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Assisted Education for Children with Chronic Diseases in Long Stay Hospitality

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***Keywords*— Assisted education, Hospital bed, Hospital pedagogy.**

***Abstract*—** *Some a priori criteria are fundamental in order to indicate an alternative for the educational assistance offered to hospitalized children with chronic pathology so that they can rely on systematic and recognized actions. In this sense, this qualitative research was carried out with health professionals and education professionals who perform this type of service. We can observe that the educator is given the role of looking for ways to identify how best to achieve the educational results of this person, parents and health professionals are emphasizing the importance of information about the child's chronic disease, observing the influence of the programs of education in a way that produces more benefits in terms of understanding and caring for children. Our focus is on understanding how the State should take the necessary measures so that the right to education of children with chronic diseases is respected and fulfilled. Since education is everyone's right, and far from any discrimination, hospitalized children must be able to take this right as a fundamental guarantee for their intellectual development. At the end of the study, we qualitatively evaluate the possibilities that such practices have in offering and providing the students with better and more modern conditions of study and, at the same time, knowing the teaching methods that allow an alternative form and effective education programs even though they are the patient undergoing medical care. From these premises.*

I. INTRODUCTION

Hospital beds are introduced as a teaching modality for Special Education, duly regulated by specific legislation (Resolution number 41, of October 13, 1995) which provides pedagogical-educational care for hospitalized children and adolescents. In view of this, it starts from the recognition that these juvenile patients, once they are away from the school routine as well as restricted from the common coexistence with colleagues, are under the threat of school failure and possible disorders to their development.

The objective of this study is to identify the needs related to these students in order to facilitate the implementation of proposals to improve education for children who experience long and repeated hospitalizations due to a chronic illness that presents intrinsic physical, mental and psychological characteristics during their stay.

Therefore, our study includes professionals who work with this group of students with chronic diseases in need of regular education, which is an extremely heterogeneous group in terms of different characteristics and needs. A common shared characteristic is their illness, which influences and determines their educational experiences.

II. DEVELOPMENT

ASSISTED EDUCATION

The MEC (Ministry of Education and Culture) established, during the year 1994, through the National Secretariat of Special Education, the responsibilities regarding the implementation of the due right to education of children and adolescents who are hospitalized, through the formulation of the National Policy of Special Education, which legally established the service of hospital classes.

Inclusion seeks to help vulnerable student groups. The current hospital stay limit for a patient with a chronic disease is approximately 12 months, although some doctors consider a duration of at least 3 months to be considered a chronic disease (Brasil, 2019). The literature indicates that in child hospitalization, the primary motivation for stimulating the child to develop.

> It is in the person who involves them, daily, in their care, whether for food, for hygiene, for playing, for a technical nursing procedure. The personal involvement of the caregiver transmits to the sick child the essential experience, the human contact (Bortolote, 2008).

In this context, educators seek and seek to adapt the planning of regular content in classes peculiar to students, so that they can assist them in their school reintegration as soon as hospital discharge is granted.

According to the definition provided by the WHO (World Health Organization), we judge chronic diseases as “long-term diseases” and, in general, “under slow progression”, with the development of the disease producing disturbing situations that affect aspects of the disease. medical, psychological, social, family and educational

The school education of children hospitalized with chronic diseases indicates that this should be an ongoing objective when providing educational assistance to these students and that this intervention requires a significant change in the institutional curriculum.

However, teachers must have information about their students' illnesses and effective ways to respond and address their students' physical and academic needs.

Schools should offer more options and more influential avenues for the participation of parents and health professionals who make up the clinical staff in daily activities in hospitals, as collaboration between parents, teachers and health professionals facilitate the development and greater trust between them. different groups, this collaboration being effective in improving and covering the attention dedicated to students with chronic diseases.

As for teachers, they need the support of other professionals involved in the daily activities of hospitals (nurses, nursing technicians, physiotherapists, etc.). This support should address the needs related to the patient with chronic diseases that arise in the hospital environment, providing clear definitions of health and its limitations.

Teachers need administrative support from hospitals to facilitate the fulfillment of their care for students with chronic diseases. This support must be provided through an attitude of commitment, trust and information, with relationships involving communication and collaboration which must be established between schools and hospitals that can offer information and support for needs that may arise during follow-up.

