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APPROACH HIGHER EDUCATION TO SOCIAL NECESSITIES: IMPLEMENTATION OF NEW SUBJECT IN HEALTH SCIENCES

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Point one or several from the seven topics of didactic interest: (Point x between the square brackets)

Key words:

Counseling, subject, European higher education area, teaching innovation project.

Abstract:

It is difficult to find in Spanish a word that can translate the meaning of Counselling and encompassing all those elements and nuances that you are your own. The translations more frequently used are "assisted advice" and/or "aid relationship" and/or advice, it also includes all the skills that are necessary to establish that interpersonal relationship.

Although the communication skills, and in particular communication of bad news and the relationship with users are currently not part of the university education within the degree in Medicine, Nursing, Physiotherapy or Psychology if it has been of concern on the part of practitioners in these areas present sufficient levels of training in this core competency. In fact, we presented/displayed a communication where the little information received in the own hospital on the part of parents with children with Syndrome of Down is reflected in particular on this genetic alteration before making decisions referred to the birth from the boy. Thus, just as the curative art is learned can be learned the abilities of communication referred the unexpected news, which will help to diminish the psychological cost for the professional and the own patient.

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1. Introduction:

A review of Literature is presented about the psychological genetic advice, in a context of a Teaching Innovation Project. Inside the first phase of action, information is evaluated and it is looked for a body of literature of the services and advice in a wide range of clinical approaches. Then, we have to find out which are the necessary abilities of communication for an adequate relationship between doctor-patient, and consultant-user to communicate very relevant information, which affects addressees' life who receive the information. In the last phase, a questionnaire is presented with which we try to assess the level in degrees as psychology, nursing and psycho pedagogy of future professionals to be able to face situations to advise adequately. All is done to achieve the last objective: it is to do a Health Sciences Subject, inside the European Framework, which adds the adequate abilities for the doctor/consultant-patient/user relationship.

In addition, a wide range of conceptions are dealt with nature and objectives of the genetic advice. However, in this area, the investigation has been criticized because
of the approach of its results instead of its process. And it has been suggested that this approach restricts its practical use. The purpose of this review is double: describe the concepts of orientation variables which appear to be used in reviewed works and discuss its possible applications in the genetic advice. It is difficult to find, in Spanish, a word that can translate the meaning of *Counseling*. The most frequent translations are (´assisted advice´ or ´help relation´ or advice. The last objective of the Counseling is to improve the relation between the consultant and the patient or the user and the customer. The achievement of what is proposed deals with the acquisition and improvement of several knowledge, attitudes and abilities for the established relation in those situations which can have emotional changes in some of the characters and when it is desired to have changes of patients' behaviors. When this relationship is established inside a specific field as the case of genetic advice, we find a process through which the affected people, or with risk of suffer a hereditary illness, are communicated about the possible consequences, the probability of develop it or pass on it, and the ways to avoid or fight it. This review evaluates the body of the investigation, taking into account the variation in conceptions of nature and the objectives of the psychological advice and the methodological limit to use psychological proofs, questionnaires or interviews. The vague character of the intervention and the lack of sharing among the studies make the review a bit difficult. To assess examples of the main type of studies, we find that they mainly evaluate six topics: definition, efficacy, knowledge, attitudes, risk perceptions and attitudes about the advice and the process of investigation.

2. Definition of genetic advice:

The advice concept is used in two different ways. Some authors point it in technique information that offer doctors [3], for example, when a doctor confirms that a person has a breast cancer, and in other occasions the advice is referred in psycho-social aspects [4] of the information that is told, for instance, analyzing the problems of a couple about reproduction [5,6].

3. The efficacy of the genetic advice:

There is little evidence about evaluations of the genetic advice efficacy. This can be explained by the controversy about the efficacy level that this context has [1,2].

