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**Circumstances of the disclosure of Down syndrome
postnatally and the support of parents in German and
Hungarian obstetric institutions**

DOCTORAL (PHD.)

THESIS

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1. Introduction

A significant number of congenital disorders are caused by chromosome malformation. According to the WHO data 800 000 new-borns come to life with a kind of chromosome disorder from the 120 million childbirth worldwide.

Down syndrome (DS) is the most common chromosome condition amongst rare diseases; it is diagnosed in the case of every 700th new-born. Non-invasive interventions out of prenatal diagnostic protocols are not able to filter out the concerned embryos with 100%. Prevalence of DS new-borns shows a gradually increasing tendency, and the majority of live born DS children are expected to reach adulthood. Considering that the average mental level of DS does not exceed the intelligent quotient of 40-50, generally they are unable for individual life, providing information of postnatally detected suspicion of DS results a crisis in parents, and it decisively influences the operation of the family. Because of the extended longevity, the role of the family, the relation between suppliers and families are changed, the maintenance of the mental integrity of the family is appraised. Circumstances of the disclosure become determining from the aspect of the structure of the family.

For physicians, providing information in case of genetic disorders to parents in case of suspected Down syndrome is a difficult task to perform. Seeing that the increase of the effectiveness of medical interventions results a higher number of children living with some kind of disorders and handicaps, presumably health care professionals have to provide bad news to parents. Bad news can be transmitted in different ways, and the quality of disclosure can affect the whole life of the child. Inadequate information giving causes crisis to the recipient and it can result serious stressed situation for the physician. Communication qualifications of the professional would help parents and this knowledge could be an aid for the physician.

Under disclosure of DS we mean the disclosure of the suspicion of DS in this study in all cases, since the diagnosis of the syndrome can be diagnosed in possession of the results of a chromosome examination, and it is the competence of a human

geneticist. Literature shows us that concerned parents would have wanted to be informed earlier also about the suspicion of DS, accordingly, communication training for health care professionals have to be developed.

2. Objectives

- completion of a survey on Hungarian obstetric institutions which is capable to show disclosure relations in case of a DS child birth.
- definition of factors that cause difficulties, and hampers parents partake in higher-level supply and a support.
- comparison of Hungarian data with the results of the German survey for better interpretability.
- outline of intervention potentials.

3. Hypotheses

The standard assumption of this research is that physicians think that Hungarian information giving is adequate for parental needs.

- 1. Providing information on the suspicion on postnatally detected DS – based on the opinion of physicians partaken in the provision –fits to the principals recommended in international literature, and it does not need to be improved.*
- 2. We assume that differences between German and Hungarian practice of disclosure can be identified, which proceed from the disparate structure of service.*
- 3. Based on the literature we suppose, that however Hungarian physician shad satisfactory theoretical training about medical aspects of DS, they did not have communication courses in gradual or postgradual level, which would help their communication with parents in these cases.*
- 4. We suppose that the majority of institutions have no information protocols, and physicians are not satisfied with their effectiveness throughout the*

information giving process, accordingly, they have a claim for further communication causes and an elaborate protocol.

- 5. As a result of the missing gradual communication courses, literatural recommendations on the optimal information process could not been adapted into the practice of information giving.*
- 6. This lack of institutional preparedness results that parents receive less psychological support, and less representatives of other civil organisation are able to work with the family immediately after the deliverance of the newborn.*
- 7. We assume that members of the professional supporter groups (psychologists, health visitors, social workers, priests, jurists, representatives of civil organisations) receive less communication trainings regarding the disclosure of DS. However, responders thought that they should play an active role in working out and practical implementation of the protocol.*
- 8. We suppose that collaboration of Hungarian institutions with civil organisations is satisfactory, they are active participants in the supplying process of parents after the childbirth, and parents have sufficient information about the availability of these organisations.*

4. Research methods

Hungarian institutions were identified through the database of the Hungarian Congenital Anomaly Registry and the questionnaires were filled in by 79 obstetrics and neonatology institutions. The nationwide coverage was 74% taking into consideration the number of yearly deliveries in Hungary, while in Germany this nationwide coverage was only 4%. Institutions with the number of live births did not exceed 100 were excluded from the study. According to these criteria, 4 institutions in Hungary and 6 in Germany were ineligible.