When programming these practices, it presupposes the establishment of an inclusive model of schools as a whole. In this model, all students with chronic diseases, regardless of their individual characteristics, conditions and abilities, can participate and learn. Furthermore, differences are not a basis for discrimination, but rather generate acceptance, respect and improvement.

III. HOSPITAL BED IN BRAZIL

At the beginning of the 20th century, according to Barros (2011 p.20), when the diseases of misery (such as leprosy, tuberculosis and syphilis) were barely differentiated from mental insanity, it was a vanguard attitude to distinguish, within the asylum, the asylum for children . The historical rescue of the Bourneville School Pavilion is relevant for this study, which add memories to the chronology of schooling in hospitals in Brazil. The Bourneville School Pavilion for Abnormal Children, from the National Hospice for the Insane in Rio de Janeiro, founded in 1902 and extinguished in 1942. In Brazil at the beginning of the 20th century, it was a common practice for children to be hospitalized in asylums. Partly for economic reasons,

The origin of the possible hospital class in Brazil being linked at the same time with the origin of special education in our country, asylums for the insane help to understand the belonging to which schooling in hospitals was framed when it finally became regulated as a teaching modality .

Thus, the same 1930s of the 20th century anticipated the closing of the Bourneville Pavilion, announcing the emergence of the first, officially recognized, special

classes in the wards of the Santa Casa de Misericórdia de São Paulo.

The educational service created in 1600 in the Irmandade da Santa Casa de Misericórdia, in São Paulo, according to Caiado (2003 p.73), was destined to the school attendance of the physically handicapped. It was found in the archives of this hospital annual reports of the school movement of students with physical disabilities (non-sensory) dating from 1931. Professor Lourenço Filho was Secretary of Education of the City of São Paulo in 1931. In 1932 another special class was created, as Escola Mista do Pavilhão Fernandinho. In 1948, according to Mazzotta (2003 p.39), a third class was installed with the appointment of Professor Francisca Barbosa Félix de Souza who remained until her retirement in of March 1980. In 1982, ten special state classes were operating at the Santa Casa de Misericórdia Central Hospital in São Paulo. technically, these classes all function as hospital classes or, still, configuring the "hospital teaching" modality, that is, each teacher has an individualized care schedule for students who are patients in the hospital. Despite having started in the 1930s, it was only after 1953 that more accurate records were found.

The right of the Brazilian hospital class was recognized by the Declaration of the Rights of Hospitalized Children and Adolescents (Resolution number 41, of October 13, 1995, of the National Council for the Rights of Children and Adolescents) due to the concern of the Brazilian Society of Pediatrics in mapping the set of care needs for children or adolescents who need health care in hospital settings.

The Ministry of Education and Sports formulates the National Policy for Special Education (MEC, 1994), proposing that education in hospitals be carried out through the organization of hospital classes, ensuring that education is offered not only to children with developmental disorders, but also to children and adolescents at risk for development, as is the case of hospitalization, since hospitalization determines restrictions on coexistence relationships, on interactive school social opportunities (relationships with colleagues and learning relationships mediated by a teacher) and the intellectual export of social life environments (Fonseca, 1999).

According to the National Constitution (BRASIL, 1988), the Statute of Children and Adolescents (BRASIL, 1990), the Organic Health Law (BRASIL, 1990) and the Law of Guidelines and Bases for Brazilian Education (BRASIL, 1996), health care must be comprehensive (promotion, prevention, recovery, etc.) and school education must be in accordance with the special needs of students (OLIVEIRA, 2004).

Seeking to adapt to the legislation in force, the MEC, through the Secretariat of Special Education, proceeded to review its documentation regarding strategies and guidelines for pedagogical work for people with special needs (Fonseca, 2003). From this review, the area of teaching hospital care and home care now have a publication that regulates these types of care called: Hospital Class and Pedagogical Home Care: strategies and guidelines (BRASIL, 2002). This document aims to structure and promote the provision of pedagogical care in hospital and home environments in order to ensure access to basic education and attention to special educational needs.