3.1. Effective taking decisions about aspects of reproduction.

Some studies have defined the efficacy as the incidence at taking reproductive decisions, what runs a potential decrease of affected newborn babies Hildes et al. [7],
for example, to inform in a pilot programme of neonatal medical for the Duchenne's muscular dystrophy (DMD) that offer the antenatal diagnosis for future women´s pregnancies at risk. However, the antenatal diagnosis is only carried in two of the seven subsequent pregnancies, effectively. The authors conclude that these programmes must not be the way to reduce the number of cases. Another study [8], of the reactions of customers before the genetic 1888 advice, it was found almost the half (43, 5%) of 628 customers who filled some questionnaires six months after their advice meeting, they inform about their influenced plans related to reproduction. Although, the change and the stability of the approaches of reproduction plan of the two groups- influenced and not influenced- were similar. This approach has always risk to have problems due to the possible veiled eugenics.

3.2. Effective to remember information.

Swerts [9], for example, analyzed the impact of both: genetic advice or antenatal Down´s syndrome diagnsosis and neuronal tube faults. He took a simple model of subsequent delivery of information and evaluation. The measures of acquired knowledge and the information that was remembered after the advice show the common effort to avoid the eugenics stigma. If orientation in this information is offered in an educational way to improve the autonomy at taking decisions of the addressees, it will be important differences about the memory about the information which is offered.

3.3. Effective to reduce anxiety.

It is obvious that the simple approach to do genetic proofs has the potential to increase the anxiety among the addressees Mennie et al. [10], who, in comparison with the identified controls as the no-carriers, carriers of cystic fibrosis (FQ) and its associates, show an important increase of generalized psychological disturbance during a period of 4 days waiting for the results of the proof. After the communication of the results, both parts came back to starter levels. A study of the psychological impact of the amniocentesis in three groups at risk (adult women, mothers who before have a son, with Down´s syndrome, and the mothers who before have a son with neuronal tube faults) find that the anxiety levels related to the proof of both differ from the groups and they show a relevant change inside them. Different

programmes of sift or proofs have different results for the participants. Although most of the literature in this range [11, 12, 13, 14, 15] refers to genetic proofs, some studies directly point the advice. One of them assessed the impact of different types of psychological advice about the encouragement state with psychological scales which were managed before and after the change of orientation about the encouragement state. The authors concluded that the use of different ways of the type of advice was related to important differences for the encouragement state.

3.4. Effective to satisfy the customer

In a study [16], 36 persons who had received advice for suffer from cancer, they were asked for assess their satisfaction with the received attention by the clinical geneticist who they had seen as well as with the general procedures in the clinic. Another case, [17], customers were asked for assess the advice sessions according to clarity, depth in the debate and their will to ask questions. However, both studies admitted the limits of the approach, because the satisfaction is a questionable measure of the process. It is not necessarily refered to the reality in the session. Like Clarke et al. [18] point that while the investigation has been centered in the result; all what is related to the process is seen very effective too. In their opinion, while the measurements of result are valid in a context of investigation, those are useless in the practice.

3.5. Effective like process

Some studies have evaluated questions of procedure during the advice and they compare results with different methods. This reduces the ethic and methodological problems with the measure of results, because the interest is not in specific numbers but in the relative yield of the different processes. The used strategies include the use of the information in a vodcast together with the advice and the use of different types of advice [12].

Two studies relate the use of three different types of advice:
´Conventional´, ´programmed´(using recordings of vodcasts) and ´patient´s structuring´, the memory of information is evaluated and the level of satisfaction [11,19].
Other researchers have also compared three ways (in group, vodcast and personal advice) it is also evaluated with the memory of information. However, the results are not conclusive. Authors conclude that advisers' abstracts were a valid reference point to measure the customer´s memory. The before-mentioned studies show the inconsistency of the definition, or the tendency to define the precise nature of the orientation and the previous objectives. Unless it is possible to specify the expected results clearly, it will always be difficult to assess the efficacy. Though, this requires an agreement about the appropriate objectives of genetic advice. How have not we to be directive to avoid the accusation of acting like eugenics? If the desired result is defined as a reduction in the number of affected newborn babies, a wide controversy is presented. If the measurement of the result is about the information that is remembered and

the emotional state during the session, we find that both aspects are influenced by many variables which deal with a relevant period after the advice.

