Перспективы дальнейших исследований в данном направлении. В дальнейшем планируется провести изучение основных технико-тактических действий у фехтовальщиков рапиристов различной квалификации с помощью оптико-электронной системы регистрации движений «Qualisys» и на основе биомеханического анализа, синтеза и моделирования определить наиболее рациональные способы их выполнения, а также создать программы по совершенствованию данных действий для рапиристов на этапе специализированной базовой подготовки.

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RAISING A DEAF CHILD IN UKRAINE: AN ECOLOGICAL SOCIO-EDUCATIONAL PARENTAL SURVEY

Kobel I.H., Ph.D.
Associate Professor, Ukrainian Catholic University, Ukraine
Fulbright Scholar 2012-2013
Barclay D., Ph.D.
Professor, Department of Social Work, Chair
Gallaudet University, USA

Стаття є викладом результатів опитування батьків із ширшого дисертаційного дослідження про життя та проблеми чуючих батьків в Україні, які виховували нечуючих дітей від народження до вступу у перший клас спеціальної школи для глухих або слабочуючих.

Статья является изложением результатов опроса родителей из более широкого диссертационного исследования, целью которого было изучить жизнь и проблемы слышащих родителей воспитывавших неслышащих детей от рождения до поступления в первый класс специальной школы для глухих или слабослышащих.

This article presents a report of the survey results from a broader doctorate study on life and problems of Ukrainian hearing parents who have raised their deaf or hard of hearing children since birth till enrolling in grade 1 of a special school for children with hearing impairments.

Ключові слова: глухота, глухі діти, чуючі батьки, соціокультурний підхід, медико-патологічний підхід, білінгвізм, українська жестова мова

Ключевые слова: глухота, глухие дети, слышащие родители, социокультурный подход, медико-патологический подход, билингвизм, украинский жестовый язык

Key words: deafness, deaf children, hearing parents, sociocultural approach, medical-pathological approach, bilingual, Ukrainian Sign Language

Background

Deaf Children, Parents, and Deaf Education

Five out of every 1,000 infants born yearly worldwide are born with significant hearing loss (>40 dB HL) [20]. By September 2007 there were 30,896 children of school age diagnosed with hearing loss in Ukraine. The birth of any child impacts the family. However, when a child is diagnosed with a hearing loss, the effects are likely to be greater, more challenging and more demanding

on the family [3;13;16;17;23] Deafness affects all of family life by creating challenges in communication which in turn test the creation of appropriate family functioning and parental management of children [7;11,12;14;15;16;18;21;26;27]. The effective development, understanding, and expression of language are fundamental to educational experience and its acquisition is crucial for deaf and hard of hearing children [19;23]. Hearing loss creates a difference in the way in which individuals communicate and acquire information, but is not in itself disabling, provided that there is a full access to language [1;4;5]. Because of their unique communication needs, deaf children are distinct from other children with disabilities or special needs. Children with learning or developmental problems can share the spoken language and can communicate with the world around them. However, because deafness can interfere with the acquisition of the spoken language of the community, children who are deaf and hard of hearing may find it difficult or even impossible to converse with other hearing family members and the parental challenge is to establish effective communication in their homes and to ensure that their children receive the necessary support from professionals and schools [18;23;24;27]. Despite the implementation of various educational approaches at increasingly younger ages, children with hearing loss, as a group, are at significant risk for relatively poor academic performance, dropping out of school, and delayed development of language and critical thinking skills. This suggests that factors other than the schooling of deaf or hard of hearing children are worthy of research.

Research in Ukraine

In Ukraine, one can witness a paucity of research in the area of educational psychology, in general, and in family functioning and parental involvement in educational processes in particular [8;25]. This can in part be explained historically. In the Soviet Union, communist leaders saw the parental role and responsibility of raising children as secondary to the ideological effort targeted at children in the state school system. In this political system there was, therefore, little motivation for researchers to explore the life and functioning of families with children with special needs.

