

Progressive Hearing Loss and Family Stress

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Status of Research

- ▶ No systematic research on families with infants/children with progressive hearing loss even though they account for about 15% of all preschool cases of SNHL (Hone & Smith, 2002)

Studying the Impact of Progressive Hearing Loss in Pediatric Populations

- ▶ Nearly all research on the impact of infant and childhood hearing loss on families is cross-sectional
 - Not well-suited to the study of progressive losses, and developmental and situational changes
 - BUT likely included children with progressive losses

Research Status – Hearing Loss Characteristics

- ▶ Most studies have focused on families with infants/children with severe-to-profound hearing loss
 - Deaf Children with Deaf vs. Hearing Parents
 - Children Fitted with Cochlear implants
- ▶ A growing number of recent studies have considered the impact of early identification, diagnosis and intervention
- ▶ Newer literature coming out on children mild, moderate and unilateral hearing losses

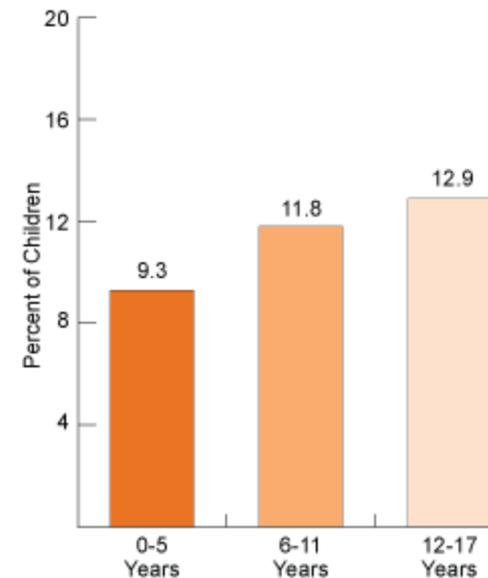
Infants / Children with Progressive Losses are Heterogeneous

- ▶ **Etiology** (e.g., Connexin 26 vs. EVA vs Ushers)
 - ▶ **Onset**
 - ▶ **Time course**
 - ▶ **Severity and configuration changes over time**
 - ▶ **Treatment, therapeutic, and educational options and resources**
 - ▶ **Family characteristics and situations**
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Things to Consider When Looking at Family Stress

- ▶ Just having children increases stress in families
 - Tends to increase with age and peaks in adolescence (HHS, 2014)
 - Increased stress with increasing numbers of children (Noh et al., 2017; Rodriguez-Jenkins & Marcenko, 2014)

Children Whose Parents Usually or Always Feel Stress, by Age

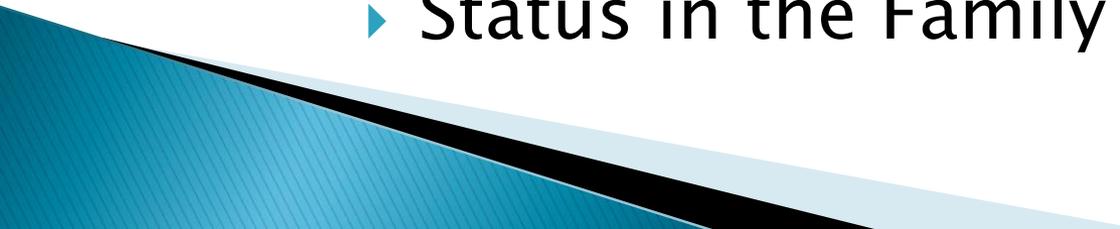


(HHS, 2014)

