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ETHICAL ASPECTS IN TREATING ADOLESCENTS WITH CHRONIC DISEASE

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ABSTRACT. Chronic disease during the period of adolescence demands a lot of specific issues dues to the particular psychological, physical and social development of this stage. Patient-doctor relationship, communication, medical consultation, information, sharing an uncomfortable diagnostic with parents or involving the family in the treatment should be carefully approach. Privacy, confidentiality and informed consent are ethical aspects that must be also taken into consideration. The management of the chronic disease during adolescence become a great challenge to the medical team. The practice of adolescence medicine is always a challenge to resolve ethical dilemmas.

Keywords: *adolescent, chronic disease, ethics;*

1. INTRODUCTION

Chronic disease is a long-lasting condition that can be controlled but not cured; the term is applied if the condition lasts for more than three months. In Unites States, chronic disease is the leading cause of death and disabilities being responsible of 70% of all deaths per year.

Chronic disease and disabilities are topics that produce a lot of controversies in our aging society. The ethical dimensions in case of chronic illness and chronic care must be ethically and philosophically analyzed. Concepts like patient’s rights, autonomy and best interest need to be revised in order to treat the patient with dignity and justice.[1]

There are many issues involved in the definition of chronic health conditions. Some of them are referring to duration, age of onset (congenital or acquired), limitation of age appropriate activity, visibility, expected survival, mobility, physiological functioning, cognition, emotional/social impairment, sensory functioning, communication impairment, course and uncertainty.[2]

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[1] Jennings, B., Callahan, D., Caplan, A. L. (1988). *Ethical challenges of chronic illness.* Hastings Center Report*,* 18*(1*), pp.1-16

[2] Suris, J.C., Parera, N.P., Puig, C. (1996). Chronic ilness and emotional distress in adolescence. *Journal of Adolescent Health. 19(2),* pp. 153-156.

2. CHRONIC DISEASE IN ADOLESCENCE

One quarter of all people living in the world is between the ages of 10 and 24 years. The World Health Organization (2014) defines adolescents as those people between 10 and 19 years of age. The great majority of adolescents are, therefore, included in the age-based definition of “child”, adopted by the *Convention on the Rights of the Child,* as a person under the age of 18 years. Other overlapping terms used are *youth* (defined by the United Nations as 15–24 years) and *young people* (10–24 years), a term used by WHO and others to combine adolescents and youth.

Adolescence is a specific period with psychological, emotional, developmental, healthy and social needs. In most of the developed countries, the gap between childhood and adulthood is growing longer because people are more focused on education and training. Family or social aspects are postponed responsibilities for a later decade of their life. The effects of the chronic illness are influencing all aspects of the adolescent life.

Among in-school adolescent, the rate of chronic disease is around 10%. Rate is surely higher if mental and physical disabilities are also taken into consideration. Globally, higher rates are among males, rural residents; poverty, a lower social and educational level are also important variables.[3]

Dealing with chronic disease in case of adolescent is a great challenge not only for the medical team but also for family members. Due to irreversible changes of the body and mind and the unique transformation from childhood to adulthood, the chronic illness has a great impact on bio-psycho-social development of the patient. The treatment of the disease, the prevention of ill health and the promotion of healthy behaviors are taking place on an unstable territory where physical, psychological and social changes are happening very rapidly. The creation of adolescent medicine as a subspecialty was imposed and not many countries have specific clinics who adequately meet the standards that these patients deserve.[4]

3. IMPORTANT FACTORS IN TREATING ADOLESCENTS: COMMUNICATION, MEDICAL EXAMINATION AND SHARING DIAGNOSTIC

Treating adolescents with chronic disease is a challenging process. During the long lasting treatment of a patient with a chronic disease, several types of relationships are changing between doctor and patient: if the diagnostic is identified at

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[3] Idem, pp.153-156.

[4] Michaud, P.P., Suris, J.C., Viner, R. (2004). The Adolescent with chronic condition. Part II: healthcare provision. *Arch Dis Child, 89*, pp. 943-949.

an early age, this relationship passes over a lot of changes and dilemmas. Starting with a paternalistic approach, continuing with a balanced one and finishing in an autonomous way, the interaction between them is traversing years of changes through the developmental stages of the childhood to adulthood. The physical transformation is subject to changes due to the natural process of gown but also limited by the chronic disease. The emotional and psychological development is tumultuously prevented by disease's effects (low self-esteem, introversion, self-isolation, low confidence in their capacities etc). The patient has irreversible and sometimes quickly changes; meanwhile treatment and medical team should continue and adapt to the situation.

