

## Communication skills of residents to families with Down syndrome babies

Assoc. Prof. Derya G. Dogan, M.D.<sup>a</sup>, Yesim Kutluturk M.D.<sup>b</sup>, Meltem Kivilcim M.D.<sup>a</sup> and Sinem K. Canaloglu, MSc.<sup>a</sup>

### ABSTRACT

**Background.** Generally, pediatricians are the first health caregivers to deliver initial diagnosis of Down syndrome (DS) to the families. However, most of the parents are not satisfied with the contents and how they receive information when their child is born with DS. Pediatric residents should target educational interventions to help parents to overcome with these issues and to provide accurate information. The objective is to assess comfort levels and training requirements of pediatric residents to communicate with parents of babies born with Down syndrome.

**Methods.** Diagnostic Situations Inventory (DSI) is a rating scale which included ten questions to assess discomfort level. A survey was sent via mobile, websites and all the social media which were available to all pediatric residents in the country. Socio-demographic factors including information about training requirement were collected as well.

**Results.** From the 326 participants, total mean discomfort level was 30.22 in DSI out of 50 which was the highest score. Discomfort level was significantly increased in female participants ( $p=0.033$ ). Being female ( $p=0.014$ ), having less residency level ( $p=0.028$ ), examining less number of patients with Down syndrome ( $p=0.025$ ) and having higher discomfort levels ( $p=0.001$ ) were found to be related with increased training requirement. From the residents, 84% declared the need for additional training.

**Conclusions.** This study showed that pediatric residents had a high level of discomfort when communicating with parents of newborn with Down Syndrome. Female residents had a discomfort level significantly higher than male residents.

**Key words:** *pediatrics resident, Down syndrome, diagnosis, communication skills, training.*

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### INTRODUCTION

Down syndrome (DS) is the most common genetic condition, 1 out of every 800 live births do get affected by DS,<sup>1</sup> and more than 85% of mothers with affected baby learn their children's diagnosis after the birth.<sup>2</sup> Generally pediatricians are the first health caregivers to deliver DS diagnosis to the families in

countries where genetic counseling is not widespread, and they are in a position to help parents to overcome the first burden when they hear that their baby is diagnosed with DS. It is reported, even after twenty years, families generally remember the first words that the doctors have used during the conversation about the initial diagnosis.<sup>3</sup> Unfortunately, families were not satisfied with the information about having a baby with DS along with the content and how to report it.<sup>4,5</sup>

The diversity among cultures, educational background, and differences in language dialect are extremely important in order to communicate genetic information.<sup>6</sup> During that situation of delivering the news about DS to the families, we do not know how pediatric residents feel, and behave with families.

As far as we know, in order to develop communication abilities only one instrument, the "Diagnostic Situations Inventory (DSI)" has been developed to examine the attitude of residents when delivering diagnosis of a newborn baby with Down syndrome to the family. Diagnostic Situations Inventory was developed by Ferguson et al. from USA and was used for improving pediatrics and obstetrics residents' understanding of issues, comfort levels and patient needs regarding screening for and diagnosing DS.<sup>7</sup>

The ultimate goal of this study was to generate a better perception about delivering news in a sensitive and appropriate manner to the families who have children with newly diagnosed DS among pediatrics residents in eastern countries.

The objective was to assess comfort levels and training requirements of

a. Inonu University  
School of Medicine,  
Department of  
Developmental  
Behavioral Pediatrics,  
Malatya, Turkey  
b. Inonu University  
School of Medicine,  
Department of  
Pediatrics, Malatya,  
Turkey

E-mail address:  
Derya G. Dogan, M.D.:  
deryagumus@yahoo.com

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pediatric residents to communicate with parents of babies with Down syndrome.

## METHODS

This was a cross-sectional, self-administered, mailed survey. The Diagnostic Situations Inventory was designed on surveymonkey.com website and was distributed to pediatric residents with a cover letter by mobile, websites, and social media at two different times on January and February 2015. Also there was a reminder letter that was mailed to residents whose questionnaire had not been received in two weeks after the initial mailing. The cover letter explained the purpose of the study and emphasized that the participation was completely voluntary. The inclusion criterion was being a pediatric resident in Turkey during the survey. Residents who were graduated before the year 2000 and after 2014 were excluded. The sample size was calculated by power analysis that it should be at least 128 participants.

According to information gathered from nine questions asked before starting to apply DSI, demographic information including the age, gender, year of education, marital status and number of the children with DS assessed during residency program were obtained. Additionally, one question was asked to determine if the resident wanted to have training in this field or not.

In order to test the comfort level of pediatric residents in delivering a diagnosis of Down syndrome, the DSI was implemented with the permission of the original author. The inventory updated by Lunney et al. in 2012<sup>8</sup> was used in this research.