Family-Centered Theory applied in this research

Bronfenbrenner [2] is credited with applying the term “family centered” to family research in the 1970s aimed at increasing the level of parent participation in early education. According to his theory, if you want to understand the way children develop it is necessary to investigate their behavior in their natural social context, while they are interacting with parents, familiar adults and other family members. Both the child and the context shape and accommodate each other as they interact. In this way, the more time the child is involved in such settings the more the settings impact the process of accommodation [10]. In other words, a family systems perspective acknowledges the mutual impact of each member’s characteristics and highly values the importance of addressing issues related to family life. Henderson and Henderson [9] stated:

Because the deaf child is a component of the family system, the deafness belongs not just to the child but to the entire family. Accepting this perspective makes it necessary for the family to seek ways to recognize itself so that all the components in the family system can participate, contribute, and draw on the family's resources equally. (p. 325)

Methodology

The aim of this current research was to gather and analyze descriptive data on deaf children and parental perspectives in Ukraine using the ecological framework as a guide. The data used for this research article is part of a much larger dissertation research study. Only select data related to demographics and the key variables of parental perspectives and family functioning are analyzed and discussed. This data can be utilized to inform practitioners and policy makers at all levels who work with child and family systems of deaf and hard of hearing children [6].

Participants

All hearing families with deaf and hard of hearing children enrolled in grade 0/grade1 of special residential schools for the deaf and hard of hearing children across Ukraine (58 schools in total) were the target population for this research.

Parents were not differentiated due to the level of hearing loss of their children (deaf and hard of hearing) for the following reasons: (a) all hearing parents of children who are deaf or hard of hearing raise their children in a similar environment, (b) although children with different hearing loss (deaf and hard of hearing) were supposedly sent to different schools, this study has confirmed that the population in any particular school comprises both categories of children, (c) it was impossible to verify the hearing status of every child prior to the study, and (d) the difference between schools for the deaf and for the hard of hearing is minor and relates only to some curriculum differences.

Instrumentation

The survey questionnaire was part of a larger survey instrument based on the National Parental Project Survey Questionnaire [18] which was specifically designed for families with deaf children. The survey instrument for this research study contained two main sections: (1) background information on hearing loss, age of identification, additional conditions, hearing aids, and cochlear implants, (2) parent’s response to the identification of hearing loss, nine items from the Impact of Deafness Scale [17], and (3) family background characteristics.

For the purpose of this study this survey questionnaire was modified to fit the Ukrainian context. Pilot investigations were conducted to ensure the clarity and relevance of the questionnaire items. The survey instrument was translated from English to Ukrainian and adapted to the Ukrainian context.

Data Collection Procedures

Survey packages were distributed to parents of the sample with the help of schools according to a jointly established procedure (see a detailed description in *Findings*). They were collected in three to four weeks depending on the timing of the next visit of the parents to the school. The principals of the schools were asked to distribute the surveys and they agreed to send the packages back to the researcher after collecting them.

Data Analysis

Information gathered through the parent survey was analyzed for descriptive statistics to discover characteristics of the sample and parental perspectives on having and raising a deaf child. In addition demographic information was analyzed to

demonstrate the diversity of families participating in the study. The SPPS statistical package was utilized for this.

Findings of the Survey and Discussion

In total, forty-eight schools (91% of those contacted and eligible) with 388 eligible students distributed survey packages to parents and returned 325 of them. The response rate calculated for the participating 48 schools is 83.8%. The response rate for the entire sample initially proposed for the study was 77.8%.

Of the 325 respondents who completed the surveys, 249 were mothers (76.6%) who also considered themselves to be the primary caregiver for the child. Thirty-three (10.2%) surveys were completed by fathers. Mothers and fathers together completed an additional 17 forms (5.2%). Grandmothers completed 21 (6.5%) forms and 5 survey forms were completed by other relatives or guardians.

Hearing Status in the Family

Among mothers, 28 (8.9%; *n*=316) were deaf and 10 (3.2%) hard of hearing. Among fathers, 26 (8.7%; *n*=300) were deaf and 9 (3.0%) were hard of hearing. Respondents identified 26 families (8%) as a "deaf family" meaning that both parents are deaf. Eight children (2.5%) have both parents who are hard of hearing; 4 children (1.2%) have one deaf and one hard of hearing parent and 2 children (0.6%) have one deaf parent and one hearing one. Information on hearing status of grandmothers (n=208) revealed that 11 (5.2%) are deaf; 4 (1.9%) are hard of hearing. Among grandfathers (*n*=169), 5 (3%) are deaf and 3 (1.8%) hard of hearing.