Teenagers with chronic disease develop preferences and priorities regarding health care (starting with the hospital image and ending with particularities of the doctor-patient relationship). Studies prove that even the design of the hospital is important for the adolescent.[5]

Doctor-patient relationship is a very important factor in treating adolescents and many studies proved the real therapeutically effect of this connection, mentioning consequences near to placebo effect.[6] Even if the relation should respect the privacy, the examination of a person under 18 should be done in the context of the family. Doctor's skills are very important for creating a trustful relationship and it is up to the pediatrician to create the best shape and the most comfortable atmosphere for both patient and family.

Most of the protocol suggests that doctor should alternate the communication (seeing the family together with the patient, than seeing the patient alone and ending with communicating with all of them, again. Communicating to parents alone after consulting/interviewing the adolescent should be always avoided for not losing the patient's trust. For teenagers, physician trust and respect have the highest rating, followed by patient power and control and then caring and closeness in the patient-doctor relationship.[7]

Because during adolescence people start to explore unhealthy behaviors and keep these practices away from parent's view, doctor should give the change and encourage the patient to disclose these behaviors in order to have a complete image of their impact on adolescent's chronic disease. For example, regular smoking rates rise from 1% at 11 years to 24% at 15 years, and over 90% of adult smokers began smoking

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[5] Ullan, A.M., Belver, M.H., Fernandez, E., Serrano, I., Delgado, J., Herrero, C. (2012). Hospital Designs for Patients of Different Ages Preferences of Hospitalized Adolescents, Nonhospitalized Adolescents, Parents, and Clinical Staff. *Environment and Behavior*, *44 (5*), pp. 668-694.

[6] Di Blasi, Z., Harkness, E., Ernst, E., Georgiou, A., Kleijnen, J. (2001). Influence of context effects on health outcomes: a systematic review. *Lancet*, *357(9258),* pp. 757-762.

[7] Britto, M. T., DeVellis, R. F., Hornung, R. W., DeFriese, G. H., Atherton, H. D. & Slap, G. B. (2004). Health care preferences and priorities of adolescents with chronic illnesses. *Pediatrics*, *114*(5), pp. 1272-1280.

during their teenage years. Other behaviors should also be taken into consideration: alcohol, sexual activity and contraception, pregnancy, drugs. It is important to get used to ask questions in a specific way to an adolescent so he/she can be easily mention the true answers. The *HEADS* questions are referring to Home life, Education, Activities, Driving, Drugs, Diet, Sex, Sleep and Suicide.[8]

Professional conversation between patients and doctors shapes diagnosis, initiates therapy and must establishes a caring relationship. The degree to which these activities are successful depends, in large part, on the communication and interpersonal skills of the physician.[9] They usually prefer communication the diagnostic directly to them rather than to their parents. Younger adolescents are more interested in keeping confidentiality of their health information, and adolescents with chronic illnesses are more interested in involving parents in their care than are adolescents without chronic illnesses.[10] Teens seem to mistrust physicians because of their previous experiences of being accompanied to the doctor by parents. Family physicians that are interesting in creating a trustful relationship with their adolescent patients should begin while patients are still children, talk directly to the child, rather than exclusively to the parent, and see the child in privacy for portions of each visit.[11]

Adolescence is a sensitive age, where the corporal image is very important and usually influences by a subjective evaluation. Frequently worried about the physical aspect, the teenagers are appreciating privacy and intimacy. Adolescents value all aspects of privacy and most of them are thinking about their physical safety during physical examinations, as well as their visibility to others. Studies proved that they are more comfortable when examinations are performed by female rather than male providers.[12] 50% of girls prefer a female provider and 23% boys prefer a male provider.

The study of Kapphahn et all[13] shows that during examination younger girls usually want a parent present, while younger boys had no preference. Girls with a female physician are more likely to have private time and only 50–60% had spoken privately with their doctor.

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[8] Segal, T. (2008). Adolescence: What the cystic fibrosis team needs to know. *J R Soc Med, 101*, pp. 15–27.

[9] Duffy, F.D., Gordon, G.H., Whelan, G., Cole-Kelly, K., Frankel, R., Buffone, N., Lofton, S., Wallace, M., Goode, L., Langdon, L. (2004). Assessing competence in communication and interpersonal skills: the Kalamazoo II report. *Acad Med., 79(6)*, pp. 495-507.

[10] Klostermann, B.K., Slap, G.B., Nebrig, D.M., Tivorsak, T.L., Britto, M.T. (2005). Earning trust and losing it: adolescents' views on trusting physicians. *J Fam Pract*, *54*, pp. 679–687.

[11] Cogswell, B.E. (1985). Cultivating the trust of adolescent patients. *Fam Med. 17(6)*, pp. 254-258.

[12] Britto, M. T., Tyvorsak, T. & Slap, G. B. (2010). Adolescents' Needs for Health Care Privacy. *Pediatrics*, *126(6),* pp. 1469-1476.

