139 - THE STIGMA IN CHILDREN WITH CHRONIC DISEASES: A MATTER OF PUBLIC HEALTH

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INTRODUCTION

The term “health” refers to a complex concept which is related to the organic, physical and mental functions (WHO, 2003) of the individual, whereas “disease” refers to his/her condition of imbalance. There is a growing concern among public health professionals regarding chronic diseases an their consequences in the quality of life, the psychological and psychosocial condition of the patient and the process of stigmatization.

In this sense, it is assumed that the stigma which results from the chronic disease is a public health issue. “Chronic disease” is understood as the long-term illness, it may be incurable, producing sequels, imposing restrictions to the individual functions and requiring adaptation (Woods, Yates, Primono, 1989). The term refers to more than three months or that requires hospitalization for more than a month (Huerta, 1990).

The World Health Organization (WHO/PAHO, 2005) estimates that 388 million people, from different age groups, will die from chronic diseases by 2015 and many of these deaths will occur prematurely, affecting the families and communities in which they are inserted. Besides the impact in physical and mental health, the chronic disease causes psychosocial repercussions, as the stigmatization/prejudice faced by the patient and his/her family, especially when the patient is a child.

Chronic diseases promote organic, psychological and social changes that require constant care (hospitalization included) and adaptation of the child and the caretaker. Among the pediatric chronic illnesses, refractory epilepsy, severe asthma, type 1 diabetes mellitus, obesity, skin diseases, cystic fibrosis of the pancreas, psychosis, skin disease, HIV encephalopathy, among others are studied.

In the case of epilepsy, very common chronic neurological disorder in childhood, often with emotional, neuropsychological, social, physical, educational, financial and quality of ife commitment, besides the strong stigmatizing factor (Schlindwein-Zanini, 2009a), it is estimated that there are 60 million carriers worldwide, playing an important impact in public health, a fact which met in 1997, the World Health Organization (WHO), the International League of Associations for Epilepsy and people with epilepsy around the project "Epilepsy Out of the Shadows "(Quagliato, 2006).

Among the pediatric chronic diseases, the respiratory and endocrine ones may also stigmatize and promote impact in public health, such as the severe asthma and diabetes mellitus type 1. In fact, asthma is responsible for approximately 2.2 million visits to the pediatrician each year, and is the leading cause of school absenteeism and hospitalization of children and can be fatal (Peyton Eggleston, 1998). The strategy of Integrated Management of Childhood Illness (IMCI), WHO and the Pan American Health Organization (PAHO), asthma was prioritized due to its magnitude in the composition of morbidity (PAHO, WHO, 2000). Type 1 diabetes, also chronic, has a rate of new cases in children increased by 3% per year, with many children with diabetes die of being diagnosed late or taking a wrong diagnosis (Brazilian Diabetes Society / IDF, 2007).

The term “stigma” has its origin from the Latin word stigma, and a synonym for stigma is scar or infamous mark (Ferreira, 1999). Stigma has notable implications for public health, as it is often experienced by people with mental or infectious illnesses (Weiss, Ramakrishna, 2006). The stigma is present in education and health, and it is a barrier to access to qualified education and health care (Quagliato, 2006). Stigma is a social process that plays a key role in increasing inequality and the violation of human rights (Garrido et al., 2009).

Considering the relevance of the issue, expected to result in increased occurrence database, in Scielo - SciELO - Scientific Electronic Library Online, for example, by seeking "stigma and public health" in Brazil, there were nine occurrences among texts related to adults and children, between the years 2006 and 2011.

On stigma, Schlindwein-Zanini et al. (2008) evaluated the perception of stigma in 94 subjects, children with intractable epilepsy and severe asthma (without comorbidities) and their caregivers with preserved cognition. Correlated the results of these chronic diseases, checking the possible differences in the perception of stigma among the two groups of children through the Stigma Scale (Child and Parent scale stigma stigma scale) and Weschsler Intelligence Scales (WISC III - version for children and WAIS III - version for adults, exclusion criteria). Analysis of variance showed that the perception of stigma is similar in both diseases, averaging 22.35 in children with epilepsy and 20.84 in those with asthma. Most of the children had scores on the scale of stigma among medium and high values, indicating that the perception of stigma is significant. Caregivers of children with epilepsy showed an average 15.35, 15.16 and those caring for children with asthma, pointing the same experience of stigma among caregivers.

