155 - CYSTIC FIBROSIS AND PSYCHOLOGICAL ASPECTS: CASE REPORT.

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INTRODUCTION

Cystic fibrosis of the pancreas is a hereditary illness; also call of mucoviscidosis, that comet mainly people of the white race, affecting the exocrine glands to them and harming to them, mainly, the intestines and pulmonary. Inexisting cure, the carriers of this illness pass for repeated hospital internments, when the painful procedures are submitted. In house, its daily one is marked by the dependence the medicines that supply to enzymes and antibiotics and by daily sessions of physiotherapy. Schlindwein (1999), in including bibliographical revision, found that cystic fibrosis is followed by masculine sterility and feminine with sub fertility, deficiencies in the growth and difficulties in the pertaining to school learning. Moreover, the people start to coexist the possibility of the precocious death, in special because the supervened one is of, generally, 25 years.

The mention to the psychological repercussions for the patients and familiar gifts in its lives is frequent. In the communication of the diagnosis, according to Federación Española Against la Fibrosis Quística (2000) is detected emotional feelings of impotence (55,69%) and alterations, as anger (41,19%), guilt feelings (20,12%), evidencing the impact that this illness produces on the familiar life (Gaidzinski, 1992). Its gravity determines the necessity of routines of life with narrow limits, disauthorizing optimistically prognostics. It assumes probability of imminent death. The carriers develop particular psychological aspects and little practically studied. In this way, he makes - necessary more studies concerning the life of these patients in order to minimize the suffering to them.

Of this form, the present work describes main aspects of the psychological attendance carried through to the cystic patient with mucoviscidosis/fibrosis of the pancreas (FC) and its familiar ones in hospital environment, with the general objective of assisting the diagnosis and the therapeutically one of these patients in the psychological scope.

OBJECTIVES

To subsidize a psychological diagnosis of the patient; To identify psychological aspects in the symptoms of the cystic sick person of fibrosis; To investigate the psychological aspects in the family, mainly in the parents, of the affected ones for the one of the illness.

METHODOLOGY

The present work is characterized as case study, of exploratory character. The consultation to the scientific production on the subject allowed the contextualization of the accumulated knowledge, contributing for the agreement of the results gotten in the comment. It was possible thus, a deepening of characteristic aspects of the cystic patient with fibrosis and its familiar ones, selected as restricted object of research.

The present study one developed in the hospitals *Governador Celso Ramos* and *Hospital Infantil Joana de Gusmão*, of the public net of the health, the State of Santa Catarina, in Florianopolis/SC, Brazil. The collection of data was carried through having searched information together the patient and its family, and in consultation to the handbook of exactly, in the period of 1999 the 2000.

Psychological interview: it consisted of evaluation of the patient and its problematic one. It was the proper patient, and a familiar one. Examination: the general survey of the patient was mentioned to it, when the data on its life had been harvested, especially those related with the infantile development (neurological, psychomotor aspects and affectivity), illnesses, and activities of the daily life (AVD). Psychological attendance: it elapsed of the clinical intervention in the psychological scope, aiming at the therapeutical evaluation and/or of the clinical picture (also the investigated one in examination). Analysis of the handbook: consultation and analysis carried through from the fiches of psychological evolution of the patient.

RESULTS

Analysis of the case study: Patient of the feminine sex, 6 years, white race, hospitalized, with cystic recent diagnosis of fibrosis of the pancreas, in medical accompaniment.

Reason of the suspicion of the diagnosis: Pneumonia of repetition, diarrhea and inflammation of sinus of the face. Familiar receiving psychological accompaniment.

Guiding: Carried through for the pediatric doctor. Period of psychological attendance: 24/ 06/ 99 up to 02/ 04/ 2000. Medication: Antibiotic (ceftazidina, amicacina, vancomicina), gastrocinetic (cisaprida), anti ulcerosis (ranitidina), pancreatics enzymes, nebulization with broncodilatatior and bromide of ipatropium (parassimpaticolítico).

