

THE EMERGING NOTION OF HOPE AND THE COMPLEX JOURNEY FOR PARENTS OF A CHILD WITH CANCER

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INTRODUCTION

HOPE – remains relatively unstudied despite its frequent presence in the context of adversity and its role in caring for children with a life-threatening health condition

- Often viewed only singularly as 'hope for a cure'
- Previous work of this team indicates hope as an integral, fluid and dynamic parental construct that changes with the progression of their child's disease

METHODS

Sample

- 35 participants (26 mothers, 9 fathers; 5 couples)
- Pediatric cancer included: leukemia (33%), brain tumors (27%), solid tumors (30%) and lymphoma (10%)
- Ethnocultural and family constellation diversity
- To date, 9 participants have completed all data collection points; 7 children have died

Data Collection

- Longitudinal mixed model design 5 data collection points over 18 months
- Grounded Theory (Glaser & Strauss, 1967): Semi-structured interviews
- Standardized questionnaires – hope, impact of the illness
- Personal diaries: online, offline, telephone
- Child health status monitoring

Analysis

- Constant comparative method
- Analysis assisted by computer software (N-Vivo)
- Peer debriefing, member checking and inter-rater reliability
- Analysis of demographic information
- Analysis is based on 86 interviews across all data collection points

STUDY AIM

To examine the emergence and potential shifts in concepts of parental hope over the temporal trajectory of a childhood cancer diagnosis, treatment, palliation and bereavement.



Meaning of Hope:

“The sweetest thing in the world is hope. Everything has an end. But there is no end for hope. I believe this.”

Father of a teenager

Fostering and Supporting Hope:

“When I just reflect back on some of the nurses who were there for us when she was very sick and the support they gave, the commitment, that gives you renewed hope, people who are good, it's their profession but an extra touch.”

Mother of an infant

Challenges to Hope:

“The period (in which the child) was actually experiencing the effect of chemo, when she was actually in a state of extreme sickness and the effects started showing themselves. That has been a very, very hard time for me. And, sometimes in that moment, I would wonder whether this is really working out especially when she becomes really sick and is in a very helpless state. Those are moments when my hope and sense of faith really, really get challenged.”

Mother of an infant

Changes in Hope:

“The little obstacles when he gets sick and he's not feeling well and you take a step back (and think) I was hoping for this and now I have to alter that hope now.”

Mother of a 5 year old child

FINDINGS

Common Themes Expressed by Parents of Children with Cancer

Meaning of Hope (definitions given):

- Remaining positive
- Looking towards the future
- Recognition of possibilities
- Living day to day
- Positive force
- Believing that their child will survive

Maintaining Hope:

- Use of spirituality and/or religion
- Receiving support from:
 - a) Health care professionals
 - b) Community (friends, agencies, church)
 - c) Family
 - d) Other families in similar situation
- Parental outlook – keeping positive, optimism
- Child's health status influences state of hope

Challenges to Maintaining Hope:

- Effects of the illness and treatment protocol on the child's health
- Fear of a recurrence
- Negativity from others
- Being around other sick children

Shifting Nature of Hope:

- Hope appears to be strengthened with improvements in the child's health and the success of the treatment
- Hope offers stability, even in crisis
- Hope may change day-to-day
- Hope is individual and unique to each parent

Conclusions:

Parents of children with cancer report hope as a concept related to positive attitudes towards the future; goodness of life and core human values. Hope helps parents to go on day by day in the face of adversity.