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Resilience in adolescents suffering from non-communicable diseases: a cross-sectional study

Resilience in adolescents suffering from non-communicable diseases: a cross-sectional study

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ABSTRACT

Aims: identify the conditions under which hospitalized adolescents suffering from chronic non-communicable diseases are resilient and; identify the major protective factors which provide resilience to disease in adolescents. **Method:** this is an exploratory, cross-sectional study, in which a quantitative approach was employed. Scenario/Institution: Pedro Ernesto University Hospital. Target subjects: Adolescents, aged 10 to 19 years, hospitalized, suffering from chronic illnesses. The *WHOQOL–Bref* test was used as a data collection tool; SAS 9.1.3 statistical software was used for data analysis. **Results:** factors within the psychological domain and '*overall*' were more significant. Furthermore, the most frequently identified protective factors were ones based on individuals themselves, as well as factors related to support and the patient's environment. **Conclusion:** life experiences and the ways in which teenagers see the world strongly influences the way they face adversity. Thus, it is essential for healthcare professionals, to be sensitive to and prepared for dealing with the specific demands of teenager patients and their disease processes.

Descriptors: Resilience, Psychological; Adolescent, Hospitalized; Chronic Disease.

INTRODUCTION

The concept of resilience is surrounded by various ideologies, related to the notion of success, and adaptation to new social circumstances. In medicine, the term means the ability of a subject to resist a disease, infection, intervention on his own or with the help of medication[1]. In psychology the term resilience is equated with the terms invincibility and invulnerability[2]. However, resilience and invulnerability are not equivalent terms. Resilience is "the ability to overcome adversity, this does not implicitly mean that the individual leaves the crisis unscathed, as the term invulnerability implies"[3].

With the advances in research within this area, we see that there are no invincible people and that resilience is not an unchangeable set of characteristics displayed by individuals. It is the result of a dynamic process that involves social and the intrapsychic factors of vulnerability and protection[4].

Thus, resilience is not an innate quality of special people. It is in fact a type of personal and social competence that can be learned, developed and promoted within people, organizations, communities and even in a broader social contexts[1].In this context, the development of this ability is a result of a combination of the individual attributes of children or young people, and their family, social and cultural environments. It appears to be an interaction between the person and the environment[5]. It is a dynamic interplay between the factors which help individuals to overcome adversity (protective factors) and factors which, hinder (vulnerability factors), whether external or internal. Overall, vulnerability factors include unfavorable life events and protective factors are forms of both internal and external support. These protective factors provide resilience and allow one to cope with adversity.

Protection processes have the essential characteristic of causing modifications of the responses of an individual to risk processes. Four major functions of these processes can be highlighted: (1) to reduce the impact of risks, a factor that increases the exposure of the person to adverse situations; (2) to reduce negative chain reactions that follow the individual's exposure to situations of risk; (3) to establish and maintain self-esteem and self-efficacy, by establishing safe attachment relationships and allow the successful fulfillment of tasks; (4) to create opportunities to reverse the effects of stress[5]. It is possible, therefore, to understand the resilience of the individual through their position and their actions in the face of negative life situations. Thus, when a teenager has a health condition and needs to be hospitalized, a stressful situation arises, in which both adolescents and their families are placed under pressure.

However, adolescents are considered resilient and are expected to use regulation strategies, which include the ability to change their behaviors, feelings and emotions to react and adapt to the contexts into which they are inserted[6]. Thus, it is expected that the teenager will regulate their emotional state and adhere to the recommended treatment, in the hope of curing their condition or prolonging their life expectancy.

Adolescence itself is considered to be a phase of major conflict, where there is an internal imbalance within young people. It is a time of weakness in which, in addition

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to the bodily changes, modifications in the individual's socio-cultural context occur[7].

All these factors alongside beliefs, values, customs (i.e. culture) determine how the adolescent perceives, relates to others and guides their life towards adulthood[8]. The discovery of a chronic disease at this stage of life can complicate matters, as the chronicity itself refers to episodes of exacerbation of symptoms and undesirable conditions of pathology, such as pain and fear of death. Chronic non-communicable diseases represent a worldwide problem. In Brazil, they account for 72.0% of deaths, particularly circulatory diseases (CHD) (31.3%), cancer (16.3%), diabetes (5.2%) and chronic respiratory disease (5.8%)[9].