Description: Preliminarily, it was suspected, for the repetition of pneumonias and episodes of diarrhea that the child was ill of mucoviscidosis. Later, also it presented inflammation of sinus of the face. In the occasion of this study, it one met hospitalized with cystic diagnosis of fibrosis of the pancreas. The period of psychological attendance had the duration of nine months and involved the Hospital Infantil Joana de Gusmão (Florianopolis/SC), the Hospital Governador Celso Ramos (Florianopolis/SC) and the Associação Catarinense de Assistência ao Mucoviscidótico (ACAM).

Comments: Important benefits of the psychological intervention for the patient and its family.

DISCUSSION

Mucoviscidosis or cystic fibrosis of the pancreas is a lethal hereditary illness that can compromise, in the patient, its gastric intestinal, respiratory, nutritional, psychological and pertaining to school functioning, besides having reserved prognostic, promoting diverse feelings in the involved individuals, that go of the depression to the desperation. These feelings that can in accordance with aggravate the level of the illness, with the necessity of hospital intervention, the proper psychological balance of the patient and of its family.

In this in case that, the approach is infant J., of the feminine sex competed by mucoviscidosis, petitioner of frequent internments, whose hospitalization, procedures and the involved team (doctor, psychologist, nurse, physiotherapist and nutritionist) are subjects and personages of its playful universe.

The patient can be directed by the medical specialist to the psychologist, as also, proper it and/or family can search the treatment psychological. That it will determine its clinical behavior (psycodiagnostic, individual or familiar psycotherapy), set appointments returns in agreement the psychologist to consider necessary, in the accompaniment with the family or the patient. The patient directed to the Service of Psychology of the institution, presented, in the beginning, aggressiveness, isolation, anxiety, fancies, fears and unreliability, little receptivity but being discerning and guided. Manifestations these, as Pig (1993), influenced for hospitalization and its cold, impersonal and threatening content, where its choice is made by necessity and/or emergency, subordinated for expectations and fears, reign-echo in the mechanisms of defense of the ego.

The psychologist, in the relation with the patient, allows the opening of a contact canal, where the participation of this will be important for its whitewashing. In this attendance the attention to its whitewashing and reintegration to the daily one will be also one of the points of the psychological work, that also makes possible one better quality of Angerami-Camon life et all (1995). The evaluation of the team on the possibilities and limitations that the person will go to have in its life the short one, medium and long run will need to be brought to it and to its family, of form to prevent inadequate attitudes of negation of the limitations, provoking the new occurrence or aggravation of the disease, or, for another part, the exacerbation of the limitation state. Of this form, Angerami-Camon et all (1995) complements that the psychotherapy search, also, to take the patient to the self-knowledge to the auto growth and the cure of determined symptoms.

The psychological preparative for the hospital procedures with the patient, including the participation of the mother had been epitasis, where the reduction of the anxiety of the patient was evident. In this direction, Oliveira and Gomes (2004), when studying the implications of the medical communication - patient chronic since infancy (with fibrosis also cystic) in the adhesion to the treatment, detach that the communication must be directed to the mothers and the patients, so that they can assume themselves of the condition of being sick, to develop itself and to be able to assume the proper desires and the responsibilities.

The psychological interventions had also had the approach in the tack of the patient to the medical treatment, through, for example, of the acceptance of the maintenance and permanence of the nasogastric sounding lead in the after-high period of hospital. Such period awaked certain concern in the team and the family, since the sounding lead was visible and object of lay commentaries. The pertaining to school environment was preoccupying, aggravating a picture of inadequation and rejection that also could take the withdrawal of the sounding lead for the proper patient. But the psychological procedure had success, propitiating the acceptance of the permanence of the sounding lead for J. beyond the planned time.

Thus, the return of the patient was supported the school, however guiding it however on the above described situation and remembering the necessity to keep contact (either physicist, appearance, verbal, or sensorial) with the external, unproved way it physician-hospital character. Such return also understood to the return the pleasant activities of the child.

