Chronic Sorrow in Parents Caring for a Child with a Chronic Medical Condition.

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Learning Objectives

1. Attendees will be able to define the meaning of Chronic Sorrow.
2. Will demonstrate understanding of the cyclical nature of chronic sorrow.
3. Will be able to suggest interventions to assist families experiencing chronic sorrow.

Background

• Chronic illnesses can be as common as asthma and as complex as a neurodegenerative disease.
• Chronic conditions may begin at birth or in early childhood.
• Diagnoses may include:
  – Pulmonary diseases such as asthma
  – Cardiovascular defects
  – Neurofibromatosis, Tubersclerosis, Epilepsy
  – Muscular Dystrophies, Cerebral Palsy
  – Metabolic and gastrointestinal diseases
  – Spinal deformities, achondroplasia
  – Leukemia, and other cancers
  – Premature birth

Define and Differentiate

What is Chronic Sorrow (CS)?
Is CS different from:
  – Bereavement
  – Mourning
  – Grief
• According to Merriam Webster bereavement is defined as “a period of mourning after a loss, especially after the death of a loved one”.
• Bereavement and mourning typically resolve over time.

Disclosure

Lori Batchelor, MHA, PhD, RN, CPN-NEA-BC, has no relationships with commercial companies to disclose.
Define and Differentiate

- According to Kubler Ross’s Stages of Grief

  Individuals who experience the sudden loss of a loved one experience:
  - Denial
  - Anger
  - Bargaining
  - Depression
  - Acceptance

Chronic Sorrow

This phenomenon occurs in various populations

- Family Caregivers
  - Individual Effected by chronic condition
  - Antecedents to chronic sorrow:
    - Adversity
    - Sadness
    - Disparity
    - Recurring or repeated losses

- Individuals Effected by other loss (9/11)

Unique role of parenting

- Parent immediately plunged into sorrow with initial diagnosis
- Making decisions that will affect:
  - Child’s course of care
  - Quality of life
  - Healthcare decisions are being made for the child based on the parents’ own
  - Heredity
  - Values
  - Expectations for themselves
  - Expectations on behalf of the child

What is the parent experience of chronic sorrow?

- Anticipation of a healthy child
- Immediate loss of the anticipated or dreamed for child: initial disparity event
- Ongoing loss for self
- Ongoing loss for child

Literature Review

Olshansky (1962) coined the term Chronic Sorrow to describe a population of parents caring for children with global developmental delay and chronic care needs.

He suggested that there are factors that may influence parental intensity of chronic sorrow.

- Social class
- Ethnicity
- Religion
- Parent personality

Characteristics of chronic sorrow in parent caregivers:

- Periodic emotional reaction to losses related to child’s illness
  - Emotional response is recurrent
  - Frustration
  - Sadness
  - Guilt
  - Fear
  - Hopelessness
- Intensifies during
  - Initial presentation of illness
  - Developmental transitions
  - Increasing healthcare demands
  - During period of new or worsened symptoms

Illness Trajectory

- Gravelle (1997)
  - A chronic condition is characterized by progression of the illness to a point that requires specialized, time-consuming, and sometimes round-the-clock care.

- Establishing the norm.
Opposing Tensions for Parent Caregivers

Kearney and Griffin (2001) proposed the notion of opposing forces for parent with chronically ill children.
Hope and Defiance versus No Hope and Despair
Parents expressed anger that their optimistic attitude toward their chronically ill child was viewed by healthcare professionals as abnormal.

Parents reported that they were inundated with negative messages from other people from professionals with their hopeless prognoses, along with families and friends, all of whom were responsible for feelings of isolation, rejection, anger, hurt, failure, and despair.

Opposing Tensions

• Parents experienced confusing and conflicting emotions due to:
  – Ambiguous prognoses
  – Personal observations in conflict with professional information
  – Lack of knowledge about what to expect next and for the future
  – Times of not knowing what to do as a parent

• In spite of negative feedback parents expressed that their child was a source of joy
  – Parents maintained hope
  – Struggled to ensure their child’s development and survival
  – Describe their child with admiration, love, and optimism.

Chronic Sorrow

• Recurrent
• Permanent (unresolved)
• Variable in intensity
• Intermittent periods of happiness
• Dual experience of loss for self (parent-caregiver) and child
  – Parent
    • Parent Caregiver loss of autonomous life
    • Impact of role on siblings, spouse
    • Financial obligations of child with chronic condition
  – Child
    • Cultural acceptance
    • Loss of dreamed for child
    • Loss of child’s autonomous life
    • Fear of new losses and disease progression

Why is Chronic Sorrow Important?

• Parents whose children have a diagnosis of a chronic medical condition may experience an ongoing unresolved grief or sadness phenomenon
  – Chronic Sorrow may impact parent’s ability
    – To manage their child’s complex health care needs
    – May lead to negative health outcomes for the child
    – May lead to negative outcomes for the family
    – May lead to negative health outcomes for parent

Chronic Sorrow: Research Question

• What is the nature and meaning of the lived experiences of parents with chronic sorrow who are caring for a child with a chronic medical condition?
  – Specifically looking at evidence in a mixed cohort of diagnoses.