4. Knowledge and attitudes.

If the customer´s satisfaction is used as a measurement of the efficacy process, also, we have to take into account the customer´s expectations as an aspect that affects the answer to the advice. Many studies are based on hypothetical questions without bearing in mind the ability of interviewees to imagine themselves in some situations. An example, [20] is the survey for 169 women from 21 to 35 years old, about their attitudes toward the proofs of prediction of the Huntington illness, because they were going to have a 50% risk to develop it. In the results it is found that although they had interest in the prediction proofs, half of the women do not tell neither their employees, nor their insurers the positive result, what implies some knowledge of potential dangers of this knowledge. Moreover, though the antenatal proof had great acceptation, theoretically (50%), only a fourth part of women thought about the interruption of the pregnancy after the positive result.

Several studies have been centered in the FQ [21, 23]. It was evaluated the taking of decisions about the reproduction, the perceptions at risk, and the attitudes towards the identification of the carrier and the antenatal diagnosis between aunts and uncles of children with FQ. The results were similar to the previous ones: approximately three fourth parts ask for antenatal diagnosis in case of get pregnant, but less than the 50% thought about have an abortion if the fetus was affected. Other examples are centered more directly in regulation of knowledge about the genetic problem [24, 25].

In a study of the knowledge of the community about the FQ carriers' detection and the antenatal diagnosis a very poor knowledge of that illness is discovered. If it is, it is mainly associated to the educational level. The people who did the survey admitted that their relatives, specially parents and brothers/sisters were the most important source of information. As it is observed, some members of the family have been point of investigation maybe due to their familiar situation [21, 23, 26, 27], it has been assumed that they must be better informed than the public in general. The studies have assessed the way which information is transmitted among the members of the family and how the advice has been understood. The authors interviewed 12 balanced translocation carriers that had 36 brothers and 21 fathers among them. Four brothers (from two different families) have not been informed and only 16 of them informed persons made the proofs. From the fathers, 14 of them have been informed. The Results of Denayer et al´works [22, 23] show a very poor FQ comprehension by the affected child´s aunts and uncles. Only a little proportion (more or less a fourth part) was aware of their risk because of being near carriers and at risk to have a child with FQ. However, almost a third has a personal opinion from this risk that would use in taking decision about the reproduction for the couple. What is observed is that the most of the people who did the survey were not reluctant to talk about their condition with relatives and friends, but it is not clear that they did it in detail to establish the understanding of relatives about the consequences. This sets out the question, if the genetic professionals or these who inform genetically have rights or even the obligation, to widespread information about genetic risks to their brothers or other people at risk situation. About these results, it seems that the knowledge of genetic in general terms or

particularly, is quite poor, even among people who, can be at risk or it is believed that have special information due to their relationship with an affected person. However, the persons in these cases had not previous experience, they had not been advised.

5. The personal disposition of the perception of risk

A particular aspect that has specifically been studied is the perception of genetic risk. These studies are also divided in two different groups: these that analyse the perceptions of the lack of advice and those that are evaluated after the advice. The first group was the purpose of a before-mentioned study, children´s aunts and uncles who attend to a FQ clinic. Only a fourth part of them knew the approximate risk to be FQ carrier and to have a child with FQ [22].

Evans et al. [26] observed the risk perception before the advice in women cases who have breast cancer precedents. They were asked how they saw the risk to have breast cancer among the population in general, as well as their personal risk. Those estimations were used as base for the advice. Only 11% of them identified the real risk and more than 50% did not know how to value the risk of their life. Also, there were people who understimated the risk and other who overestimated it. The authors set an important question that can easily be forgotten, and it is, for a relevant proportion of those women, the advice could have been a disturbing experience and even incorrect.