In view of that as many children as adolescent have the necessity to be accepted in its half one, communed the sick people confidences to few or nobody, on its illness, remembering that 48.67% omit total that has fibrosis cystic (Federación Española Against la Fibrosis Quística, 2000). In pertaining to school age and the adolescence, the trend is to hide its illness of the friends, either for distrust of discrimination or feeling themselves ashamed of its appearance, when if they compare with its healthy colleagues and they perceive that they are in disadvantage with relation to its physicist.

It is in this phase, in the pertaining to school age, following until the adolescence, that the parents demonstrate more concern with the profit of weight of its children. The difficulties with the physiotherapy, the fear of a respiratory infection, the financial chemistry of pancreatic enzymes, problems, hospitalizations and the removal of the familiar conviviality, are expressed emotional shakes. The psychologist can anticipate it the future situations, related to the adolescence, when the cystic fibrosis become more resistant the treatment, for being more independent, mainly to the physiotherapy, and starts to it hates the periods of hospitalization. In the following internment he had the necessity of the use of the catheter, invasive surgical procedure.

The operation was followed of certain aggressiveness, resistance to medical clothes and anxiety on the part of the patient. These reactions had been cured in the almost daily psychological attendance. Its opportune to remember that, in all the internments had daily attendance psychological, that include the preparation for hospital procedures or surgery. The gone one to the surgical center generates illness fancies, fears and anxiety, as much for the patient, who started to better accept the implantation of the catheter, as for its family. Although instructed that the surgical act would be carried through by the doctor, the patient and the family asked for the presence of this psychologist in the implantation of the catheter. For patient and familiar the presence in the surgical center this presence, was as its proper presence, since them the access was interdicted.

The daily pay-surgical psychological preparation can understand the presence of the Psychologist in the unit, the daily pay-anesthetically room and even in the room of surgery, following mainly the effect anesthetic. The patient answered well to the psychological procedure, in the after-surgical one initially reacted with certain apathy and resistance, passing soon to good contact, good acceptance and joy for the overcoming of the episode. In these cases, the aggressiveness of the patient can be disclosed under the negative form and refuses in relation to the postoperative cares.

The aggressiveness of the patient is, generally, unconscious, being and active in the depressions. Many times, the passive patient "well" is seen by the team, therefore not manifest complaints, when she considers yourself to be well. Frequently, in this behavior parentally "well" he has apathy pictures, masked depression that, usually, will result in complications and difficulties for the patient and immediate postoperative team in or the delayed one, and in its process of whitewashing and partner-familiar and professional reintegration (Angerami-Camon et all, 1995). The release, exactly that partially, of the aggressiveness a significant improvement in the cares and treatments of the patient and in the rapidity of its recovery can to provoke. Factors as confidence, availability, pipe the side to the patient so that it displays its feelings, orientation and not to mystify of the fancies are basic (Angerami-Camon et all, 1995).

In the following hospital internment, this psychologist was called by the Unit of Emergency of the hospital, where J., its parents and the doctor were congregated. The patient revealed, reluctance, cries, fidget, attachment to the col of the parents and tension, front more an internment and of the not constant of its physical health. The previous internments had not been so surprising for the patient. Angerami-Camon et all (1998), in turn, clarifies that the urgency involves the not visible, where the individual lives deeply diverse psychological situations (fear, anxiety, resentments, shakes in the autonomy and sensations of queerness, alteration of auto-esteem and in the corporal image, suffering, losses, uncertainties and changes) that the used time of internment and medical procedures get worse as.

Having in this routine of the unit of Emergency a distinction of the performance of the psychologist in relation the unit of Internment and to the doctor's office. In this way, it is perceived that the psychological urgencies are not restricted to the suicidal picture, involving, also, other distinct states, as well as the type of employed intervention. In contrast of the previous internments, the psychological intervention initiated in the unit of Emergency and not in the one of internment. In this, different of the previous ones, it had the psychological preparation for the gastrostomy that got good reply of the patient and its mother, who always present, it received orientation psychological and it participated of the process.