Families with Hearing Children

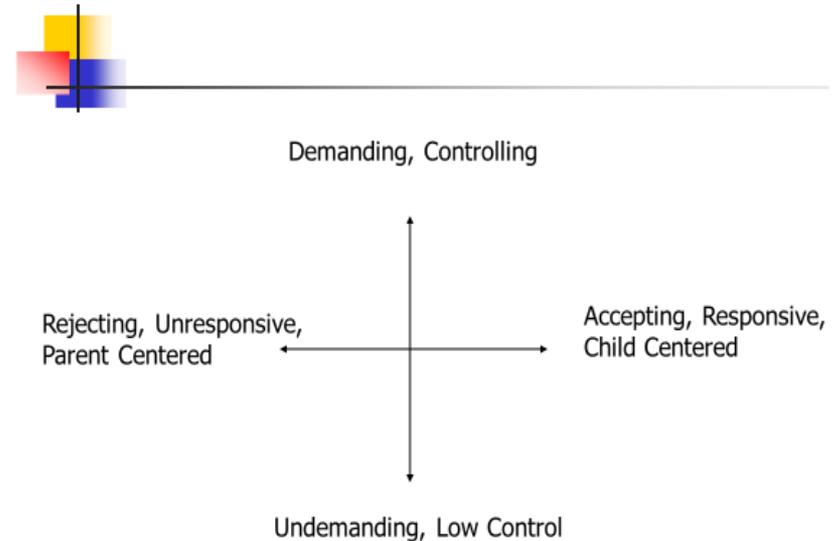
- ▶ Families with hearing children and their situations are highly variable
 - Difficult to identify significant family issues in an individual family with an individual child
 - Influences are multidirectional, dynamic and transgenerational
- ▶ Wide-ranging effects
- ▶ Most families are doing the best they can and want the best for their children

General Parent-Related Predictors

- ▶ Maternal Education
 - ▶ Age
 - ▶ Income and Cost of Raising a Child
 - ▶ Work Demands
 - ▶ Urban vs. Rural
 - ▶ Social Support Network
 - ▶ Parenting Style
 - ▶ Social-Emotional Skills
 - ▶ Status in the Family
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Parenting Style

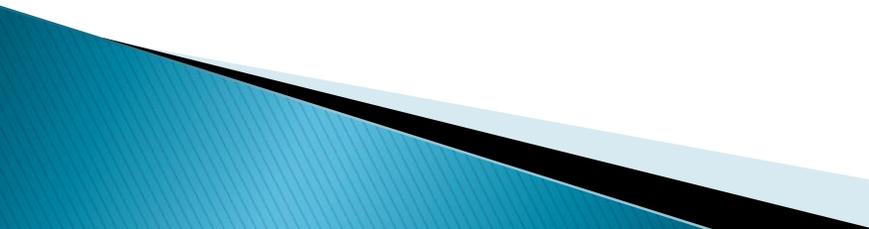
- ▶ Baumrind (1967, 1971)
 - 2 dimensions
 - Demanding, Controlling vs. Undemanding, Low Control
 - Accepting, Responding, Child Centered vs. Rejecting, Unresponsive, Parent Centered



More Recent Framework

- ▶ **Three dimensions** (Kawabata et al., 2011; Ketelaar et al., 2016)
 - **Positive Parenting Style**
 - Sensitivity, warmth, responsiveness, interact in a positive and meaningful way, set standards but responsive to child needs
 - **Negative Parenting Style**
 - Strict rules, punitive discipline, inflexible
 - Interferes with healthy social–emotional development
 - **Uninvolved Parenting Style**
 - Ignoring, disregarding, unpredictable
 - Associated with aggressive behavior in children

General Child-Related Predictors

- ▶ Age
 - ▶ Sex
 - ▶ Language/communication skills
 - ▶ Social-emotional development (e.g., temperament, emotional regulation, empathy, resilience)
 - ▶ Behavior
 - ▶ Literacy and school performance
 - ▶ Physical skills and appearance
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Impact on the Family with a Infant/Child with Hearing Loss

- Emotionally fragile at screening and diagnosis (Russ et al., 2004)
- Extreme levels of stress initially
- Mourning process can vary
- Parents often overwhelmed by the decisions that they have to make quickly that have long-term consequences (Fitzpatrick et al., 2016; Hyde 2010)
- Overwhelmed by the technology (Fitzpatrick et al., 2016)

