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BREAKING BAD NEWS – INFORMING PARENTS ON SUSPICION OF PRENATALLY DETECTED DOWN SYNDROME IN OBSTETRIC INSTITUTIONS: HUNGARIAN EXPERIENCE

MATE ORSOLYA[1], HENRIETTE TIGYI[2], ZSUZSA KIVES[3], SANDOR JANOS[4]

For health care professionals, breaking bad news postnatally to parents in case of suspected Down syndrome is a difficult task to perform. The aim of the study was to investigate the Hungarian practice as well as deficiencies from the perspective of the physicians providing first information in order to improve the current system. For better interpretability of the results, we compared the practice of providing first information in Hungary (74% national coverage) with 23 obstetric institutions in Germany. In Germany, communication training has already been incorporated into the curriculum of medical and health care higher education. It was found that 95% of the Hungarian and German institutions have no protocol for providing information. In Germany, the professionals get significantly more communication training (p=0.06) and more contact with civil organizations (p<0.01). In Hungary information stressing the negative aspects of the situation is more often given (p=0.024), while less consolation (p=0.017) and printed brochures are provided for parents (p<0.01). Hungarian physicians feel more often (p=0.022) they are not capable of helping the parents. The Hungarian practice of providing information needs improvement. The possible tools for improvement are the introduction of communication training in undergraduate and postgraduate education of health professionals as well as working on and elaborating policies concerning the breaking of bad news.

Descriptors: DOWN SYNDROME; PARENTS; COMMUNICATION; TRUTH DISCLOSURE; HUNGARY

INTRODUCTION

Physicians, especially obstetricians and pediatricians, are frequently placed in the unenviable position of informing parents that they have delivered a child with a disability, most commonly Down syndrome (DS). Despite the current practice of screening, more than 1 *per* 733 (1) livebirths are diagnosed with DS each year and 49% of children with DS are live born in Hungary (2), and this is still the most common chromosome condition amongst rare diseases, and a good example to investigate the difficulties to break bad news to parents after delivery.

Bruckman et al. (3) provide a useful definition of bad news: "… situations where there is a feeling of no hope, a threat to a person's mental or physical well-being, a risk of upsetting an established lifestyle, or where a message is given which conveys to an individual fewer choices in his or her life".

Several authors have reported that the concerned parents would have wanted to be informed earlier, as soon as their physician suspected the diagnosis of DS, even before the results of chromosome testing were known (4-6). The quantity and quality of the received information is determined for both the parents and the child, as this is an extremely sensitive period in their lives. It can affect the early bonding between the parents and the child (7-9), and can result in distrust towards the physician (8). If the early bonding between the parents and the child is harmed, it could even endanger the possibility for the disabled child growing up in the family.

Since the 1970s, several papers have been published focusing on the postnatal communication of DS and parental dissatisfaction with the disclosure (4, 9-25), identifying the significant factors influencing parental satisfaction, but only two studies examined the communicative situation from the viewpoint of the physician delivering the bad news (26, 27).

Ramirez (28) proved the disclosure of bad news to cause emotional stress for the physician and to raise the risk of burn out.

The studies by Cunningham (14), Horwitz (24) and Ferguson (15) indicated a decrease of parental

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[1] Department of Nursing, Faculty of Health Sciences, University of Pécs, Pécs, Hungary
[2] Department of Health Promotion, Institute of Public Health, Recreation and Health Promotion, Faculty of Health Sciences, University of Pécs, Pécs, Hungary
[3] Department of Public Health and Epidemiology, Institute of Public Health, Recreation and Health Promotion, Faculty of Health Sciences, University of Pécs, Pécs, Hungary
[4] Department of Biostatistics and Epidemiology, Institute of Preventive Medicine, Faculty of Public Health, University of Debrecen, Debrecen, Hungary

Correspondence to:
Orsolya Máté, MD, PhD, University of Pécs, Faculty of Health Sciences, Department of Nursing, 04 Vörösmarty u. Pécs, Hungary, e-mail: orsolya.mate@etk.pte.hu

dissatisfaction with the unexpected diagnosis of DS when a protocol and appropriate communication training for physicians delivering the suspected diagnosis of DS where applied.