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 and the Task Force of the Faculty of Health Sciences, University of Pécs.

After the comparison of the results of literature analysis the questionnaire focuses on the 5 following topics:

1. Current practice of the information giving process
2. Factors influencing the practice of giving information
3. Evaluation of the practice of giving information
4. Determination of parental needs
5. Recommendations for improving the practice of disclosure

Besides these topics the questionnaire examined the role of different professionals. The aim was to introduce the role of the below mentioned professionals in the course of the disclosure from the perspective of physicians answering the questions: physicians (obstetrician, gynaecologist, and paediatrician), psychologist, health visitor, social worker, priest, jurist, representatives of civil organisations.

In Hungary the questionnaire was completed by only one person per institution with the assistance of a representative of the Hungarian Congenital Anomaly Registry. Completion of the questionnaire was voluntary, but not anonymous. In Germany, the

double translated questionnaires were sent electronically to heads of 200 departments for obstetrics or neonatology based on the list of the German paediatric association (Deutsche Gesellschaft für Jugend und Kindermedizin, 2008). In Germany the completion of the questionnaire was voluntary and anonymous.

Statistical analysis

For statistical analysis, SPSS 13.0 for Windows and Fisher exact test for the analysis of correlations were used. Results were considered to be significant at $p < 0.05$ (95%).

5. Results

The current practice of information giving process in German and Hungarian obstetric institutions

Neither the majority of Hungarian (94,9%) nor German institutions (91,3%) have protocols for information giving regarding congenital and postnatal disclosure. In spite that in both countries attendants have similar thoughts on the medical and social aspects of DS, opinions about the first informing show significant differences. Significantly more Hungarian physicians ($p < 0.001$) would inform parents about increased family allowance in case of DS children raised in the family, than German colleagues. Mental disability ($p = 0.024$), associated congenital anomalies ($p = 0.006$) would be mentioned less frequently in Germany than in Hungary. In Hungary, psychological support is ensured in 67% of the institutions for parents with DS child. In the German sample, the majority of parents in similar situation are supported psychologically by professional in obstetric institutions. In Hungary, this support is primarily made by the paediatrician and the obstetrician, contrarily in Germany paediatricians ($p \leq 0.001$) have more significant role in this task than obstetricians ($p = 0.017$).

In German institutions, parents were administered printed materials more frequently ($p < 0.001$). Almost all of the German printed materials (94%) included an address list of organizations ($p < 0.001$). In Hungary, address list of the available specialized health care providers was included in only 31% of these materials ($p \leq 0.01$). Responders of both countries found materials structurally eligible ($p = 0.619$) and comprehensible ($p = 0.363$).

Factors influencing the practice of giving information

The training

In the German sample, there were significantly higher proportions of experts belonging to several different professional groups (for obstetricians $p=0.006$, for paediatricians $p=0.015$, for psychologists $p=0.021$, for social workers $p=0.034$, and for priests $p<0.001$) who had special communication training.

Contact with civil organisations

German institutions had connection with civil organisations working with DS children significantly often ($p<0.001$) though current relation with groups of those with special needs are not diverge significantly ($p=1.000$). There is a significant difference between the opinion of Hungarian and German physicians about the factors strengthening the efficient disclosure of the suspected diagnosis from the side of the parents. Bad physical condition of mothers after delivering a baby ($p<0,001$), bad mental status of parents ($p<0,001$), low health culture of parents ($p=0,013$), low mental abilities of parents ($p=0,003$) are more dynamic inhibitory factors according to German responders.