The stigma sometimes can be observed by health professionals, estimated qualitatively, but can also be measured by instruments such as Perception Stigma Scale - EPE, the Stigma Scale and Parent Child Stigma Scale. Thus, Psychometrics, may also interact with other important areas of knowledge of psychology, such as Neuropsychology and Clinical Psychology and Hospital (Schlindwein-Zanini, 2009a).

We emphasize the importance of the various aspects that may have a chronic illness, including psychological and social repercussions that must be considered by professionals in the care of the patient and his family (Schlindwein-Zanini et al., 2008). In this sense, it refers to individuals who feel stigmatized may experience social isolation, concealing his illness from others, feel different from others, find that others may not like it, be sad when he talks about his illness with others, noting that

friends receive better treatment in relation to others, and suffer social prejudice (Schlindwein-Zanini, 2009a).

OBJECTIVES

·Review studies on the topic of stigma in children with chronic diseases and public health because of its relevance.

·Discuss about the stigma of chronic illness in children and public health, emphasizing the professional duties of Health Psychology in the context of chronic disease.

METHODOLOGY: CRITICAL REVIEW OF LITERATURE.

RESULTS E DISCUSSION

Health Psychology, chronic disease and stigma

Health Psychology aims to understand how biological, behavioral and social influence in health and disease (APA, 2003). Based on the model biopsychosocial, Health Psychology uses the insights of Biomedical Sciences, Psychology and Social Psychology Clinical-Community (Remor, 1999) seeking, as cites Matarazzo (1982) guided by the American Psychological Association - APA):

"The promotion and maintenance of health, prevention and treatment of disease and the identification of etiologic and diagnostic correlates of health and disease and related disorders. It also aims to analyze and progress of the health care system and the development of health policy"

That is why the work of the psychologist who is dedicated to the area of health takes into consideration the contact with other professionals, such as doctors, physiotherapists, physical educators, nurses and nutritionists, an essential conduct in this approach. This interdisciplinary may be done in various contexts: hospitals, community health centers, non-governmental organizations and at the homes of individuals. Thus, its interdisciplinary approach also provides a more complex way of understanding the problems and allows professionals to share the difficulties raised by the context. From the recognition of their own feelings and difficulties, the professional can be instrumental in establishing a more affective and less communication with the families assisted mechanical (Nieweglowski, Moré, 2008).

Thus, the psychologist who is active in the area of health can assess the chronic disease process (sometimes followed by death) of the child and their experience of stigma and their caregivers, which in turn may aggravate his/her cognitive and emotional condition. In this way, the APA (1999) defined the Pediatric Psychology as an interdisciplinary field for the physical, cognitive, social and emotional development, and the relationship with health and disease in children, adolescents and families, highlighting the global development of the child and adolescents.

INTERVENTION OF HEALTH PROFESSIONALS

The intensity that causes stigma may depend on variables such as type and severity of the disease, the psychic structure of the patient, the environment and the existence of adequate psychological care to the individual. Associated with these issues, there is the perception of the patient, family dynamics, tests, hospitalizations, medications, comorbidities, and disease progression (physical and / or mental) itself. It is in this context that the health professionals such as psychologists, physiotherapists, physical educators, etc are inserted.

The intervention of the psychologist is of paramount importance, considering that is a mental health worker, armed with procedures that allow, in addition to the psychodiagnostic and psychotherapy. This can promote, among other benefits, the reduction of the stigma associated with chronic illness perceived by the child who is affected. The psychological care can minimize the effect of stigma, collaborating with the improvement of the child's psychological condition. Whetten et al. (2008) cite, also, that stigma is linked to risky behavior and a poorer adherence to drug treatment.

The personal capacity to resist to the process of stigmatization and prejudice may be stimulated with the participation of patients in support and sharing groups. Planing the assistance with the participation of the patient can identify how services can contribute to slow down the effect of discrimination on the specifics of the daily life of each one, improving the quality of psychosocial care. Reducing the impact of stigmatization depends on actions in the legal (Garrido et al, 2009). Consequently, one should seek to promote policies and restructure health education adopted in the Unified Health System (SUS), so that this stigmatization and even the chronic lack of information to be fought (Silva et al., 2007).