Diagnostic Situations Inventory reflects varying degrees of ambiguity in many challenges related to the diagnosis of DS. Five of the items measure discomfort with medically ambiguous questions for which there were no clear medical answers, and the other five items measure discomfort with unambiguous questions for which more factual information could be provided. Since the inventory is prepared both for pediatric and obstetric residents, the tenth question ("A patient who has been told that her screening test indicates she is at a greatly increased risk for having a child with Down syndrome decides against having a definitive diagnostic test") of the inventory which is about prenatal diagnosis was changed to a question ("A parent asks you if her child would be able to do his/her own self-care like other healthy

children") about self care with the permission of the author. Responses were scored using Likert scales with "1" being "Not at All Uncomfortable" and "5" being "Extremely Uncomfortable" for each item. The greatest possible total discomfort score was 50, with a potential range from 10 to 50. The higher scores were considered as more uncomfortable.

The study protocol was approved by the Ethic Committee of Inonu University.

Statistical analysis was performed using SPSS 17.0. Results were expressed as descriptive statistics. Data were analyzed with Pearson's chi-square for uncorrelated data and independent *t*-test for correlated data. As a method of analysis mean and standard deviation value were used. P values of <0.05 were considered significant.

## RESULTS

Mails were sent to 1000 residents and responded by 341 residents. By year 2015, there

TABLE 1: Socio-demographic characteristics of pediatric residents (N: 326)

Variables	Subgroups	n	%
Number of participants	University hospitals	239	73.3
	Training and research hospitals	87	26.7
Training need	Yes	274	84
	No	52	16
Gender	Women	200	61.3
	Men	126	38.7
Age	≤ 23 years	1	0.3
	24-26 years	45	13.8
	27-29 years	154	47.2
	30-32 years	97	29.8
	≥ 33 years	29	8.9
Marital status	Married	182	55.8
	Single	144	44.2
Number of children	0	228	69.9
	1	76	23.3
	≥2	22	6.8
Residency level	1 th year	63	19.3
	2 th year	70	21.5
	3 th year	75	23
	4 th year	87	26.7
	5 th year	31	9.5
Postgraduate time	≤ 6 years	231	70.8
	> 6 years	95	29.2
Number of patients with DS	0-9	63	19.3
	10-19	70	21.5
	20-29	69	21.2
	30-39	28	8.6
	≥40	96	29.4

were a total of 2441 pediatric residents (1368 of them in university hospitals and 1073 of them in training and research hospitals). The response rate was 34.1%. Fifteen participants were removed because of inaccurate or missing data, and 326 responders were included in the study. There were 239 (73.3%) pediatric residents from university, and 87 (26.7%) were from training and research hospitals. Out of the total residents, 61.3% were women, and 19.3% were in their first years. Socio-demographic characteristics of the participants are presented in *Table 1*.

Total mean discomfort level was  $30.22 \pm 7.21$  in DSI out of the highest score of 50. The mean score for ambiguous questions was  $17.77 \pm 3.73$  and non-ambiguous questions  $12.45 \pm 4.19$ .

Average mean score for each item was 2.60. The question about the advice related to increased risk of heart problems got the lowest mean score ( $2.06 \pm .96$ ), and the question about overhearing of a mother of saying a colleague that "Down children never amount to anything" got the highest mean score ( $4.16 \pm 0.99$ ). The mean scores of all items are shown on *Table 2*.

Mean discomfort level ( $p = 0.033$ ) and total ambiguous level ( $p = 0.008$ ) were significantly

higher in female residents than male residents with Pearson chi-square statistical method. Female doctors (176; 53.99%) stated more training than male (98; 30%) doctors ( $p = 0.014$ ).

By independent T-test, being female ( $p = 0.014$ ), having less residency level ( $p = 0.028$ ), examining less number of patients with Down syndrome ( $p = 0.025$ ) and having higher discomfort levels ( $p = 0.001$ ) were found to be related with increased training requirement. The mean residency year was  $2.79 \pm 1.28$  in the group who needed training, and it was  $3.21 \pm 1.17$  in the group of who did not need training ( $p = 0.03$ ). Using the same statistical method the mean number of examined patients with DS was  $29.9 \pm 1.50$  in the group of who need training, and it was  $35 \pm 1.43$  in the group of who don't need training ( $p = 0.03$ ).

Most of participants from university hospitals (84.1%) and training and research hospitals (83.9%) indicated the need of additional training about delivering information to families who have newborns with Down syndrome.