The difficulties most common of social interaction in the chronic illness in infancy start when one of the parents becomes main the responsible one for the child (Federación Espanõla against la Fibrosis Quística, 2000). To the measure that the father and other adults become disengaged long of the time of double the sick mother-son more, other relationships in the family start to suffer partitions: conjugal, father-son, father-other children, other relatives and friendships. The pressure accumulates on the relationship mother-son, being accused to be super protective, that, in turn, it complains of not being understood or being supported by the family or friends duly. It is necessary that the couple shares the different demanded moment's to illness, already that life occurs some changes in do couple and the family.

The contribution of the grandmothers depends very on the previous relationship with the family. In this direction, J. and its familiar ones had presented good relationship and good resolution when dealing with such situations. The questioning concerning the supervened one of J., death, loss and routine in after-high was boarded, mainly with its mother. Topics of this nature, in general, more are questioned by familiar and/or patient, when they perceive that each time more, the hospital procedures and attendance, together with the medication and the internments, go if intensifying.

From the psychological, attendance concretion of the therapeutical bond and too much procedures the mother (that always she followed the girl, since the father worked outside to provide the family) revealed collaborative the professional and affectionate stops with the girl, being corresponded by J., that requested its constant presence. The genitor told concerning other previous hospital internments, with the accomplishment of invasive procedures, that nor always had the agreement of the patient, leaving psychological sequels.

Such sequels, that added to the typical picture of the FC, intervene in such a way with the treatment of the illness as in the psychological pictures of the child and its family. It is important to involve the parents or responsible in the treatment of the son, when they will be ready for such. Being thus, Beattie and Lewis Jones (2006) comment that the chronic illness can have physical and psychological effect that affect the social functioning of the individual. In the following internment, this psychologist integrated the team of the Governing Hospital Celso Branches, more not acting in the Infantile Hospital Joana de Gusmão.

The patient, then, interned in this pediatric hospital unit, and hospital license in one day of Saturday, together with its brother and its parents came this psychologist, in the other hospital. One noticed, that aspects among others, the patient did not present the anxieties, the fears (also to white clothes), unreliabilities, aggressiveness, regretted behavior, alimentary alteration with incompetence, fancies (also of abandonment and hospital procedures), distrust in going the school, that revealed in the beginning of the psychological intervention, has nine months more than behind. It was demonstrated conflict and receptive to this professional, beyond bigger tack to the hospital and extra-hospital treatment. In this scope, Coast Júnior (2001) remembers that psychology, as science of the health, must intervene so that the taken care of individual can acquire and keep health behaviors. Later, J. was transferred to Blumenau/SC and, since then, does not have reference of new hospital internment of the patient in Florianopolis/SC.

It is perceived that the process of integration/socialization, assimilation, illness improves, overcoming of traumas and difficulty in the learning, among others, of the FC carrier involves the team of health in such a way (as the psychologist, doctor, physiotherapist, nutritionist and nurse), but also professional of other areas, as the educator. It has that to remember the importance to respect the other, visualizing it not only for an only angle, but in its totality while human being.

CONCLUSION

Concerning the presented clinical case one concludes that it has: limitation of the desires of the patient (to sleep outside, to travel), changes of life for the fibrocystic and its family (alterations of schedules, the social life, the psychological leisure, riots, hospital internments, medication, finances, renunciation of employment and studies). It has tension to the speech of the FC in the familiar nucleus, parents reveal isolation, one of the parents social becomes main the responsible one for the child, super protection of the parents in relation to the fibrocystic son, complaints of the healthy brothers, alterations in the pertaining to school life of the patient (it lacks to the lessons, discrimination, occultation of the illness, changes in the academic income), it search for the quality of life and improves of the supervened one.

The psychological intervention search, also, the tack to the treatment and the promotion of quality of life for the mucoviscidosis patient, through attention to its whitewashing and reintegration to the daily one, as well as in the attainment of the quality of life (beyond its evaluative and therapeutical procedures).