Evaluation of the practice of giving information

German physicians seemed to be similarly satisfied ($p=0.290$) with their performance in providing information (95.2%), than Hungarian physicians (82,9%). Only 9.1% of these professionals considered that they were not in the position to provide enough help. Significantly more Hungarian physicians felt that they were not capable of providing enough help to parents with DS children ($p=0.022$). Both Hungarian and German physicians thought that relation with civil organisations can support their work ($p=1.000$), and it has a positive effect on parents.

Parental needs

Physicians of both countries agreed that the well-prepared provision of disclosure ($p=0,570$) and well-designed information ($p=0,083$) is the key factor from which the parents can benefit most. Providing information is considered to be the task of paediatricians ($p=0.231$), less regarded to obstetricians ($p=0,202$) and psychologists ($p=0,170$). Besides the physicians, special education teachers ($p=1.000$),

psychologists ($p=0.600$), social supporters ($p=0.429$), priests ($p=0.139$), jurists ($p=0.102$) and health visitors ($p=0.058$) are also able to provide support to parents according to both German and Hungarian responders.

Recommendations for improving the practice of disclosure

One element of the development of informing practice would be the elaboration of a protocol according to both countries ($p=0.075$), however communication trainings were thought to be the most important, as well German physicians thought that further communication trainings are needed ($p=0.064$). Both countries found the presence of the parents ($p=1.000$) and the new-born ($p=0.171$) important at the time of providing information by the obstetrician and the paediatrician ($p=0.506$). German as well as Hungarian physicians thought the conditions of providing information are optimal if the obstetrician and the paediatrician together provided the information in a separate room ($p=0.621$), a few days after the birth ($p=0.101$) and if the parents are given an opportunity to ask questions ($p=0.699$) and discuss their problems ($p=1.000$) with the physicians. Physicians of Germany and Hungary agrees that informing should happen rather before leaving the hospital ($p=0.331$) but not immediately after the deliverance of the baby ($p=0.189$), and breaking the news should not be the individual task of the obstetrician ($p=1.000$). Neither of the countries thought objective short informing optimal ($p=1.000$).

6. Conclusion

The most important conclusion of this research is that informing parents postnatally about suspected Down syndrome needs improvement in Hungary. Early information giving and parental support is not eligible in most of the Hungarian obstetric institutions. Hungarian and German institutions have no protocol for providing information in case of suspected Down syndrome. Concerning the content of the information, 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.

German sample shows that there are significantly more professional groups which are supported in behalf of communication development. Hungarian physicians do not have opportunity to participate on communication trainings in undergraduate and postgraduate level. In this case their communication skills are not improved to be orientated to international standards. Therefore, providing information is more individual, it depends more on the attitude of the physician; which does not serve parental needs. Presumably a protocol for information providing is considered to be more important for Hungarian professionals.

The majority of Hungarian physicians (75%) seemed to be satisfied with their performance in providing information. At the same time every third responder felt that they are not capable of providing adequate help to DS parents on institutional level. German colleagues are significantly more satisfied.

Physicians in each country see that parental interest in the course of disclosure is also determined by different professional groups. The involved professional groups and their role differ in countries. Results show that although physicians in Hungary demands support of civil organisations, only every fifth institution have current working connection with other organisations. Presumably, Hungarian physicians do not feel themselves concerned in this case, and on the other hand, civil organisations are underdeveloped to cover all demands. As we supposed earlier, these differences may origin from the diverse provisioning structure of the countries. Differences of

the preparedness of the institutions also have important roles in this topic. More equal participation of professional teams may significantly improve the comfort of participants, and should fulfil the required psychological support for parents during and after the information providing process.

In summary it can be said that similarity of professional knowledge and conception of needs are dominant, although there are differences in preparedness (eg. communicational qualifications, involving professional groups into the work).

