Caregiver Burden Across the Lifespan
dysphagia does not segregate

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Diagnosis & carers

- Denial
- Loss
- Social stigma
- Isolation

Pressures on carers

- Depression
- Anxiety
- Fear
- Financial hardship
- Link to poor health outcomes

Pochard et al (2005)
What causes pressure?

- Amount of care?
- Patient age?
- More than 1 bed in room?
- Physical burden?
- Degree of impairment?
  - TBI, cancer

Pichard et al (2005)

What do caregiver’s report?

- Stress related to:
  - feeding tube, passive coping, disrupted schedule
  - female, family position, unemployed, long hours
  - Reluctance to write advanced care plans
  - Fear & responsibility

What do patients report?

- Biomechanical
  - speech, choking, fatigue, malnutrition
  - beyond head & neck cancer or stroke
- Psychosocial
  - stigma, burden of change, emotion, social limits
- Not correlated with severity
- Changes can decrease or increase pressures
Caregiver burden in pediatrics

- Is the burden different in pediatrics?
  - similarities
  - differences

Socio-economic factors

- Financial challenges
- Ease of access to health-care system
- Ease of navigation through health care system

Child factors

- Degree of disability
- Age
- Underlying etiologies

References:
- Reina et al., 2004
- Craig et al., 2003
- McManus et al., 2011
- Rouse, 2002
- Reina et al., 2004
- Hsieh et al., 2009
Caregiving

- Feeding requirements
- Other requirements/responsibilities
- Caregiver-child relationship

Coping factors

- Intra-personal
- Emotional distress
- Chronic stress
- Family support
- Limited social opportunities

Emerging data

- Investigated contributions of feeding and swallowing problems on caregiver & family (n=101)
- Scales
  - Pediatric Feeding & Swallowing Disorders Family Impact Scale-Revised
  - Parent Stress Index
  - Functional Health Status-2

Reina et al., 2004
Franklin & Rodger, 2003
Veness & Rieilly, 2008
Craig et al., 2003

Reina et al., 2004
Sleigh, 2005
Craig et al., 2003
 Hewston & Singh, 2009
Socioeconomic factors

- Household Income
  - Family impact ❌
  - Parental stress ❌

Child factors

- Functional Health Status
  - Family impact ❌
  - Parental stress ✓
- Age
  - Family impact ❌
  - Parental stress ❌
- Co-occurring developmental delays
  - Family impact ❌
  - Parental stress ❌

Caregiving

- Tube feeding
  - Family impact ❌
  - Parental stress ❌
Coping factors

- Number of children
  - Family Impact ×
  - Parental Stress ×
- Hours of assistance (family & professional)
  - Family Impact ×
  - Parental Stress ×
- Marital status
  - Family Impact ×
  - Parental Stress ×

Patient & family-centered decision making:
default starting place, modified by prognosis & family preferences for role

Default starting place of shared decision-making
1. Assess prognosis and certainty of prognosis
2. Assess family preference for role in decision-making
3. Adapt communication strategy based on patient and family factors
   and reassess regularly

Parentalism or Doctor Decides
Autonomy or Family Decides
Shared Decision Making

Evidence Based Practice

Clinical Expertise

Informed
Patient Preference

Best Evidence

ASHA 2011
Family-Centered Care

Assess burden

- Directly question caregivers as a component of assessment
- Use a published scale
- Develop your own questionnaire used in practice

Synthesize information

- Listen to what caregiver says
- Observe what caregiver does
- Integrate what you know about patient
Make recommendations

- Access to resources
  - sharing experience, financial, emotional
- Modify treatment plans
- Work with other team members

Shared experiences

- Pediatrics & adults: shared experience is beneficial
- Support groups
- Group therapy
- On-line communities

Supporting caregivers

- Provide services to meet emotional and financial needs
  - challenging for SLP
  - teaming is important
  - emotional needs
  - can we do this?
Caregiver Burden Across the Lifespan