Theoretical Conceptual Framework

• Olshansky
• Nursing Consortium Research on Chronic Sorrow
  – First developed questionnaire
• Concept Analysis: Chronic Sorrow
• Middle Range Theory of Chronic Sorrow
Eligibility

- Inclusion:
  - participants must:
    - be a parent or parent caregiver of a child (birth to 18 years) who has a chronic medical condition (Mokkink, van der Lee, Grootenhuis, Offringa & Heymans, 2008)
    - be 18 years of age or older
    - show presence of chronic sorrow as indicated by the Adapted Burke Questionnaire (ABQ), score of 16 or >.

- Exclusion:
  - foster parents and adoptive parents.

Population

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17 individuals were screened and 12 met inclusion criteria. All participants were biological mothers of child with a chronic condition.

For qualitative research data saturation is achieved when no new topics are revealed.

Methodology

- Interpretive, hermeneutical phenomenology
  - Heidegger
  - Lived Experience
  - Hidden meaning
  - “Life World”
  - Researcher as an Instrument

- Data Collection: audio recording
  - Verbatim transcription
  - Data Emersion
  - Coding

Findings

- Overarching Truth: Life Goes On
- Six Themes:
  - Surreality of Diagnosis
  - Unrealistic Expectations
  - The Battle
  - Keeping It Together
  - Doing Whatever It Takes
  - Serendipities

Theme

- Surreality of Diagnosis
  - Unprepared
  - Being at a loss
  - Learning the diagnosis felt
    - Unreal
    - Shocked
    - Stunned
  - Sensing loss of hope for their child

One mother said...

"It felt like every time I made a plan, it would not happen... I would think... we're going to do this really great thing [but]... We'd end up in the hospital getting care."

- Unrealistic Expectations
  - Full burden of care
  - Caregiver vs. Parent
  - Trying to find purpose
  - Hopelessness
  - Social Isolation
  - Loss of "Normal" life
Theme

- **The Battle**
  - Family Roles
  - Who takes priority for career?
  - Who takes responsibility for primary care?
  - Healthcare
  - Knowledge of diagnosis
  - Engaging parent caregiver as the expert
  - Cultural and Social Expectations
  - Parental roles
  - Care of child
  - Discipline of child

  "It just seems like there is something crazy happening on a daily basis, if not several times a week… it’s just that constant anxiety level that I stay at to be ready for stuff that happens," one mother said.

Theme

- **Keeping It Together**
  - Life and family
  - Couples: sleep versus physical intimacy
  - Counseling
  - Family time before outside activities
  - Spiritual
  - Journaling
  - Prayer and meditation
  - Faith
  - Help from others
  - Pride and humility

  One mother said...

  "It wasn’t the head piece, it was the heart piece. It was a sort of the dissociating from my emotions… staying, focused on the information. I’m not ready to feel it… that’s not going to help… I need to keep it together."

Theme

- **Doing Whatever It Takes**
  - Parenting role secondary to Advocate role
  - "Fight Mode"
  - Self and Family Sacrifice
  - Family unity
  - Physical well-being
  - Respite

  "I'm in the back of an ambulance, and I've been awake this whole time... it's probably one or two in the afternoon, and I haven't eaten since 4:30 or 5:00 the evening before. I haven't slept. I feel completely out of it. I look at one of the paramedics back there with me and I said, 'I might throw up.' And the paramedic said, 'She is not going to live.' And I threw up."

Theme

- **Serendipities**
  - Empathy
  - Kindness
  - Siblings and the unexpected
    - "As a child, she is learning so much about life."
    - "... they are different people than they would have been. Absolutely."
    - Maturing spiritually
    - "It's a more grown up tangible faith now."

  Comparisons of their burdens to other parent caregivers

Strengths and Limitations of Research

- **Strengths**
  - Qualitative Rigor
  - Credibility or truth value
  - Applicability or transferability
  - Consistency or dependability
  - Neutrality or confirmability
  - A Priori knowledge-awareness
  - Data Saturation
  - Audit trail with PhD Qualitative Researcher

- **Limitations**
  - Small population
  - Lower score on ABQ
  - Two part interviewing
  - A Priori knowledge-unintentional bias
  - Other factors

Implications for Healthcare Professionals

- **Practice**
  - Family Centered Care delivered by all team members.
  - Recognition of the Parent as expert on their child and family sub-culture.
  - Provision of timely, accurate, concise, and complete information.
  - Refrain from judgment and be genuine with parents and family.

- **Future Research**
  - Cultural factors
  - Father focused research
  - Develop comprehensive CS assessment tool
The majority of healthcare professionals are oblivious to the lifelong burden of being a parent-caregiver for a child with a chronic condition and managing their own experiences of chronic sorrow. All healthcare disciplines have the opportunity to provide adaptation and coping strategies to parent caregivers and patient families, through implementation of holistic family-centered care.