While in the curriculum of several medical schools, e.g., Vienna (29) Heidelberg (30) and London (31), the course of medical communication (e.g., crisis communication, breaking bad news, informed consent) represents an important part of medical studies, it is still not obligatory included in medical education in Hungary (32).

These educational differences between Hungary and Germany have motivated our study as well as the fact that the Hungarian medical education historically was based on the German example and this historical influence still determines the Hungarian health care system.

The aim of the study was to investigate the Hungarian practice of breaking bad news to the parents of a newborn with DS, and for better interpretability to compare the results of the Hungarian survey with the results of the practice of 23 German institutions. It was not the aim to study the German practice entirely and to make exhaustive comparison.

METHODS

The practice of Hungarian obstetric institutions was assessed in 2008 through a nationwide survey. In 2009 the examination was extended to German institutions. The Hungarian institutions were identified through database of the Hungarian Congenital Anomaly Registry of the National Centre of Healthcare Audit and Inspection and the questionnaires were filled in by heads of 79 departments for obstetrics or neonatology with the help of the interviewer of the aforementioned organization. In Germany, the double translated questionnaires were sent electronically to heads of 200 departments for obstetrics or neonatology. In both countries, the questionnaire was completed by only one person *per* institution, who in 98% of the cases happened to be the head of the given institution. Completion of the questionnaire was voluntary, but not anonymous.

The nationwide coverage was 74% taking into consideration the number of yearly deliveries in Hungary, while in Germany the questionnaire was filled in and sent back by 30 departments for obstetrics or neonatology. In this case, the nationwide coverage was 4%.

Institutions with the number of live births in the year preceding the survey exceeding 100 were included in the study. According to these criteria, 4 institutions in Hungary and 6 in Germany were excluded from the study.

The survey instrument

As none of the existing surveys has dealt with the information we were seeking, a questionnaire was created in co-operation with the Hungarian Down Foundation, as well as the colleagues from the Hungarian Congenital Anomaly Registry of the National Centre of Healthcare Audit and Inspection and the Task Force of the Faculty of Health Sciences, University of Pécs. Primarily those factors were identified which had a determinate role in parental dissatisfaction with disclosure of postnatal information of the suspected diagnosis of DS, according the international literature in English in the last 30 years.

In total, we identified 22 studies, collectively sampling more than 6000 parents who had received a postnatal diagnosis of DS for their children. The studies, which were from a variety of countries, were performed between 1964 and 2005, and sampled primarily mothers.

The factors were evaluated which are considered by at least 80% of the studies as main reasons for parental dissatisfaction with disclosure of the suspicion of DS.

These most important factors were: complete and accurate information, timing of disclosure, quality of disclosure (kindness, sensitivity, professionalism, disclosure of negative/positive aspects), time for questions, informing the parents together, contact information to local support groups, and quality of written materials).

The survey gathered answers to close-ended questions on 5 topics:

Topic 1: The current practice of giving information

Presence of an information protocol in the hospital, disclosure of negative aspects, forms of parental supporting, handing over written information.

Topic 2: Factors influencing the practice of giving information

Who are those of medical staff who have acquired graduate/postgraduate education/training regarding medical aspects and communication of DS, relationship to local support groups?

Topic 3: Evaluation of the current practice of giving information

How do the responding physicians assess their own competence concerning delivering bad news, of the hospital and of collaboration with support groups?

Topic 4: Parental needs

Parental needs at the first time of disclosure concerning its form, the information given and the person informing on the diagnosis.

Topic 5: Recommendations for improving the practice of disclosure

The ideal conditions for informing the parents, according to the responding physicians.

Statistical analysis

For statistical analysis, SPSS 16 for Windows and Fisher exact test for analysis of correlations were used. Results were considered to be significant at $p \leq 0.05$.

RESULTS

The Hungarian survey provided a representative overview of the national practices because 79 obstetric institutions with 70.226 deliveries participated in the study. The nationwide coverage was 74% considering the number of yearly deliveries (N=95.137) in Hungary. The response rate in the German survey was low. Altogether, 23 obstetric institutions with 27.786 deliveries *per* year took part, representing an overall 4% national coverage.