Child Characteristics

Age of the Children and School Enrolment Delays

The child's average age was 91 months (*SD*=11.9). The youngest age was 60 months (*n*=3; 0.9%) and the oldest 124 months (*n*=1). The age distribution of children shows that the majority of children had no delays in school enrolment. Two hundred and thirty children fit into age groups 1, 2, and 3: 18 children (5.5%) in group 1; 79 (24.3%) in group 2; 133 (40.9%) in group 3). Ninety-five children are considered to be enrolled in school programs with the following delays: 72 in group 4 (22.2%) with 1 year; 22 in group 5 (6.8%) with 2 years; and 1 in group 6 with a 3 year delay.

Hearing Status of the Children, Gender and Type of the School

One hundred and fifty-five (48.4%; *n*=320) children were reported as deaf; 110 children (34.4%) were reported as hard of hearing. Parents of the remaining 55 children (17.2%) stated that they didn't know which of these two categories applied to their child; 5 surveys returned this question unanswered. Thirty-five children with unidentified hearing status (58.3%; *n*=60) live in rural areas and the same number study in schools for deaf children. Only 90 respondents (28%) reported hearing loss of their children in decibels. Other respondents either did not provide this information or checked the "don't know" box.

Of 325 children, 175 were boys (53.8%) and 150 were girls (46.2%). Of the deaf children, 88 (56%) were boys and 67 (43%) were girls. One hundred and two (65.8%) deaf children were enrolled in schools for deaf children, and 53 children (34.2%) were enrolled in schools for hard of hearing children. Eighty-four deaf children live in rural areas and 71 children live in urban. Forty-eight deaf children were enrolled in school with delays of 1 to 3 years.

Of the hard of hearing children 55 were boys and 55 were girls. Half of these children live in urban areas. Fifty eight (52.7%) hard of hearing children were enrolled in schools for deaf children, and 52 (47%) children were enrolled in schools for hard of hearing children.

Identification of Hearing Loss

The average age when hearing loss was suspected was reported as close to 17 months. The average age when hearing loss was confirmed was reported as 24 months. (an elapsed time of 7 months between suspicion and confirmation). However, 77 parents (23.7%) reported no time gap between suspicion and confirmation; 16 (4.9%) reported confirmation less than 1 month after the initial suspicion; 112 (34.5%) waited 6 months; 59 parents (18.2%) reported it took up to 12 months; 11 parents (3.4%) waited for confirmation up to 3 years; and for 5 parents (1.5%) it took between 37 and 48 months for their suspicions to be confirmed by a hearing test.

The degree of hearing loss seemed to influence the confirmation age. Children who were deaf were suspected to have hearing problems on average at age15 months (*n*=155; *SD*=11) and had a confirmed identification on average at age 22 months. The elapsed time between suspicions and confirmations was 7 months. The first suspicion of a problem for those who were identified as hard of hearing appeared, on average, when they were almost 20 months (*n*=110; *SD*=16) of age and their hearing loss was confirmed at 27 months. Thus, children who are deaf received confirmation of hearing loss at a younger age than did hard of hearing children.

Parental Reflections on Raising a Deaf Child

The respondents were asked to respond to 9 statements designed to examine the impact of the child's hearing loss or deafness on them and their families related to family dialogue, parental pride, family stress, communication skill, impact on future dreams, time for self, inclusions in family discussions, life difficulty level, and communication barriers. The respondents reported agreement or disagreement on a five-point scale. These statements are shown in the Table 19 in descending order.

Lack of communication with the child turned to be the most frustrating issue for 77.6% of respondents Only 25.3% of the respondents considered their skills of communication as adequate for their child's need. As the result of poor communication at home only 33.2% of children were regularly involved in family conversations.

Table 1

Impact of Deafness on Parents and Families – Percentage of respondents answering 'agree' or 'strongly agree' in the following descending order of impact common to the respondents:

9. I feel that there are many things I cannot seem to communicate to my child	%	77.6

5. Because of hearing loss I had to forget many dreams and hopes for my child %	62.8
1. We have more family discussions about our deaf child than about other things %	63.1
8. My life is very difficult because my child requires so much time and additional efforts %	59.4
6. In spite of extra time devoted to my child I still find time for myself %	52
2. I feel proud of what we have done and are doing for our child %	59.2
3. Much stress in our family is related to child's hearing loss %	40.6
7. My child is regularly included in family conversations because we have an effective communication system	33.2
4. My skills of communication are adequate for my child's needs %	25.3