In this sense, it is worth emphasizing the importance of social support networks and healthcare teams, in providing emotional support and assistance with disease control, as the control of symptoms can have a very positive impact on the way teenagers face the problem.

In this time of broad, deep and accelerating changes, systematic knowledge concerning resilience could provide a valid and effective instrument for all those who intend to improve their professional performance.

This work aims to: identify factors concerning resilience in adolescents hospitalized with chronic non-communicable diseases and; to discuss the main protective factors used in assisting adolescents in relation to the damage caused by these diseases.

METHOD

This is an exploratory, cross-sectional study that is part of a research project entitled "Study on resilience in adolescents with chronic non-communicable diseases." The project was conducted in the Infirmary Aloysio Amâncio da Silva, Adolescent's Health Study Center (AHSC), Pedro Ernesto University Hospital (PEUH), Rio de Janeiro. This study had the support of the National Council for Scientific and Technological Development (CNPq, in Portuguese).

The target subjects of this research were adolescents who suffer from some type of chronic disease, in accordance with the World Health Organization's guidelines. Inclusion criteria: adolescents between 10 and 19 years of age, of both genders, with a medical diagnosis of any chronic non-communicable disease who were admitted to the hospital and agreed to participate in the research by signing the consent form. In the case of minors, the legal guardian is the one who must give consent.

Exclusion criteria: adolescents who are unable to respond the questionnaire due to psychiatric disorders or any disease that prevented speech or writing. Data collection was performed in April 2013. We used the WHOQOL-Bref questionnaire as a data collection instrument. The short version of the questionnaire contains 26 questions divided into four domains: physical, psychological, social relationships and environment.

The issues of domain 1 (physical) correspond to pain and discomfort (question 3); dependence on medication or treatments (question 4); energy and fatigue (question 10); mobility (question 15); sleep and rest (question 16); the activities of daily living (question 17) and; work capacity (question 18). The issues of domain 2 (psychological)

correspond to positive feelings (question 5); thinking, learning, self-esteem (question 6); memory and concentration (question 7); body image and appearance (question 11); negative feelings (question 19); spirituality, religion and personal beliefs (question 26).

The issues of domain 3 (social relations) refer to personal relationships (question 20); social support (question 22) and sexual activity (question 21). The issues of domain 4 (environment) include physical security and protection (question 8); physical environment: pollution, noise, traffic and climate (question 9); financial resources (question 12); opportunities for acquiring new information and skills (question 13); participation in recreation/leisure and opportunities for taking part (question 14); home environment (question 23); health and social care: accessibility and quality (question 24) and; transportation (question 25). Finally, fundamental issues such as perceptions of life quality (question 1) and; satisfaction with health are assessed (question 2).

After collecting data, an analysis of the domains and categories was performed; using the answers to the questionnaire by SAS 9.1.3 statistical software. First, we performed a calculation of the scores for each question; this was performed according to the syntax of the World Health Organization. After this a transformation was carried out, we applied a basic statistics for the quality of life in each domain.

Subsequently, an analysis of variance (ANOVA) was carried out using a multiple regression model with 5% significance to analyze the degree to which each area explains the answers to individual questions. This method presents two tests, the F-test and Student's t test.

Multiple regressions were also used to analyze the relationship between the variable gender and the domains. Furthermore, we applied an F-test for the total of each patient for each domain in order to check which areas were most significant.
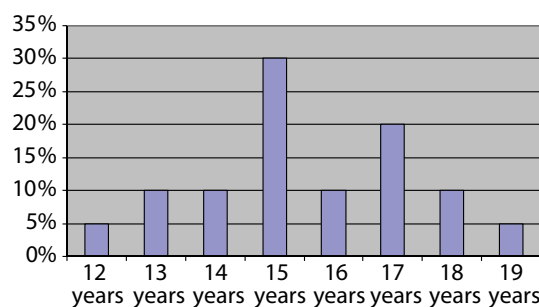
This study was approved by the Ethics Committee of Research at the State University of Rio de Janeiro under the Protocol number CEP/HUPE 2690/2010 and CAAE 0134.0.228.258 – 10, in accordance with the Resolution 196/96 of the Brazilian Health Council.