A communication course with respect to the practical aspects of the information status was elaborated for the development of the quality of the current situation. This course is based on international examples, and it aimed the participants to be endowed with adequate competences for optimal information giving. The lesson plan of the course is introduced below:

Lesson plan for the communication course on postnatal disclosure of DS

Education	Record		Important aspects	Time
1. seminar leader	2. seminar leader	Introductory section:	Only a short introduction	5 minutes
		Discussion of the definition of bad news	The prior element of the course is the role-play	
		significance of proper disclosure of bad news		
		Discussion of the course process:		
		1. role-play in small groups		
		2. discussion of recorded videos		
		3. evaluation		
1. seminar leader 2. seminar leader	1. seminar leader	Preparation of the role-play	Selection of the situation-with consideration of time factors-is the task of the seminar leader	10 minutes
		1. Working out concrete situations		
		2. Exposition of these situations		
		3. Selection of a situation by the participants		
		4. Creation of groups: 1-1 seminar leader as supervisor		
1./2. seminar leader		Acting out the role-play in 2 groups	Need to pay attention to time, it is necessary to break the role-plays after 5 minutes	15 minutes
		1. selection of performers from the group (writing up the names, at the end signing the declaration of consent) acting out and recording the same situation in both groups with the help of 1-1 camera man		
1. seminar leader	2. seminar leader	Discussion of the role-plays with the participation of the whole (each seminar leader introduces his/her own video)	It is necessary to break the debate if remarks do not concern the role-plays	25 minutes
		1. feedback of the performers and group members		
		Internal: impression of performers in the midst of the situation	Need to fix the time of important parts for later analysis	15 minutes
		External: reflection of participants		
		2. Playback of the first video recording for all course participants	Characters generally judge themselves more critically than exterior observers, accordingly objective feedback is important	
		3. Feedback		
		- What was found good/to be followed?		
		- Are there any recommendations for development?		
- What things would participants do differently?				
Possibility to repeat the playback of controversial parts				

		Finally the discussion of the second situation based on the above mentioned principles with the guidance of the 2. course leader		
		In case of the lack of time, analysing only the first 30-60 seconds of the video (greeting, construction of contact, interrogation)		
<i>1. seminar leader</i>	<i>2. seminar leader</i>	Summary 1. ask the participant playing a parent about perspective change, how a relative may feel in a similar situation 2. emphasize good sections of the role-play, finally the appreciation of positive aspects	Pay attention to time	<i>5 minutes</i>
<i>2. seminar leader</i>	<i>1. seminar leader</i>	Closure - asking impressions and opinions regarding the course Evaluation of the course	Only comments concerning the course are allowed	<i>10 minutes</i>
			Definitely keep to time, finish in time	<i>5 minutes</i>
		1. Collect the filled questionnaires		
		2. Participants sing declarations of consent		

7. New results of the research

1. Providing information on the suspicion on postnatally detected DS – based on the opinion of physicians partaken in the provision – does not fit to the principals recommended in international literature, and it needs to be improved.
2. A part of the differences between the Hungarian and German practice of information and support origins from the disparate structure of service.
3. Organised support for parents based on the correspondence of professional groups is missing in Hungary.
4. Representatives of the professional groups have fewer roles in the support of the family after the deliverance of the new-born because of this unorganised network.
5. In spite that disclosure is the competence of the physician, there are no available gradual or postgradual trainings for Hungarian obstetricians and paediatricians concerning DS.
6. The lack of information protocols and communication trainings does not affect the self-judgement of physicians regarding the quality of information providing; therefore there is a need of these professionals for communication courses.
7. Facing the German sample, Hungarian professional groups supporting the parents of postnatally detected DS children (psychologists, health visitors, social workers, priests, jurists, representatives of civil organisations) do not receive communication trainings regarding the disclosure of DS. However, responders thought that they should play an active part in working out and practical implementation of the protocol.
8. Collaboration of Hungarian institutions with civil organisations is not satisfactory, and it results that these organisations are not able to continue their positively rated work effectively.

Possibilities to improve the Hungarian status of providing information in case of the suspicion of a detected DS are the following:

- a.) development of a multidisciplinary communication protocol with the collaboration of representatives of the affected professional groups.
- b.) introduction of a special communication training for the affected medicinal and hygienic staff on communication of bad news, in Bsc and postgraduate level.
- c.) development of institutional relations with the convocation of a multidisciplinary supplying team based on the protocol.