In order to compare hearing families with families with deaf and/or hard of hearing members means of scores were calculated. Positive responses received a score of '3' (agree) or '4' (strongly agree). Score '0' stands for 'don't know/probably not'; '1' stands for 'strongly disagree'; 2 stands for 'disagree'. Items 3, 5, 8, and 9 were recoded as they had been compiled in a reverse mode (negative). In this context the higher scores reflect a more positive response to the diagnosis of their child. Maximum score could have been 36. Mean of all rating scores for all parents is 18.49 (*n*=325; *Mdn*=19.0; *SD*=5.84). In order to get an overall picture of parental feelings towards raising a deaf or hard of hearing child and compare families a combined mean was computed for all nine items (*M*=2.05; *Mdn*=2.11; *SD*=.65) (see Table 2).

Table 2

Parent's Feelings on Deafness: Mean of Ratings; Combined Mean of Ratings

	All families (N=325)	Families with D/HH members (*n*=26)	Hearing families (*n*=299)
Mean of all ratings	18.49	20.88	18.28
Mdn of all ratings	19.00	23.50	18.00
SD	5.84	8.315	5.54
Combined *M* (Sum of scores:9)	2.05	2.32	2.03
Combined *Mdn*	2.11	2.61	2.0
SD (for combined mean)	.65	.92	.61

Families with deaf or hard of hearing members show more positive attitudes to deafness and reveal less stress: mean of rating scores is 20.88 (*n*=26) vs.18.28 (*n*=299) in hearing families, and combined mean is 2.32 vs.2.03 in hearing families (maximum possible is 4).

Summary

This study has identified and reviewed some of the challenges and stresses experienced by hearing parents following the diagnosis of hearing loss in their child. This study confirmed that for this sample of hearing parents it was common to go through stages of grief and coping traditionally described in international research. The data presented the following major issues and concerns of parents:

- A child's identified hearing loss impacted them both emotionally and financially and they did not have access and were concerned about the stigma attached to seeking personal counselling;
- After identification of their child's hearing loss parents did not have access to reliable information regarding how to best care for their child;
- Poor communication was identified as the most challenging and stressful factor which was shared and also named as a lifetime concern by most participants;
- Financial burdens were imposed on families by the necessity of purchasing expensive hearing aids, hiring private teachers for sessions of speech development as well as expensive weekly trips to the educational placements which were located far from the place of living;

Participants identified communication as the most important issue in the process of decision making, and their biggest challenge and concern in the coming years. Decisions about how to communicate with their deaf or hard of hearing child at home imposed a lot of pressure due to a lack, biased, incomplete, and inaccurate information from professionals.

Parental thoughts in the survey on the way they communicated with their children at home brought to light general dissatisfaction with their home communication due to poor knowledge of signs by parents and other family members and children's delay in spoken language and poor vocabulary of spoken Ukrainian.

Survey findings also revealed that families with deaf and hard of hearing members show more positive attitudes to deafness than families consisting of hearing members. Almost 60% of respondents reported being proud of what the families had done and were doing for their deaf or hard of hearing children.

The findings of this study were consistent with recent Ukrainian literature that urged the rethinking of existing approaches to providing support services for families whose children have disabilities or special needs. Participants' experiences and difficulties in finding knowledgeable professionals and community personnel suggest the need to consider the creation of a new type of service for Ukraine which would extend the current child-centered focus to incorporate a family-centered approach. These services would

target not only the child but would serve to make a difference in the life of both the child and the family. The support should be tailored to be responsive to the various domains of the family life.

Suggestions for Future Research

The data of the study was solely based on surveys. Future research should include qualitative and mixed method research methods to better capture meanings behind the data.

A broader and richer picture of family life and family functioning could be developed by adding additional dimensions to the observation of family dynamics. Expansion of the study to other settings such as special kindergartens for children who are deaf or hard of hearing and regular schools with self-contained classes for children with hearing loss would help to address the concern that the setting of this study, residential schools for the deaf, may have had an influence, which contributed directly to the findings.

Future studies could include the examination of differences in perceived impact and satisfaction with family life for families with multiple members who are deaf. Thus, the number of participants could be increased and involve more families with deaf and hard of hearing members as well as families with more than one deaf child.

Further research might explore the relevant factors affecting parental expectations and how these expectations influence their decisions regarding the education and socialization of their deaf and hard of hearing children as well as their hopes for future life of their children.

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