The overwhelming majority of the Hungarian physicians agreed that the well-prepared provision of disclosure (92.7%), where an adequate amount and well-designed information is given (98.4%), is the key factor from which the parents can benefit most. The German observations were similar (100% and 85.7%, respectively).

Hungarian physicians thought the conditions of providing information are optimal if the obstetrician and the pediatrician together provided the information in a separate room, a few days after the birth and if the parents are given an opportunity to ask questions and discuss their problems with the physicians. This pattern has been observed in the reference German physicians' view as well. The only slight and statistically nonsignificant difference was that the German physicians seemed to prefer the presence of the newborn more than the Hungarians (Figure 1). Besides the physicians, health visitors, special education teachers, psychologists and patient organizations are able to provide support to parents according to the Hungarian responders (Table 1). Compared to the German study, the role of social workers was considered less important among the Hungarian responders (p=0.011). The majority (75 out of 79) of the Hungarian institutions had no protocol for breaking bad news. In practice, when they first provide the information, their communication is focused mainly on the positive aspects of the situation (e.g., DS children are friendly, early intervention programmes have to start as early as possible). In addition, the increased amount of child care benefit is also mentioned. The parents also were informed by the physician about the potential mental disability and associated congenital anomalies. The messages on the opportunity of leaving the newborn in the hospital and the shortened life span are usually avoided (Table 2). Psychological support is ensured in 67% of the institutions. In less than one third of the institutions (22 out of 79), printed material with a brief summary on DS was given to the parents. Address list of the available specialized health care providers was included in only 32% of these materials. It was mainly the pediatrician who made the printed information available to the parents (Table 3).

Similarly to the Hungarian observations, only a minority (8.7%) of the participating German institutions reported that they had an information protocol. Mental disability (p=0.024), associated congenital anomalies (p=0.006) and the increased child care benefit (p<0.001) are less frequently mentioned in Germany than in Hungary. In German institutions, the parents were administered printed information materials more frequently (85.0%; p<0.001), mainly from pediatricians (82.4%). The involvement of obstetricians (64.7%) was more frequent in Germany (p=0.003) than in Hungary. In spite of the Hungarian situation, almost all of the German printed materials (94.1%) included an address list of patient organizations (p<0.001).

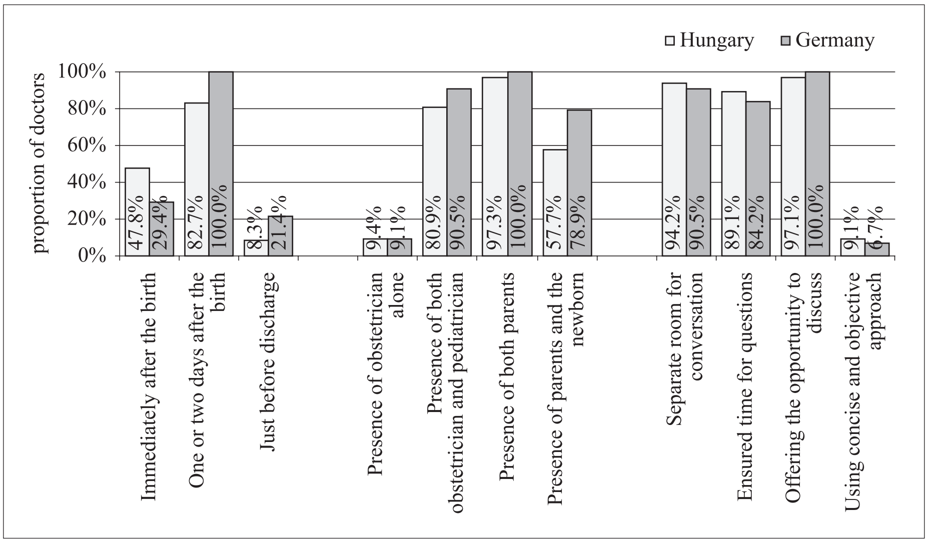

Figure 1. *Circumstances of informing parents of their newborn's Down syndrome diagnosis according to the proportion of Hungarian and German physicians considering those necessary*