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CYSTIC FIBROSIS AND PSYCHOLOGICAL ASPECTS: CASE REPORT.
ABSTRACT

The cystic fibrosis is a hereditary chronic illness, that can compromise, in the patient, its gastric intestinal, respiratory, nutritional, psychological and pertaining to school functioning, beyond having reserved prognostic, having emotional repercussions in such a way in the patient as in its family, that can in accordance with aggravate the level of the illness, with the necessity of hospital intervention and the proper psychological balance of the patient and of its family. In such a way, the present work approaches involved psychological aspects in cystic fibrosis (FC), describes the main factors of the psychological attendance carried through to the fibrosis patient and its familiar ones in hospital environment, with the general objective of assisting the diagnosis and the therapeutically one of these patients in the scope of Psychology. Concluded that it has important benefits of the psychological intervention for the patient and its family.

Word-key: cystic fibrosis; child; psychological aspects.

FIBROSE CYSTIQUE DES PÂNCREAS ET ASPECTS PSYCHOLOGIQUES: UN CAS CLINIQUE.
RÉSUMÉ

Fibrose cystique des pancreas est une maladie chronique héréditaire, qui peut compromettre, dans le patient, son fonctionnement gastrintestinal, respiratoire, nutritionnel, psychologique et scolaire, outre deavoir pronostic réservé, ayant des répercussions émotionnelles tant dans le patient que dans sa famille, qui peuvent s'aggraver conformément au niveau de la maladie, avec la nécessité d'intervention hospitalière et avec l'équilibre psychologique lui-même du patient et de leur famille. De cette forme le présent travail aborde des aspects psychologiques engagés dans fibrose cystique des pancreas (FC), décrit les principaux facteurs de la participation psychologique réalisée au patient fibrocístico et leurs parents dans environnement hospitalier, avec l'objectif général d'deassister le diagnostic et de la thérapeutique de ces patients dans le contexte de la Psychologie. Il s'est conclu qu'y a importants bénéfices de l'intervention psychologique pour le patient et sa famille.

Mot-clef : fibrose cystique ; enfant ; aspects psychologiques.

FIBROSIS ENQUISTADA Y ASPECTOS PSICOLOGICOS: INFORME DEL CASO.
RESUMEN

La fibrosis enquistada es enfermedad crónica hereditaria, que puede comprometer, en el paciente, su intestinal gástrico, sistema respiratorio, alimenticio, psicologico y escolar, más allá de reservar pronóstico, teniendo repercusiones emocionales en tal manera en el paciente y en su familia, de acuerdo con el nivel de la enfermedad, con la necesidad de la intervención, del hospital y a los equilibrios psicológicos apropiados del paciente y de su familia. En tal manera, los actuales acercamientos de los tratamientos implicaron aspectos psicológicos en la fibrosis enquistada (FC), describen los factores principales de la atención psicológica llevada al paciente de la fibrosis y sus familiares en el ambiente del hospital, con el objetivo general de asistir a la diagnosis y terapéutico de estos pacientes en la psicología. Se ha concluido que el tratamiento psicológico tiene ventajas importantes para el paciente y su familia.

Palabras-llave: fibrosis enquistada; niño; aspectos psicológicos.

FIBROSE CÍSTICA DO PÂNCREAS E ASPECTOS PSICOLÓGICOS: UM CASO CLÍNICO.
RESUMO

A fibrose cística do pâncreas é uma doença crônica hereditária, que pode comprometer no paciente, seu funcionamento gastrintestinal, respiratório, nutricional, psicológico e escolar, além de ter prognóstico reservado, tendo repercussões emocionais tanto no paciente como em sua família, que podem agravar-se de acordo com o nível da doença, com a necessidade de intervenção hospitalar e com o próprio equilíbrio psicológico do paciente e de sua família. Desta forma, o presente trabalho aborda aspectos psicológicos envolvidos na mucoviscidose / fibrose cística do pâncreas (FC), descreve os principais fatores do atendimento psicológico realizado ao paciente fibrocístico e seus familiares em ambiente hospitalar, com o objetivo geral de auxiliar o diagnóstico e a terapêutica destes pacientes no âmbito da Psicologia. Concluiu-se que há importantes benefícios da intervenção psicológica para o paciente e sua família.

Palavras-chave: fibrose cística; criança; aspectos psicológicos.