IV. PEDAGOGY OF THE HOSPITAL CLASS

It is known that chronic diseases translate into great difficulties for patients, as well as for their families and also for the health system, as they tend to cause certain limitations in capacities, responsibilities or even social roles, which are essential. medications, specific diets, medical procedures, assistance and supports, as well as the personal intervention carried out by caregivers and professionals from the diverse fields of health. Even more, and according to the specifications of the Ministry of Health, obstacles can arise in terms of the adaptation of students and teachers, either due to deficiency in cognitive capacity, or learning losses caused by the inability to attend school (Saúde, 2013).

The preparation of teachers and their relationship with health personnel are essential to the education these students receive. The quality of student teaching is in the hands of the teacher. However, because of the close relationships that students with chronic illnesses develop with their nurses, the characteristics of each child and their associated illness are often better understood by these professionals than by their teachers. Often, families maintain a more direct relationship with health professionals than with their child's educator. For this reason, it is important to establish the role of each professional in the context of the education of children with chronic diseases.

Therefore, Darela MS (2007), deduces that even offering care for diseases, sometimes incurable, in a deep relationship of connection with life, the health team has the possibility of restoring, in addition to the organism, the forgotten subjectivity of the child, as they undertake comprehensive care behaviors. In the context of children, chronic diseases have long durations and seriously

compromise daily life and therefore require intensive and lasting treatment.

The temporary threshold for caring for and treating a chronic illness is approximately 12 months, although some doctors consider illnesses lasting for at least 3 months to be part of the list of chronic illnesses. When a prolonged illness appears in a school-aged child, the affected student can fall far behind even before 3 months if proper actions are not taken. Educating a child who experiences long and repeated hospitalizations and who presents physical, mental and psychological characteristics during the appearance, course and feeding of the disease can produce disturbing situations that affect medical, psychological, social, family and educational aspects.

According to Leal (2009), another way found by families as a means of facing the diagnosis of their child's chronic disease is familiarization and acceptance of the diagnosis. Therefore, such factors are associated with the uniqueness of the people involved, as well as the real state of the disease and the context in which the disease occurs. In this way and so that treatment and education occur in a synchronized and adequate way, it is necessary to emphasize that health professionals and educators clarify doubts, demystify myths and offer support to each other, since the emergence of a disease almost always appears as a shock to the values, habits and beliefs of families.

The school is the fundamental place for the student to meet systematized knowledge. However, in order to enable pedagogical and educational follow-up and guarantee the continuity of the school procedure for children and young people in regular education, guaranteeing the conservation of the connection with the school of origin, through a flexible and adapted curriculum of the teaching action, a differentiated reception program to children and young people admitted to Hospitals, who need special educational support, so that they do not lose their connection with the school, offering systematic and differentiated care, within the scope of Basic Education, individual or collective in Hospital Class or in bed, according to the needs of the student who is unable to attend school provisionally. In addition to an environment suitable for the Hospital Class,

According to Ceccim and Carvalho (1997) the perception that, even when sick, the child can play, learn, create and, above all, continue to interact socially, often helps in the recovery, so the child will have a more active attitude towards the victim through the situation. In this way, we can highlight two forms of pedagogical follow-up: occasional hospitalizations and recurrent or extensive hospitalizations.

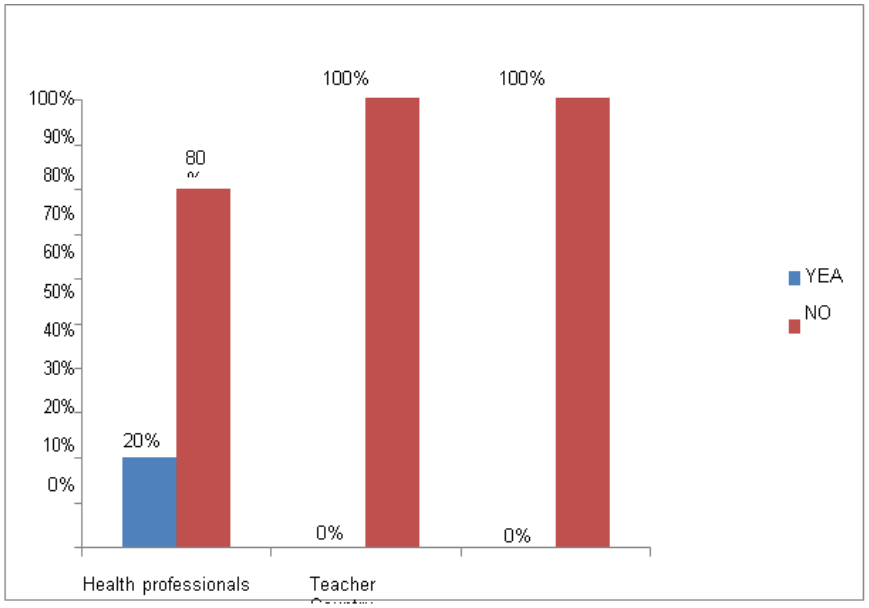
The creation of teaching and learning classes in hospitals is the result of public policies and studies resulting from the consideration of the educational needs of children who require hospitalization, whether short or long term. So that, throughout this chapter, it is about this pedagogical space that has been constituted by its excellence and urgency, in Brazilian society.