Table 1. *Professions needed to support parents of Down syndrome newborns according to the physicians' opinion**

Potential source of support	Hungary (needed/not needed; N/N)	Germany (needed/not needed; N/N)	p[#] (Fisher exact test)
Medical physician	97.2% (70/2)	100.0% (22/0)	1.000
Health visitor	96.9% (63/2)	82.4% (14/3)	0.058
Child development specialist	94.0% (63/4)	94.1% (16/1)	1.000
Psychologist	92.9% (52/4)	86.7% (13/2)	0.600
Patient organization	92.7% (51/4)	88.9% (16/2)	0.632
Priest	68.6% (24/11)	92.9% (13/1)	0.139
Social worker	61.5% (24/15)	100.0% (13/0)	0.011
Lawyer	57.1% (24/18)	25.0% (3/9)	0.102

* Nonresponders were not included in statistical testing

Working connection with patient organizations is in operation in 20.5% of the Hungarian institutions, aiming at improvement of the parents' psychological distress, preparing the parents for special tasks of child care at home and influencing the family not to leave the newborn in the hospital. The German institutions maintain more (69.6%) work-related connections with self-help groups (p<0.001), however, their aims seemed to be very similar to those of the Hungarian institutions.

In Hungary, less than one-third of the professionals who were potentially involved in providing information concerning postnatal suspicion of DS had any kind of training. The best trained of them are health visitors, psychologists and pediatricians. In the German sample, there were significantly higher proportions of experts belonging to several different professional groups (for obstetricians p=0.006, for pediatricians p=0.015, for psychologists p=0.021, for social workers p=0.034, and for priests p<0.001) who had special communication training (Figure 2).

34.2% of the Hungarian physicians felt that they were not capable of providing enough help to parents to DS children; on the other hand, 82.5% of them thought that he or she did complete the task of providing first information properly. The German physicians' view is more coherent: they seemed to be similarly satisfied (p=0.290) with their performance in providing first information (95.2%), with only 9.1% of them considering that they were not in the position to provide enough help (p=0.022).

According to 73.9% of the Hungarian physicians, one element of developing disclosure practice should be elaboration of the information protocol. German responders stressed the importance of information protocol significantly less frequently (50.0%; p=0.075). Hungarian physicians highlighted the introduction of communication training as the most important element for improving the current

Table 2. *Physicians' opinions as to whether it is important to mention certain statements when first explaining the diagnosis or suspicion of Down syndrome*

Statement	Hungary (needed/not needed; N/N)	Germany (needed/not needed; N/N)	$p^{\#}$ (Fisher exact test)
The child will be mentally disabled	76.7% (56/17)	52.2% (12/11)	0.024
The child will be physically disabled	65.7% (46/24)	72.7% (16/6)	0.540
The child will develop heart and other congenital disorders	76.5% (52/16)	45.5% (10/12)	0.006
The child will have a short life span	12.9% (9/61)	4.3% (1/22)	0.442
Child care benefit increased	84.3% (59/11)	35% (7/13)	<0.001
Problems disappear leaving the baby in hospital	10% (7/63)	4.3% (1/22)	0.674
The child can be admitted to a children's home	47.1% (33/37)	36.4% (8/14)	0.375
The child can be taken to an early development center	91.5% (65/6)	100% (21/0)	0.330
With early development the child' abilities can be improved	95.8% (69/3)	100% (20/0)	1.000
Early intervention programmes must start as soon as possible	94.5% (69/4)	90.9% (20/2)	0.620
At special centers all abnormalities can be detected	79.4% (54/14)	70% (14/6)	0.378
There are parents' groups providing services	94.3% (66/4)	100% (20/0)	0.572
They can usually be breastfed and they behave just like other babies	87.8% (65/9)	95.2% (20/1)	0.178
Many children with Down syndrome learn to read and write	87% (60/9)	85% (17/3)	1.000
Many Down children can take part in artistic activities	90.3% (65/7)	100% (21/0)	0.344
They are very friendly and nice	95.9% (70/3)	100% (21/0)	1.000
They can work and live a supported independent life	90.4% (66/7)	95% (19/1)	1.000

