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Health related quality of life in parents of children with speech and hearing impairment

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ABSTRACT

Objectives: Hearing impairment and specific language disorder are two entities that seriously affect language acquisition in children and reduce their communication skills. These children require specific treatment and higher levels of care than healthy children. Their language abilities also strongly influence parent–child interactions. The purpose of our study was to evaluate the health-related quality of life (HRQOL) of the parents of hearing-impaired children and the parents of children with speech difficulties (specific language disorder).

Methods: Our study subjects included 349 parents (182 mothers and 167 fathers) of preschool-aged children with receptive expressive language disorder and 131 parents (71 mothers and 60 fathers) of children with severe hearing impairment. A control group was composed of 146 parents (82 mothers and 64 fathers) of healthy children of the same age. HRQOL was assessed using the SF-36 questionnaire.

Results: For all groups of parents, the mothers had poorer scores compared with the fathers, but large differences were apparent depending on the child's impairment. In the control group, the scores of the mothers were significantly lower than the fathers' scores in only two (of eight) health domains. In contrast, the scores were lower in three domains for the mothers of speech-impaired children and in six domains for the mothers of hearing-impaired children, representing the greatest difference between the parents. When compared with the control group, both the mothers and fathers of speech-impaired children scored significantly worse in five health domains. Fathers of hearing-impaired children scored significantly worse than controls in three health domains. The lowest scores, indicating the poorest HRQOL, were observed for mothers of hearing-impaired children, who obtained significantly lower scores than the control mothers in all health domains except the emotional role.

Conclusions: The parents of preschool-aged speech-and hearing-impaired children experience poorer HRQOL than parents of healthy children of the same age. Mothers of hearing-impaired children are especially affected, demonstrating a negative impact in almost all health domains.

1. Introduction

Health-related quality of life (HRQOL) is a multidimensional concept that includes the physical, mental, and social functioning of a person. It represents subjective health and focuses on the impact that someone's health status has on quality of life. In the last 20–30 years, assessing the quality of life has become popular for evaluating the efficacy and efficiency of diagnostic and therapeutic procedures in medicine and as one of the main public health instruments for estimating the burden of a disease or disability on the quality of life of a certain population [1–3]. It is an accepted parameter in international classification systems such as the WHO Classification of functioning (ICF), where all aspects of a person's life (including development, participation and environment) are incorporated instead of solely focusing on the diagnosis because a diagnosis reveals little about one's functional abilities. Identifying the limitations of function offers valuable information that can be used to plan and implement interventions [4].

Significant effort has been invested in constructing practical subjective health measurement tools that are appropriate for widespread use across diverse populations. As a result, several internationally recognized questionnaires have been created [5],

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including the SF-36 Health Survey. This survey measures health concepts that were selected during two large empirical studies, the Medical Outcomes Study and the Health Insurance Experiment. The SF-36 Health Survey was validated by researchers from across the world who were gathered under the International Quality of Life Assessment (IQOLA) Project. This project established norms and documented the translations as required for international use [6].

Health-related quality of life is of significant clinical interest both when dealing with the patient and when including close relatives and caregivers into medical treatment, especially in pediatric cases [7]. Any incompetence or limitation in child development has the potential for causing significant stress for the child's parents [8–11], although each disease presents unique challenges. While care giving is a normal parental duty, providing the high level of care required by a child with long-term functional limitations can become burdensome and may impact both the physical and mental health of the child's parents [12].

Specific language disorder and hearing impairment are two distinct entities but have important characteristics in common: they reduce language acquisition ability and verbal communication skills, resulting in limitations in social communication. Consequently, parents experience trouble communicating with their children, especially if there are additional emotional and behavioral problems, which are not unusual in children with hearing or speech disturbances. These problems sometimes develop as a consequence of a frustration arising from not being understood and not being able to communicate clearly.

Specific language impairment (SLI) is a common childhood developmental disorder that is characterized by difficulty with language and is not caused by known neurological, sensory, intellectual, or emotional deficit [13]. The estimated prevalence of SLI in kindergarten children is 5–8% [14–17].