A hospital educational care program comprises a set of educational support actions that are carried out in the hospital for the care of the student who, due to illness, cannot attend school for a while due to his stay in the hospital. Winnicott (1999) warns for the importance of the bond between the child and the person who cares for him or interacts with him. The author draws attention to the fact that there is always a relationship of dependence between individuals. For the author, individual isolation would be harmful to health, to the point of feeling independent and vulnerable. In this line of reasoning, if this person is alive, without a doubt, there is dependence on the family or on the members of the health team who provide care. According to this line of thought,

V. DATA ANALYSIS

To obtain the results, the interviewees answered a questionnaire containing 10 (ten) questions. Fifteen (15) people were interviewed, being 05 health professionals residing in the municipality of "President Kennedy" ES, and 05 (five) parents of students who attend the Pestalozzi Institution of Presidente Kennedy -ES, 05 teachers who provide service at the Institution President Kennedy–ES Pestalozzi.

The information obtained in the questionnaires allowed guiding a greater analysis of the subject addressed. The responses made it possible to analyze and prepare the comparative graphs, as expressed below:



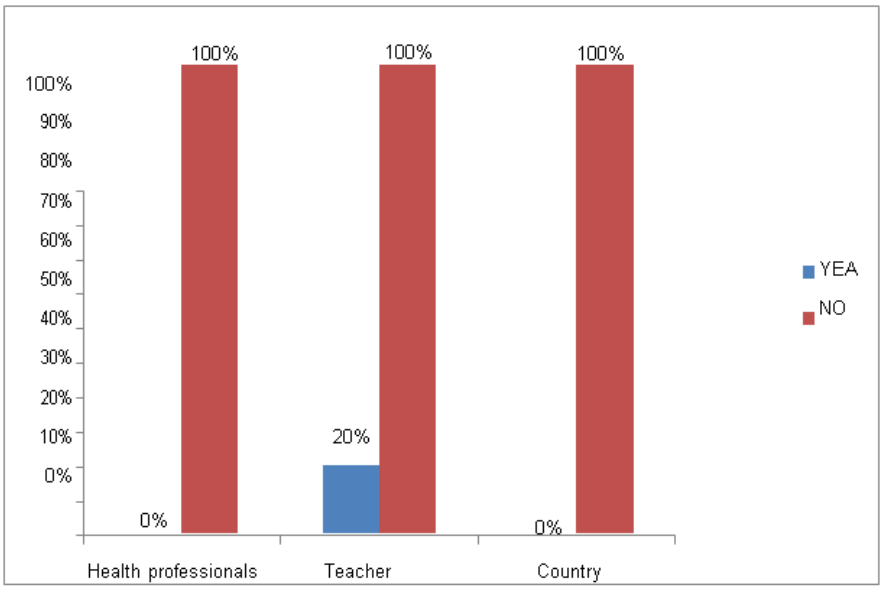
Graph 1: Do you know the rights of students who are in a hospital bed?

Source: Material produced by the author to illustrate the research..

The first question questions the level of knowledge of the interviewees on the subject addressed, it is observed that the lack of information regarding the legislation is 100% in relation to teachers and parents, who are directly in contact with the student in the patient situation. (Graphic 1).

