth year.**

**We pray to the One of the thirteen attributes, and say,  
We believe wholeheartedly in reincarnation...**

# **Environment promoting grief and growth**

**Naomi was 11.5 when she died.**

**These are her insights about treatment of bereaved parents:**

- **Enable open and authentic conversation between the doctor and bereaved parents**
- **Respect the processing time, don't rush the process.**
- **Ability to contain contradictions and tragedy as part of life.**
- **Her insights correlate academic study of bereavement and growth.**

*Kaniel, S. (2015). Trauma as an Opportunity: Control and Meaning as Main Mechanisms for Post Traumatic Growth. Ramot: Tel Aviv University Publishers.*

# Implications for Research, Policy and Practice

- **Parent seem to need and want access to bereavement consulting.**
- **Bereavement consulting is most effective for parenting experiencing complex mourning.**
- **Offer continuity of care prior to and following the child's death.**
- **Provide services for the whole family (parents, sibling and grandparents)**

Donovan, L.A. (2015). *Palliative Medicine*, 29: 3, 193-210.

Lichtenthal, W.G. (2015). *Journal of American Society of clinical Oncology*, 33, 2246-2253.

# **Bereavement in the clinic:**

## **Coping with the death of other patients**

- Hold a staff meeting to decide how and whether to inform other patients. Coordinate the story.
- Find out what each patient already knows and answer questions truthfully.
- Focus on the differences between the condition of the patient who died and the condition of the patient
- Be empathetic toward the patient's pain.

# Summary

- Adjustment to the child illness may predict the adjustment to his death.
- The child death is a crisis for his parents.
- The staff feels responsible for maintenance of family function following the death of a patient.
- Parent appear to need and access bereavement consulting
- Active coping facilitate bereavement and promote trauma growth.
- We all share the hope for know no more loss

**This song is dedicated to our staff in Hadassah Medical Center,  
who accompanies our patients and their families  
through dark times with love**

Every day, the world around us,  
real-life angels are doing the things they do.  
Real-life angels build bridges instead of walls.  
They don't play hide-and-seek with the truth,  
they do whatever they can to help you.  
Real-life angels understand difficulties  
and always give the benefit of the doubt.

They take your hand in theirs  
when you could use a little reassurance.

They walk beside you when you could do with a little guidance  
and direction in your life.

And they support you in your attempts  
to do what is right.

Real-life angels multiply your smiles  
and add to your integrity.  
They make you feel like,  
"Hey, I really am somebody who matters."  
Then they quietly prove to you how beautiful  
and true that feeling really is.