Consequences

- ▶ Can impact the overall health of the family (multidirectional)
- ▶ Can interfere with involvement in timely intervention and treatment (Fitzpatrick et al., 2014; Ingber et al., 2010)
- ▶ But timely and effective intervention reduces overall stress levels
 - Early intervention and cochlear implants have had a substantive impact

Influencing Factors

- ▶ Age of onset
- ▶ Age of identification and intervention
- ▶ Nature and extent of the hearing loss
- ▶ Appropriate fitting and use of sensory devices
- ▶ Availability, access and soundness of the peri- and post-fitting (re)habilitation
 - Rural vs. Urban
- ▶ Medical conditions
- ▶ Other co-morbid handicapping conditions
- ▶ Social support network
- ▶ Emotional status of family

Support

- Support networks affect stress levels and tend to become more restricted for families who have a child with hearing loss (Quittners, 1991, 2010)
 - However, the level of support is more critical than the size of the support network

Impact of Increased Family Stress

- ▶ Can interfere with timely diagnosis, intervention and education
 - ▶ Stress levels impact parent–child interactions and may impact cognitive and language development
 - ▶ Can impact social–emotional skill development (Hintermair, 2006; Mulier–Nix et al., 2004)
 - ▶ Increases risk for poor parent–child attachment (Hamner & Turner, 1990; Greenberg & Marvin, 1979)
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Global Stress

- On measures of global stress mothers and fathers are similar
 - In some studies parents of children with hearing loss do not significantly differ from parents of hearing children
 - Situational differences
 - Child differences
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Mothers

- ▶ On specific issues, mothers show greater levels of perceived stress than fathers
 - ▶ Worry about the impact of the hearing loss on themselves and their family
 - ▶ Reduced free time
 - ▶ Inadequate support from spouse
 - ▶ Depression
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Fathers

- ▶ Stress related to child acceptability
 - ▶ Demands on emotional, physical, and economic resources
 - ▶ More denial
 - ▶ Less likely to develop constructive coping strategies
 - ▶ Less active involvement BUT respond well to interventions and counseling if engaged
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Income

- ▶ Families with lower income show higher levels of stress
 - ▶ Combination of low income and living in a rural area is a substantive barrier to receiving services
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Age of Identification and Intervention

- Very intense parental stress levels with early identified babies, and children with sudden onset -- but the duration is shorter (Russ et al., 2004)
- Infants receiving early identification, diagnosis and intervention show more typical auditory, speech and language development, which ultimately reduces family stress and normalizes family interactions
 - Quittner et al. (2010) found that language delays and behavior problems were strong predictors of parental stress in hearing parents of deaf children

Age of Identification and Intervention (cont)

- The sooner support services are received after identification the more likely parent–child interactions will be normal
 - However, progressive losses in young children might be late–identified if hearing was normal at screening
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Remain at Risk for Delays in Speech and Language Development

- ▶ Vohr et al. (2009) found that although very early intervention (< 3 mos) was associated with improved language development, by 12 to 16 months of age most infants with moderate–profound hearing loss demonstrate delays in both oral and signed language
- ▶ Fitzpatrick et al. (2007) found that parents express regret (guilt) over the gaps between age and speech and language development

Milder Hearing Losses

- ▶ Infants/children with mild, minimal and unilateral hearing losses tend to not demonstrate marked delays
- ▶ Inconsistent responsiveness can cause family stress
- ▶ Also can result in academic and behavioral issues that can cause stress
- ▶ Inconsistent treatment approaches and down-playing the impact by professionals can exacerbate family stress (Fitzpatrick et al., 2015)

Other Child Characteristics

- Additional handicapping conditions increase the level of stress in the family
 - Health
 - Cognitive
 - Behavioral*
 - Social-Emotional*
 - Motor
 - Speech and Language*