* Nonresponders were not included in statistical testing

Table 3. *Participation of professions in handing over printed information brochures in the institutions that provide printed material*

Profession	Hungary (participating/not participating; N/N)	Germany (participating /not participating; N/N)	$p^{\#}$ (Fisher exact test)
Obstetrician	18.2% (4/18)	64.7% (11/6)	0.003
Pediatrician	68.2% (15/7)	82.4% (14/3)	0.464
Psychologist	13.6% (3/19)	11.8% (2/15)	1.000
Health visitor	22.7% (5/17)	5.9% (1/16)	0.205
Social worker	13.6% (3/19)	11.8% (2/15)	1.000
Priest	4.5% (1/21)	5.9% (1/16)	1.000

practice of providing first information (85%) and even German physicians agreed that more communication training would be useful (100%).

DISCUSSION

This survey was the first to examine the practice of delivering postnatal bad news to parents in Hungary. In the international literature, only a few similar studies could be found examining the topic of breaking bad news from the perspective of the physician (25, 26).

The aim was to explore the Hungarian practice with regard to giving information as well as to compare it with the presumably higher standard of the practice of some German institutions, on the basis of data found in the literature. We also aimed at exploring deficiencies in the Hungarian practice and finding the possibilities of improvement. We did not aim to explore the complete German picture as the primary aim of the study was enhancement of the interpretation of results.

Literature tells us (4-7, 14, 34) that those parents who received information about the positive aspects of the situation from the doctor while providing the first information, look back to the birth of their DS child as a positive experience. Compared to this and the German practice, in Hungary bad news are also broken during the provision of first information, thus Hungarian physicians do not follow the recommendation of the relevant literature (34). Medical professionals are the first to make the parents face the situation; it is also them who provide the majority of psychological support, but less frequent than in Germany, where a wider range of professionals are involved in the procedure, presumably due to the wider spectrum of communication training and German traditions. (In Hungary, even 20 years after the change of the regime, it is not usual that priests are present in hospitals.)

Skotko (5, 34) and Cunningham (14) have also noted that it is very important to provide parents with an adequate amount and quality printed material in this difficult situation. However, in Hungary only every third parent receives printed materials and only one-third of those materials contain an address list; thus only every tenth parent can get hold of useful printed information. Civil organizations were mostly formed after the change of the regime, thus they do not have such a long history as their German counterparts. They are also severely underfinanced, which makes co-operation with the hospitals more difficult. Germany seems to be better prepared in this respect; the co-operation with civil organizations is frequent and accessibility is more developed.

During the provision of information, doctors in both countries seemed to be satisfied with their performance in the given circumstances. However, Ewans (33) has shown that physicians cannot always judge their own practice with regard to giving information with necessary objectivity. In Hungary, few physicians and less even health professionals receive communication training that can provide help in this particular situation. Presumably that is why 30% of the Hungarian physicians feel that they are not capable of providing adequate help to DS parents.

The opinion of physicians filling in the questionnaires in both countries seems to be matching with regard to the need for improvement of giving information and considering parental needs. However, due to the lower number of communication trainings, the techniques recommended by the relevant literature cannot be built in the general practice of Hungarian physicians. We have known since Cunningham (14) and Hedov (18) how positive the effect of information protocol can be on parental satisfaction and our study also revealed that Hungarian physicians would welcome the help of the protocol during the provision of information. They also thought it would improve the standard of giving information.

Working out a protocol is considered to be more important by Hungarian physicians than by German physicians, presumably because they could rely on it during consultation as they have less communication training.

Due to the German indicative results, the application of the outcomes is only restricted, primarily they are at the level of hints, and conclusions can only be made with caution.

CONCLUSION

Although comparison of the practice of communicating bad news has revealed differences only in a few areas, the need for more communication trainings has appeared as a need for Hungarian physicians in order to improve the standard of providing information as well as for facilitating the work of the health care professionals who provide such information. The aforementioned communication trainings should be necessary, primarily for the health professionals involved, also at the BSc and postgraduate level.