## DISCUSSION

This study demonstrated that pediatric residents from an eastern country are not

TABLE 2: Diagnostic Situation Inventory score items and scores of discomfort

Diagnostic Situation Inventory Questions	Mean pre dis-comfort	SD
1) The parents break down upon hearing the diagnosis (in the physician's office), and say, "why me?"	3.21	0.98
2) The mother asks how much different it will be to raise a child with Down syndrome than her other children.	2.91	0.99
3) The father seems distraught and says that the family just does not have the resources to handle a Down syndrome child.	3.80	0.99
4) After receiving a diagnosis of Down syndrome for their newborn baby, both the mother and father seem extremely depressed and do not say much or ask any questions.	3.69	0.94
5) The mother comes into your office in tears because she overheard a colleague of yours say that "Down syndrome children never amount to anything."	4.16	0.99
Total ambiguous questions (1-5)	17.77	3.73
6) A parent asks you if her child would be able to go to a regular school and learn with the other children.	2.79	1.06
7) Parents ask if there is an increased chance of having a second child with Down syndrome if they conceive again.	2.17	1.06
8) The parents are troubled about the increased chance of heart problems and want advice on what to do.	2.06	0.96
9) The mother refuses to believe that her baby has Down syndrome because she is only 25 years old and "young mothers do not have babies with Down syndrome."	3.01	1.25
10) A parent asks you if her child would be able to do his/her own self-care like other healthy children.	2.43	1.09
Total unambiguous questions (6-10)	12.45	4.19

comfortable when delivering information about newborns with Down syndrome to their families. Female residents, being in their first three years of residency and examining less than 30 patients with DS was associated with higher discomfort and increased training requirement.

DSI was developed in Kentucky University to improve the incompetencies of obstetrics-gynecology and pediatric residents when counseling the parents of babies with DS. The residents' knowledge and comfort levels were assessed by using pre and post-test with an education CD-ROM.<sup>7</sup> After 6 years, DSI has been modified by Lunney et al. and has been accepted as a research with web-based tutorial. In that study, Lunney has found the mean discomfort levels of residents 23.05 with the highest discomfort level 35.<sup>8</sup> The mean discomfort level of Turkish residents was 30.22 with the highest score 50. Probably the greater dissatisfaction among Turkish residents is the result of not getting any structured clinical training regarding delivering bad news to the families.

In the study of Lunney 97% of residents have declared that training is necessary, on the contrary 84% of Turkish residents have wanted training. Because of knowledge and discomfort levels of residents were assessed with pre-tests and post-tests within an educational programme in Lunney's study, residents might have been more willing to get training.<sup>8</sup>

In this study, female residents had higher discomfort levels than males, and they were found to be more willing to get training. The gender difference is not mentioned in the research of Lunney's.<sup>8</sup> Studies have shown that female physicians have different communication skills than males. Having better patient management of female doctors due to good communication are known.<sup>9</sup> In a meta-analytic review, Roter et al. found that female doctors engage in more positive talk (such as encouragement), ask more psychosocial questions, discuss more about emotions and demonstrate more partnership building behaviours.<sup>10</sup>

By providing appropriate communication and assisting others with health and community care services, pediatricians may increase strong attachment with the patients and his/her family. Families seek up-to-date, accurate, balanced information.<sup>5,11,12</sup> If families get knowledge from reliable healthcare givers, they can feel more optimistic about having a baby with DS. Optimistic feelings encourage healthy parent

child relationship and optimal emotions, growth and development.<sup>13</sup>

The post-tests in Lunney and Ferguson researches' have shown that the comfort levels of residents have increased with the educations by CD-ROM or web-based tutorial<sup>7</sup>. Our survey differed from the original in that we could not test the knowledge level of residents about DS due to a technical impossibility. For example, all of our surveys and their results are subject to self-reporting and responder bias. Furthermore, physicians who have a specific interest in DS may be more likely to respond better than those with less interest. Response rate was 34.0%. This may be sufficient number of participant for the web-based research across the country.

This study represents a first step in understanding Turkish pediatricians' attitude and willingness to have an education in delivering diagnosis to the families with DS. Communication is a learned skill and not a personality trait.<sup>14-16</sup> In order to provide a good life and adaption to the diagnosis for families, first and foremost pediatricians have to be knowledgeable about DS and interventions.<sup>5</sup> There is a substantial need of receiving a formal training to improve pediatricians' comfort levels in delivering diagnosis of DS. Pediatric residency programs must incorporate delivering bad news to the families with DS into pediatric training beyond knowledge provision to achieve trainees' competence and skill development.<sup>5</sup>

Further research examining which educational interventions are most influential in changing physician attitude in delivering bad news may help prompt more widespread adoption in medical education. Web-based tutorials,<sup>8</sup> simulation-based<sup>17</sup> and competency-based communication skills<sup>18</sup> workshop/curriculum were reported to be helpful and have been studied to be effective models among pediatric residents.

Having higher comfort levels when communicating will be useful for not only DS but also the other diagnosis like spina bifida, autism and fragile X syndrome.<sup>8</sup>

## CONCLUSION

This study showed that pediatric residents had a high level of discomfort when communicating with parentes of newborn with Down Syndrome. Female residentes had a discomfort level significantly higher than male residentes.

There is a necessity of receiving a formal

training to improve Turkish pediatricians' comfort levels in delivering diagnosis of DS in medical schools and applying it to continuing medical education. ■

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