However, it seems to be little investigation about how the risk is perceived and if there is information about it, the influence level is unknown in the case of the adviser. But if there is a wide body of psychological research with theoretical character. Some of these studies [28, 29, 30] are based on false or hypothetical situations which are faced when they face it during the advice. For example, with university population, it was assessed the subjective evaluation of the previous risks in false sessions of advice. These studies point the importance of linguistic elaboration and the influence that it can have about the treatment and understanding of the information of risk.

Robles-Bello and Sánchez-Teruel were also interested by the perception that addressees of diagnosis information have about how the new is offered and with this objective, 34 families were interviewed in an Early Childhood Attention Establishment. All the interviewed families had had a child with Down´s syndrome. The interview is designed from the perspective of the second definition of psychological advice, so in the session emotional support was offered with the opportunity to talk, show their attitudes and worries about the situation that lived when they knew their children´s birth. In our interview, we saw that families had not previous information about the Down´s syndrome before their children´s birth, because from the 34 interviewed families, 32 of them had not any type of information. The other two cases have information but it was obvious, because their parents were doctors, and they have Down´s syndrome cases in the family. When they were asked about where they had achieved information about the Down´s syndrome, 9 of them have known it reading books, special magazines. In a case, they were informed through the Down´s Syndrome Catalonian Foundation and another case, a doctor explained them. The rest were given information by the CAIT. Doctors are the first at making the diagnosis and telling the family it and consequently, they should give the first support services. Although, from the doctor´s point of view, a positive information cannot be given. Not only give the appropriate

information about the Down´s syndrome, but also are not sometimes them who give it because only a family feels informed by a doctor. Besides, it is true that most of cases is the doctor who first tells the child´s birth with Down´s syndrome. In our interviews, we see that 28 times it is the doctor who tells it, in 4 cases it is a nurse, one case the cardiologist, and in one occasion the midwife. The cases that the doctor does not tell the new are more deplorable, because families define it like disastrous. Most of mothers, when they are asked for it, cannot avoid to crying though much time has passed and they say: ´the doctor did not want to face it´. If we ask: Who tells the mother about the diagnosis? We discover that the father is the first person to know it. In 29 occasions is him who tells the mother it, with worry and emotion without giving additional information. In two cases, the nurse; in another occasion, is a sister and another time, a nun. If we analyse the spent time from the birth to the moment when the mother knows it, in the 8 figure, we find that in 12 occasions it is communicated immediately, in 8 cases the mother knows it 2-3 days after the birth, in 5 cases, several hours later, and 3 mothers know it the following day after the birth.

Not only information, but also the parents' comments make you think about the person who has to say the diagnosis and the information about Down´s syndrome. He/she should be sensitive or at least, he/she needs to train for advise psychologically.

In the moment that a child is born with Down´s syndrome, it can affect in a positive or negative way in the future of a person. This item is refered to the way of communicating parents that their child has a psychic problem. It seems very complex, because it carries much responsibility.

6. Conclusions

As conclusion, we can do several observations. Firstly, in all these studies, after or before the advice, the users seem to have a very poor understanding level of information which is obtained from the advice sessions, thus they cannot understand the real genetic risk. In addition, this happens in populations at risk for have precedents as well as in relatives. It could be though that it should have some extra knowledge, but it is not true.

Secondly, it seems to be that experts do not give information well and information from the sessions where supposedly, it is confused, because of the medical information about the concrete risk to suffer an illness.

In third place, the addressees´ information are confused for the different types of risk (if they are carriers, etc.) and the ambiguity of the results in the medical proofs.

In fourth place, there is much confusion in the message which they wish to tell. All in all, it seems obvious that the way to communicate by the doctor acquires great importance. Hence, the necessity to create this expert consultant to tell the type of information. We had the possibility to face this type of situations and to check by ourselves, how information is communicated and how is the relationship between doctor and patient in a concrete framework as telling the new of a child´s birth with Down´s syndrome.

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