The consequences and comorbidities linked to chronic illness in childhood (mood, memory nd attention disorders, anxiety, cognitive deficits, neurological damage associated with effects of the medication used for extended periods, for example), discrimination / stigmatization, social isolation, constitute a public health issue and require that the psychologist has, on the condition of the patient and his family, an understanding of clinical, neuropsychological, social, and above all, human.

Often we hear that "health is everyone's right." However, establishments, physical and financial resources are not sufficient to ensure health for all. There is a need for the presence of health professionals, to guide, enlighten, and "bring" the patient to be treated, and when he came, that can be received, heard without discrimination, to then be able to rely on the team and their therapy. There are patients with chronic disease crisis condition and their caregivers who are isolated in their homes for fear of being stigmatized. This would be one of the faces of a public health problem, leading to underreporting of health indicators.

Another consideration relates to the chronicity of these diseases and their social, educational, emotional, cognitive, organizational, financial and psychosomatic impact on the patients' lives, especially children, who, accompanied by a caregiver, usually the mother, often do not have access to a psychologist. The psychologist, in turn, can work these issues and link them to adherence to treatment (even when the prognosis is poor). In this case, the psychologist also serves as a conduit between the perception of the patient and the health team. Another facet of public health concerns, though, the high number of deaths (often premature) of individuals with chronic diseases, affecting many people (besides the patient's family) in different spheres - physical, mental, psychosocial (including on the stigma / discrimination) and cost - a fact that deserves attention from health policy.

In addition to the stigmatizing aspects already mentioned, one can note also polytherapy and drugs (including psychotropics), considering their side effects (eg, cognitive, aesthetic and motor coordination), bringing more serious complications for children's development.

Austin's research (1989) measured the conception of himself and behavior at home and at school of 128 children with epilepsy and 126 children with asthma, to compare differences in psychosocial adaptation. The results indicated that children with epilepsy experienced a significantly poorer psychosocial adjustment. The study Schlindwein-Zanini (2007) confirms these data, and highlights that chronic and limiting the tendency to link the bearer to experience some stigma.

Thus, questions about chronic illness in childhood and stigma are relevant to the interests of professionals in Health.

CONCLUSION

This article highlights aspects in the context of stigma and chronic pediatric health care network, as the existence of stigma in individuals with chronic diseases in childhood is a public health problem, children with chronic diseases with a condition of crisis tend to perceive stigma; diseases such as refractory epilepsy, severe asthma, type 1 diabetes mellitus, obesity, skin diseases, cystic fibrosis of the pancreas, psychosis, skin disease, HIV encephalopathy, among others, show live social, educational, emotional, organic, psychosomatic neuropsychological and financial, there is a need for research studies of stigma in children with chronic diseases related to public health.

Health professionals are important in the setting of mental health and collective health staff working in community centers, clinics, hospitals, primary health care and psychology of childhood and adolescence. Professionals should have an understanding of clinical neuropsychology, human and social condition of the patient and his family, the health-disease related to chronic illness and grief experienced by the patient and his family and respect them considering bioethical principles.

The need for global health care programs and public health policies aimed at children with serious chronic diseases are identified. And the psychologist in the health effects can substantially reduce the stigma of chronic diseases, in both patients and their caregivers.

Finally, we sought here a different perspective on the stigma in the lives of those with chronic pediatric stigmatization that this plan is not restricted to psychosocial or social education, but has an impact on related human health - if the problem, even if indirectly , public health, involving health institutions and its professionals.

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THE STIGMA IN CHILDREN WITH CHRONIC DISEASES: A MATTER OF PUBLIC HEALTH

ABSTRACT

The chronic disease is a disease with long-term emotional, neuropsychological and social sequelae, as the stigma, it may be incurable and cause restrictions to the patient and his/her quality of life, requiring then the psychologist in the treatment team. The aim of this research was the study of the relation among stigma, public health, Health Psychology and chronic disease in childhood; and also highlight the duties of the Health Psychologist professional in the chronic disease and it stigma context. The methodology was a critical review of the literature. The study brings the conclusion that the stigma in children with chronic diseases (as epilepsy, asthma, diabetes), is a public health issue. There is a tendency to see these problems as stigmatized, with socioeducational, neuropsychological, emotional, organic and financial repercussion. The health professionals area must have an global, clinical, human and social vision of the patient and his/her family situation, considering the total health and public health policies.