Little information is available on the health-related quality of life of the parents of children with SLI. A study by German authors [7] using the SF 36 Health Survey showed that the mothers of speech-impaired children had lower scores than the mothers of healthy children for the majority of subscales, indicating poorer health status. In another study, the same authors found that the mothers also had a higher prevalence of depression compared with the control group [18]. Several other studies that tested maternal stress reported higher stress scores and higher prevalence of stress because of the child' speech disability [19,20]. However, none of these studies focused on the fathers.

According to the Diagnostic and Statistical Manual of Mental Disorders-IV-TR (DSM-IV-TR), specific language impairment is subdivided into expressive language disorder and receptive-expressive language disorder [21], with the latter being less favorable in terms of symptoms and prognosis. Children with developmental receptive-expressive disorder have significant speech comprehension disturbances, meaning that they understand spoken language at a level that is lower than expected for the child's general level of intelligence. This disorder can lead to ongoing impairment in an individual's communication and later academic and social skills [22–24]; thus, it represents a major public health problem. Children with receptive expressive language disorder are also more likely to have additional disorders, such as impairments in motor skills, cognition, attention deficit disorder and emotional behavioral problems [25], and these additional disorders are of greater concern for the mothers than the language delay itself [19]. These additional problems and the overlap between symptoms can confuse parents and sometimes professionals as well, making the differential diagnosis between receptive-expressive language disorder, pervasive disorder, and mental retardation difficult [26].

For the parents of children with severe hearing impairment, communication is also a great challenge because the parents have to learn new strategies rather than rely on intuitive communication [27]. This process of adaptation can result in disrupted interactions that strain parents and children, which may negatively affect parenting roles [28,29]. In the last two decades, this parenting stress in the parents of hearing-impaired preschool children was quite extensively studied, especially in connection with cochlear implantation, but the results of the studies were somewhat inconsistent. Most studies that investigated parenting stress showed that the subjective feeling of distress was greater compared with the parents of healthy children [30–32]. One study that investigated psychic symptoms (employing validated questionnaires) showed that there was a need for psychosocial support in 18% of parents, but an even greater percentage of parents (42%) were highly motivated in favor of psychosocial interventions [33]. However, according to other authors [34,35], mothers of hearing-impaired children showed similar parental distress as a normative group. There are numerous explanations for these differences, including sample size, age at diagnosis, the amount of support provided to the parents, and the measures of stress that were used. Context-specific stress measures showed greater sensitivity, finding significant elevations in parenting stress relative to the hearing population as opposed to general stress measures [36].

Stress level also changes with time. In a longitudinal study comparing mothers of young children, mothers of 2-year-old infants with hearing loss reported high levels of stress, but differences from a normative sample were not found at 3 and 4 years of age [37]. The stress level in parents of hearing-impaired children was perceived as highest immediately after the diagnosis, when parents experienced the greatest loss of the quality of life, but their psychological state tended to stabilize with time and treatment [38].

The data about differences in parental stress regarding the type of the hearing device used for severe hearing impairment (classical hearing aid vs. cochlear implant) are limited and inconsistent. One study reported that the stress level in parents of children with cochlear implants (CI) was similar to the stress level in parents of healthy children, but that the parents of hearing aids (HA) users exhibit increased stress levels [32]. Another study [39] reported increased stress in both groups of parents but with more distress in the parents of CI users, most likely because of the operative procedure, complicated fitting and adaptation process. In the same study, the parents of the CI children showed heightened expectations in comparison with the parents of HA children. Currently, the use of CI in addition to extensive habilitation enable many children with severe hearing impairment to hear and understand verbal language and, at a certain age, to communicate orally in a manner that is similar to their healthy peers. However, these advances have simultaneously raised parental expectations and can thus lead to frustration if desirable outcomes are not achieved. In a study investigating the impact of CI on families, mothers as a group held relatively high expectations with regard to their child's communication, social and academic abilities following the cochlear implantation [40].

In general, children's language abilities strongly influence parent–child interactions in both deaf and hearing populations [41]. Parenting stress has been linked to poor child outcomes [42–44]. Parents of hearing-impaired children with less language report higher levels of parenting stress and perceive their children as being more difficult [36]. The purpose of our study was to estimate the expected negative influence of children's speech and hearing problems on their parents' subjective health by measuring parental health-related quality of life and focusing on the physical, emotional and social aspects of this impact.