Health professionals, when approached, report that they do not know the legislation and most are unaware of the subject and also do not see the need to worry about the legislation, they believe that parents should seek to know to carry out the collection. When we ask the teachers, everyone knows that there are laws that guide the hospital class, however, they did not bother to study the subject, they prefer to leave it to the school manager so that they can solve it with the family. Regarding the parents surveyed, they do not have any knowledge, they did not know that there was this right, they were informed that they would need to present certificates to justify the absences, and the content was delivered in the form of a handout, where there was a deadline for return, that is, , there is no pedagogical monitoring of these students,

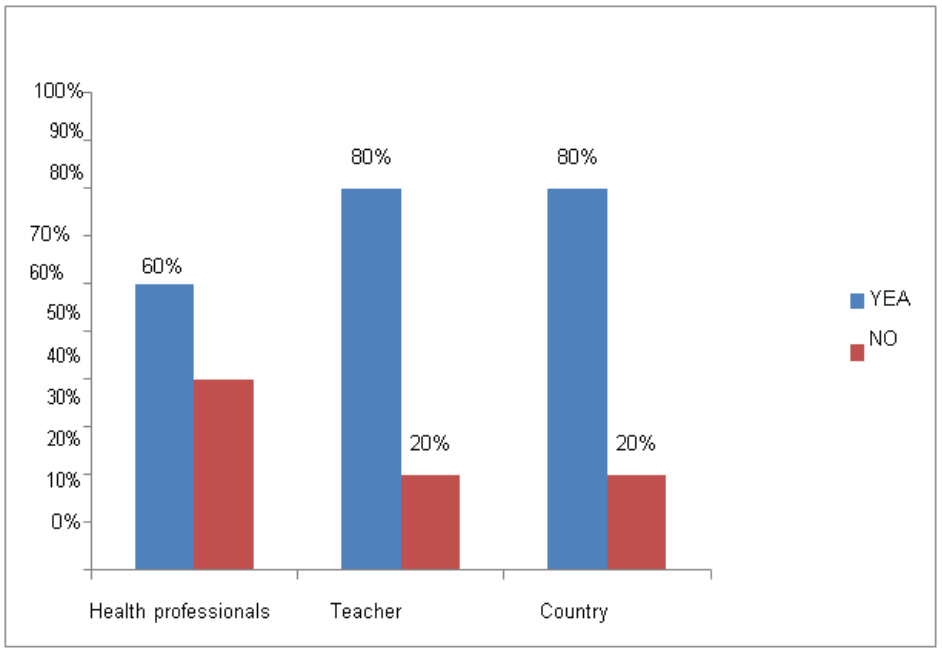
When addressing the knowledge of patients in the municipality who need a hospital class, the answer was as follows:



Graph 2: In your city, have you ever witnessed any assistance to students in hospital beds?

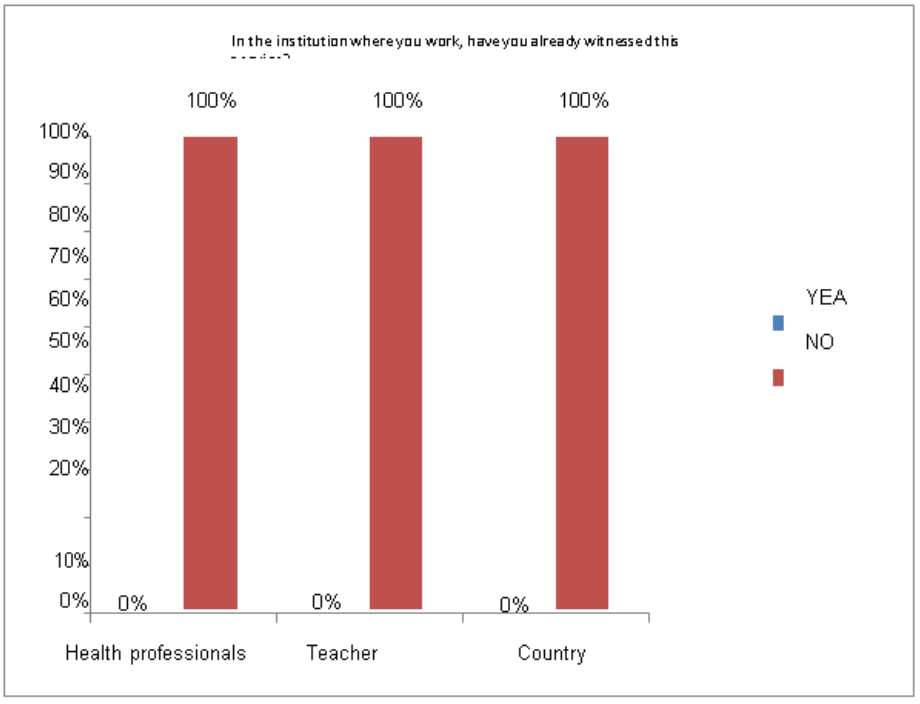
Source: Material produced by the author to illustrate the research.