KEYWORDS: public health, chronic disease, stigma, public health policies, child.

STIGMATISATION DANS LES ENFANTS AVEC LES MALADIES CHRONIQUES: UNE QUESTION DE SANTE PUBLIQUE

RÉSUMÉ

La maladie est une maladie chronique avec séquelles à long terme affectif, neuropsychologique et sociaux, tels que la stigmatisation, des restrictions peuvent être incurables avec le patient et leur qualité de vie, nécessitant le psychologue du personnel de santé. Les objectifs étaient d'étudier la relation entre la stigmatisation, la santé publique, la psychologie et la maladie chronique dans l'enfance; mettre en évidence les tâches professionnelles de la psychologie de la santé dans le contexte des maladies chroniques et de sa stigmatisation. La méthodologie a été revue de la littérature critique. Il est conclu que la stigmatisation chez les enfants atteints de maladies chroniques (comme l'épilepsie, asthme, diabète), un problème de santé publique. Ils ont tendance à se voir stigmatisés, avec des répercussions sur le statut socioéconomique, neuropsychologiques, émotionnel, financier et organique. Les professionnels de la santé doit avoir une vision globale, clinique, la condition humaine et sociale du patient et sa famille dans les soins de santé totales et les politiques de santé publique.

MOTS-CLÉ: santé publique, maladie chronique, stigmatisation, politiques santé publique, enfant.

EL ESTIGMA EN NIÑOS CON ENFERMEDADES CRÓNICAS: UNA CUESTIÓN DE SALUD PÚBLICA

RESUMEN

La enfermedad crónica es una enfermedad de largo plazo, puede haber restricciones incurables con secuelas emocionales, neuropsicológicas y las sociales, como el estigma y su calidad de vida del paciente, entonces requiriendo al psicólogo en el equipo del tratamiento. La puntería de investigación era el estudio de la relación entre el estigma, la salud pública, la psicología de la salud y la enfermedad crónica en niñez; y también destaque los deberes del profesional del psicólogo de la salud en la enfermedad crónica y ella contexto del estigma. La metodología era una revisión crítica de la literatura. El estudio trae la conclusión que el estigma en niños con enfermedades crónicas (como epilepsia, asma, diabetes), es una edición de salud pública. Hay una tendencia a ver estos problemas según lo tachado, con la repercusión socioeducativa, neuropsicologica, emocional, orgánica y financiera. Los profesionales de area de la salud debe tener una visión global, clínica, humana y social del paciente y de su situación de la familia, en vista de la salud total y de las políticas sanitarias públicas.

PALABRAS CLAVES: salud pública, enfermedad crónica, estigma, políticas sanitarias públicas, niño.

O ESTIGMA EM CRIANÇAS COM DOENÇAS CRÔNICAS: UMA QUESTÃO DE SAÚDE PÚBLICA

RESUMO

A doença crônica é uma enfermidade de longa duração com seqüelas emocionais, neuropsicológicas e sociais, como o estigma, podendo ser incurável com restrições ao paciente e a sua qualidade de vida, necessitando do psicólogo na equipe de saúde. Os objetivos desta pesquisa foram estudar a relação entre estigma, saúde pública, Psicologia da Saúde e doença crônica na infância; destacar atribuições do profissional de Psicologia da Saúde no contexto da doença crônica e seu estigma. A metodologia foi uma revisão crítica da literatura. Conclui-se que o estigma em crianças com doenças crônicas (como epilepsia, asma, diabetes), é um problema de saúde pública. Elas tendem a se perceber estigmatizadas, com repercussões socioeducacionais, neuropsicológicas, emocionais, orgânicas e financeiras. Os profissionais da área de saúde devem ter visão uma visão global, clínica, humana e social da condição do paciente e da família, em atendimento à saúde total e políticas públicas de saúde.

PALAVRAS-CHAVE: saúde pública, doença crônica, estigma, política pública de saúde, criança.