RESULTS

Twenty adolescents participated in this research, ten of whom were female. Educational levels were distributed mainly amongst the elementary school (50%) and high school levels (45%). There was only one patient in higher education (5%).

Graph 1 shows the distribution of subjects according to age, in which it can be observed that the participants are between 12 and 19 years of age.

Graph 1. Distribution of the subject according to age. Rio de Janeiro, 2013

Source: Prepared by the authors, 2013

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Graph 2 shows the distribution of subjects by chronic non-communicable disease. There is a high incidence of cancer patients suffering from systemic lupus erythematosus.

Graph 2. Distribution of the subjects according to chronic non-communicable disease. Rio de Janeiro, 2013
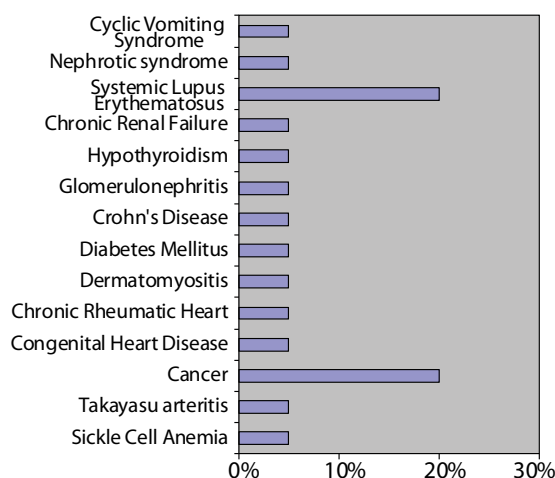
Source: Prepared by the authors, 2013

Table 1: Descriptive statistics of domains 1, 2, 3, 4 and *overall*. Rio de Janeiro, 2013

Variable	Average	Standard Deviation	Minimum	Maximum
Domínio 1	58,75	12,179	42,8571	89,2857
Domínio 2	59,5833	13,9901	29,1667	79,1667
Domínio 3	74,1666	14,281	50	100
Domínio 4	63,2812	16,7482	28,125	93,75
Overall	80	17,631	31,25	106,25

Source: Prepared by the authors, 2013

Observing Table 1, we can conclude that domain 3 showed the highest average score (74.1666), maximum (100) and minimum (50). Domain 1, had the lowest average score (58.75) and the lowest standard deviation (12,179).

Table 2: raw data for the application of the multiple regression model to the issues as related to the domains. Rio de Janeiro, 2013

Variable	Model	Domain 1	Domain 2	Domain 3	Domain 4	Overall
1	0,0457	0,2325	0,9752	0,7828	0,4777	0,0062
2	0,0007	0,2325	0,9752	0,7828	0,4777	0,0005
3	0,2677	0,3219	0,049	0,2133	0,2142	0,8321
4	0,8253	0,2682	0,8267	0,9185	0,6046	0,3943
5	0,0004	0,1522	0,0002	0,1433	0,9184	0,653
6	0,1604	0,0995	0,0651	0,2264	0,4798	0,5693
7	0,0044	0,8176	0,0007	0,1358	0,6524	0,5216
8	0,0015	0,0255	0,3089	0,1103	0,0022	0,1013
9	0,2307	0,9557	0,8638	0,8141	0,2396	0,4926
10	0,0091	0,0935	0,0342	0,9637	0,8335	0,3017
11	0,8563	0,6479	0,5563	0,7668	0,8542	0,5738
12	0,0143	0,3455	0,3828	0,0677	0,4336	0,022
13	0,0707	0,5124	0,9572	0,4159	0,0054	0,2428
14	0,0004	0,4984	0,0032	0,2357	0,0101	0,1527
15	0,2292	0,8231	0,2751	0,6909	0,6481	0,8014
16	0,0322	0,2298	0,8594	0,6237	0,4961	0,1286
17	0,0001	0,088	0,0403	0,1963	0,2313	0,0282
18	0,7053	0,21	0,6426	0,454	0,7367	0,7416
19	0,0137	0,6801	0,0434	0,4291	0,1685	0,4128
20	0,001	0,2773	0,71	0,0031	0,1934	0,5684
21	0,4324	0,8085	0,8352	0,1913	0,5897	0,6883
22	0,1549	0,6995	0,9985	0,0842	0,8289	0,4676
23	0,109	0,8112	0,0876	0,5785	0,1117	0,8959
24	0,0434	0,1396	0,724	0,7736	0,8679	0,1493
25	0,033	0,7684	0,8905	0,0427	0,0027	0,1178
26	0,5835	0,7895	0,1331	0,6814	0,4982	0,9239