A protocol could be an effective tool in the practice of braking bad news. The representatives of the respective civil organizations as well as communication experts should be able to provide significant professional support in developing the protocol.

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Autori izjavljuju da nisu bili u sukobu interesa.

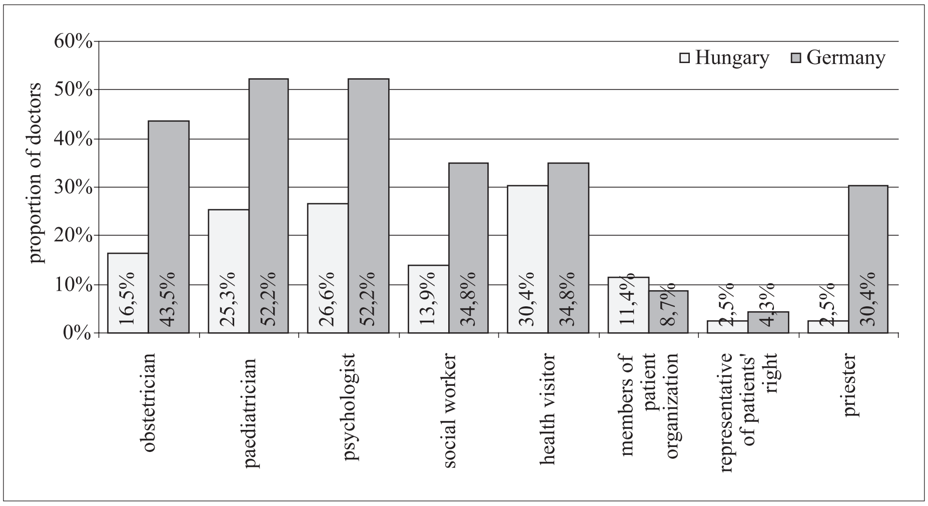

Figure 2. *Proportion of those Hungarian and German physicians who consider that the training of particular professionals is adequate for being able to communicate with parents of Down syndrome newborn*

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Sažetak

PRIOPĆAVANJE LOŠIH VIJESTI – KAKO IZVIJESTITI RODITELJE O SUMNJI NA DOWNOV SINDROM U OPSTETRICIJSKIM USTANOVAMA: MAĐARSKA ISKUSTVA

M. Orsolya, H. Tigy, Z. Kives, S. Janos

Za zdravstveno osoblje je priopćavanje loših vijesti roditeljima nakon rođenja djeteta vrlo težak zadatak. Cilj ove studije bio je istražiti praksu u Mađarskoj, kao i nedostatke sa stajališta liječnika koji daju tu prvu informaciju, te kako poboljšati sadašnji sustav. Praksu priopćavanja loših prvih vijesti u Mađarskoj (pokriveno 74% stanovništva) usporedili smo s 23 opstetricijske ustanove u Njemačkoj radi boljeg tumačenja rezultata zabilježenih u Mađarskoj. U Njemačkoj je usavršavanje komunikacijskih vještina već uvedeno u nastavni program više medicinske i zdravstvene izobrazbe. Studija je pokazala da 95% mađarskih i njemačkih ustanova nema nikakav plan postupanja za pružanje takvih informacija. U Njemačkoj stručnjaci imaju priliku steći značajno više znanja o komunikacijskim vještinama (p=0,06) i kontakata s civilnim organizacijama (p<0,01), dok se u Mađarskoj češće daju informacije koje naglašavaju negativnu stranu određene situacije (p=0,024), uz manje utjehe (p=0,017) i tiskanih materijala za roditelje (p<0,01). Mađarski liječnici češće imaju osjećaj da nisu u mogućnosti pomoći roditeljima (p=0,022). Mađarsku praksu davanja informacija treba poboljšati. To se može učiniti uvođenjem izobrazbe u komunikacijskim vještinama u dodiplomsku i poslijediplomsku nastavu za zdravstveno osoblje, kao i razradom politike priopćavanja loših vijesti.

Deskriptori: DOWNOV SINDROM; RODITELJI; KOMUNIKACIJA; PRIOPĆAVANJE ISTINE; MAĐARSKA

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