[13] Kapphahn, C.J., Wilson, K.M., Klein, J.D. (1999). Adolescent girls' and boys' preferences for provider gender and confidentiality in their healthcare. *J Adolesc Health, 25*, pp. 131–142.

This gender difference in dealing with chronic disease is frequently explored by studies.[14] Suris studied the emotional distress and the suicidal thought among adolescents with and without chronic illness. The study identifies a significantly greater proportion of females with chronic illness who reported emotional problems, feeling in a bad mood, feeling sad, believing nothing amused them, having suicidal thoughts, expressing depressive symptomatology and having personal problems needing professional help. In contrast, no significant group differences were found for males in non-chronic illness group and chronic illness group. No gender differences were found regarding recent contact with a mental health specialist.

The right to be examined with no present parent depends on the country. Legally speaking, patient under 18 is not supposed to be examined without a caregiver's approval. In UK, for example, 16-18 years old patients can consent to treatment but cannot refuse life-saving treatment. The legal criteria for competence usually require the ability to give informed consent and understand the benefits and risks of treatment or non-treatment.[15]

The ethical approach of the doctor should balance the beneficence and autonomy in the benefit of each individual patient. Ending with the paternalist model (appropriate to the doctor-little patient relationship) and the independent model expected by the adolescent, the physician should fulfill a lot of criteria (all legal) who generate dilemma: the right to confidentiality is one of the fundamental rights of the patient. But, on the sliding scale of the adolescent maturity, the child's decisions override the parents.[16] Who's in charge of the decision: should doctor respect the patient's decision (anyway, it is the obligation to respect the teenager's privacy and confidentiality increases as is the maturity increase) are parents should come first? Apart this difficulty of deciding who's decision is first, doctor is falling into another dilemma: is he having a paternalist mode by adopting his role of benefactor or he's an external figure in order to empower the patient and to guide him to his own decision?

A special issue regarding chronic illness in adolescence regards compliance. Non-compliance is an often unrecognized or frustrating reality, which physicians find difficult to accept or deal with. Possible determinants of adolescents' level of compliance may be divided into demographic factors, patient and family characteristics, aspects of the illness and treatment regimen, and quality of the patient-doctor relationship. Compliance should be viewed as a reflexion of the experience of chronic illness as well as the expression of specific adolescent developmental issues.[17]

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[14] Suris, *op.cit.* pp.153-157.

[15] Segal*, op.cit,* pp. 15-27

[16] Pavilanis, A.V. (1989). Ethical Questions in Adolescent Contraception. *Can Fam Physician*, *35*, pp. 1317–1320.

[17] Alvin, P., Rey, C., Frappier, J.Y. (1995). Compliance thérapeutique chez l'adolescent malade chronique. *Archives de pédiatrie*, *2*(9), pp. 874-882.

Adolescents with chronic conditions had lower emotional well-being scores, worried more about dying soon and about school or future work, and had poorer body image.[18] (Wolman et all, 1994) The consequences of their disease have great impact on their lives and also their family's lives.[19] The noncompliance among patients (especially teenagers) is a major problem. Studies are describing that noncompliance is inversely related to survival and that patient characteristics may be predictive of compliance under certain circumstances.[20]

Maintaining informational privacy (keeping information confidential) are the most salient to the adolescents. Younger adolescents are usually concerned with information being disclosed to others, whereas older adolescents worried more about information being disclosed to parents. Other privacy aspects (psychological, social, and physical) are also important. To protect psychological privacy, adolescents are cautious about revealing sensitive information for fear of being judged by providers.

The clinician should be careful not to be judgmental or scolding because this may rapidly close down communication. Sometimes the patient gains therapeutic benefit just from venting concerns in a safe environment with a caring clinician.[21] To protect social privacy, adolescences are reluctant to talk with unfamiliar or multiple providers and they don't not want to discuss issues that they perceived as unrelated to their health care.[22]

4. CONCLUSIONS

Treating adolescents with chronic disease is a challenge to the medical team. The effects of the illness are determined by the irreversible changes of the patient in all aspects of his profile (psychological, physical and social) and influenced by the patient's family support. Adolescence medicine is attempted by the unique relationship between doctor and patient always submitted to various ethical dilemmas.

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[18] *Wolman, C., Resnick, M. D., Harris, L. J., Blum, R. W. (1994). Emotional well-being among adolescents with and without chronic conditions.* Journal of Adolescent Health*,* 15*(3),* pp. 199-204

[19] Iorga, M. Starcea, M., Munteanu., M., Sztankovszky, L.Z. (2014). Psychological and social problems of children with kidney chronic disease. *European Journal of Science and Theology. 10 (1).* pp. 179-188.

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[21] Teutsch, C., (2003). Patient-doctor communication. *Med Clin North Am*. *87(5),* pp. 1115-1145.

[22] *Britto (2010), idem,* pp. *1469-1476.*

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