Availability and Soundness of Services

- Federal, State and Local Guidelines and Dictates
 - Case Managers
 - Medical Professionals
 - Audiologists
 - Speech–Language Pathologists
 - Educators
 - Social Workers
 - Psychologists
 - Parent Training Programs and Support Groups
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Availability and Soundness of Intervention Programs

- With young children general stimulation and parent training approaches are common
 - SKI*HI
 - State designed programs
 - Sunshine Cottage
 - Muenster Parental Program
- Individualize and specialized schools
- Regular school-based services
- Tailored parent counseling and instruction
- Family and online support groups
- Telehealth

Family Counseling

- Emotional counseling
 - Informational counseling
 - Referrals
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Levels of Emotional Support

- ▶ Providing an accepting and **supportive** environment
 - Professionals are considered a significant source of support (Lederberg & Golbach, 2002; Meadow-Orlans & Steinberg, 1993)
 - Total levels of professional support, over time and across sources, has a cumulative and positive effect on the behaviors of mothers and hearing-impaired infants/children (Meadow-Orlans & Steinberg, 1993)

Family-Centered Counseling

- Provide information and feedback in an empathetic manner
 - Avoid being directive, narrowly child-focused
 - Don't be afraid of providing emotional support
 - Yet be straightforward and truthful about severity and potential impact, even in cases with mild and unilateral losses

Family-Centered Counseling

- Allow families to inform you of their needs and their child's needs
 - Adopt an open-ended questioning style, allowing the parents to have input
 - Promote parental expression of feelings
- Help families identify hassles of daily living that increase stress and strategies to reduce those stressors (Pipp-Soegel et al., 2002)

Providing Information

- Provide information as the parents want and need to know it
 - Family needs assessment questionnaires
 - Provide appropriate and timely Information about resources
 - Provide information about rights to services
 - Balance between providing enough information and overwhelming families
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Providing Information

- Be aware that informational needs change over time as does the specificity with which information should be presented
 - Parents need and want repetition of information over time
 - Supplementary information in multiple forms can be helpful
 - Handouts
 - Links to informational websites
 - Links to parent and professional forums
 - Audio and video recording of sessions
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Service Provision

- Services shouldn't be a secret to families
 - Knowledge of resources and appropriate timelines reduces parent stress levels (Hintermair, 2006)
 - When parents of hearing-impaired children are underserved they often direct their frustration toward professionals such as physicians and audiologists
- ▶ Devote time to knowing available resources, appropriate professionals and where to make appropriate referrals
- ▶ Coordinate with other professionals

Child Counseling and Instruction

- Self-esteem
 - Self-acceptance
 - Friends and social network
 - Place within the family
 - Cultural issues
 - Focus on strengths
 - Seriously consider feelings and beliefs
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Goal Development

- Facilitates the counseling and instructional process
 - Opens the (re)habilitation process to greater parental involvement
 - Provides a starting point, an anchor for the family and professionals
 - Provides markers to judge progress
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Setting Goals

- Look beyond the audiogram and the hearing loss
 - Establish goals that relate to function of the whole child within his/her environment
 - Establish goals that relate to the integration within family and community
 - Consider seriously the parent's, larger family and child's needs, goals and expectations
 - Because needs change over time goals should be fluid
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Multidisciplinary Approach

- Play an active role in the development of the IFSP and IEP when feasible and appropriate
 - Maintain communication with family and case manager
 - Actively communicate with all of the rehabilitation specialists working with the child
 - Seek/provide information and feedback about the appropriateness of the hearing aid/cochlear implant fittings and rehabilitation services
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Impact of Family Counseling

- ▶ Lower levels of family stress
- ▶ More positive interactions
- ▶ Parents communicate with their children more consistently and fluently
- ▶ Empowerment
 - Mothers who believe they can stimulate language skills in their young children tend to have children with higher language skills (DesJardin, 2006)
- ▶ Improved child developmental outcomes
- ▶ Improved family health status