It is observed that the health professionals who were the agents of the research and the parents in question agreed that they had never been aware of students in the municipality receiving care in a hospital class. Among the teachers, 20% said they knew of a case in the municipality of hospitalization with follow-up of the hospital class, but the majority of the interviewees claimed not to know of any case in the municipality. (Graph 2)



Graph 3: Do you know4 someone in your municipality who would have this right to care?

Source: Material produced by the author to illustrate the research.



Graph 4: In the institution where you work, have you already witnessed this service?

Source: Material produced by the author to illustrate the research.

As can be seen in Graph 3, the interviewees claim to know someone who needs educational assistance in a hospital bed, as was to be expected among health professionals the identification is lower 60% know someone, among teachers and parents the information reaches 80% of respondents. (Graph 3)

It is noticed that unfortunately people become aware of the problem, but do not make it possible to solve it. Hospital Educational Assistance should be collective actions, involving the family, the school, the multidisciplinary team, the municipal and state Department of Education and the philanthropic unit. Thus, it moves the construction of pedagogical-educational strategies that contribute to improving the student's clinical condition, ensuring that their rights are preserved in this moment of fragility caused by the disease. The main thing is that this change of view makes us see our children and adolescents clearly and, therefore, makes it possible to increasingly focus on them, on their interests, needs and possibilities.

We also address the fact that the interviewees have ever witnessed this service at the institution they work for:

In Graph 4, we can see that all the interviewees have never witnessed this service in the municipality, which makes us reinforce that despite such importance, Educational Hospital Service has been a topic of little prominence, especially in relation to the urgency of ensuring the implementation of classes. hospitals in all institutions, guaranteeing universal education coverage for all children and adolescents, according to their conditions and possibilities.

Therefore, given that the equal right to education in the hospital environment, in addition to being a social issue, is a public health issue, it becomes contradictory not to find these Hospital Classes in the context of most hospitals, that is, there is a contradiction in relation to what is guaranteed or provided for in the legislation. Thus, the concerns that led to the study of this topic begin with the realization that a child's development cannot stop due to hospitalization.

VI. FINAL CONSIDERATIONS

From this research, it was possible to verify that the great challenge of the hospital class is information, discovering the true meaning of the hospital class is to go beyond the previous knowledge that one hears about. It is important to know the current legislation and how to use it in practice to favor those who need this type of care. Much is said but little is done. We were surprised that when we searched for information relevant to the subject, we came across a lack of preparation and knowledge to discuss the subject.

Hospital classes are essential nowadays, since we live in a globalized world, where access to information is a channel of knowledge for everyone, although we still have people who settle down and do not seek the rights of their children, thus, in this perspective that, we seek to understand the hospital environment considering its educational interfaces in the face of the challenges in the teachers' performance, as well as the possibilities and confrontations in favor of the health of the child in treatment, in an approximation with teaching-learning.

Children and adolescents, due to their current health condition, are unable to share the intellectual social experiences of their family, their school and their social group. to families, since the health status of their children makes parents worried, causing them to forget the children's studies, prioritizing hospital treatment, for not knowing or not understanding that the association of health with the educational and recreational process accelerates the process of recovery, promoting early hospital discharge and the continuity of the minor development.

Proof of this was the study carried out by Fonseca (2003), which shows that, in addition to providing the guarantee of the right to continue their studies, so that they are not harmed in their schooling, the Hospital Class also contributes to their improvement within your clinical picture.

We noticed, through the statements of the interviewed teachers, that, even though the need for pedagogical support in the hospital is recognized, resistance is still high, as greater value is attributed to clinical practices.

Hospital pedagogy shows its relevance in this process as it makes it possible to think about the school process in the hospital context, in the perspective that does not leave aside attention to organic aspects, to health care, but carries investment in education. This movement goes beyond supplying the absence of school content, it is the process that invests in the continuity of life.

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