Source: Prepared by the authors, 2013

After analysis of Table 2, we note that at least one of the domains explains issues 1, 2, 5, 7, 8, 10, 12, 14, 17, 19, 20 and 25. The '*overall*' domain with p- value (0.0457) and (0.0007) explains, respectively, the variation of the responses to questions 1 and 2.

It is observed the domain 2, with a p-value of 0.0002 explains question 5 and 7, with a p-value of 0.0007, and question 19, p-value of 0.0434.

From an analysis of domain 3, we can suggest that this domain explains answers to

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question 20 with a p-value of 0.0031.

As for domain 4, we can state that this explains the four variables contained within it: variable 8, 13, 14 and 25 are explained (p-values of 0.0022, 0.0054 0.0101 and 0.0027 respectively).

It is notable that some variables, as well as being explained by their domains of origin, can be explained by other domains. This situation can be found in relation to questions 3, 8, 10, 12, 14, 17 and 27.

The variable 3, it is not explained by its domain of origin (1) but is explained by domain 2 (p-value of 0.049) because its answer may relate to some psychological factor. Variable 8 is explained not only by domain 4 (its origin), but also by domain 1, because there may be some physical factors at play as well as the relationship with the environment. Variable 10, which is not explained by variable of origin, can be explained by domain 2 (p-value of 0.0392) due to an indication of relationships to psychological aspects. Variable 12, is not explained by its domain of origin (4), can be explained by the *overall* domain (p-value of 0.022). Besides being explained by domain 4, variable 14 can be explained by domain 2 (p-value of 0.0032). Variable 17 cannot be explained by its domain of origin (1), but is explained by domains 2 and the *overall* domain (p-values 0.0403 and 0.0282, respectively).

Variable 25 is explained by its domain 4 and can also be explained by domain 3 (p-value of 0.0427). This may be a strong indication of the relationship between the environment and social relationships.

Finally, it is observed that variables 16 and 24 are significant, but no single domain explains them. This may have occurred because, despite being an effective model, the domains were not sufficient to explain the responses obtained to the specific questions.

Table 3: Multiple Regression of the gender variable, in relation to the domains. Rio de Janeiro, 2013

Varia-ble	Mo-del	Do-main 1	Do-main 2	Do-main 3	Do-main 4	Ove-rall
Gen-der	0,805	0,5437	0,7331	0,8095	0,451	0,4425

Source: Prepared by the authors, 2013

Table 3 demonstrates that no domain explains the gender variable.

Analyzing Table 4, we note that all domains have a p-value of lower than 0.05, which shows there is a strong indication that the correlation coefficient is different from 0 and thus the variables may be correlated. This is except for domains 2 and 3 in comparison to the *overall* domain (p-values of 0.1049 and 0.2341). In fact, most of the variables has a

Table 4: Table of correlation analysis between domains according to p-value (correlation coefficient). Rio de Janeiro, 2013.

	Domain 1	**Domain 2**	**Domain 3**	**Domain 4**	**Overall**
Domain 1	1	0,52080(0,0185)	0,68356(0,0009)	0,75378(0,0001)	0,53508(0,0151)
Domain 2	0,52080(0,0185)	1	0,56345(0,0097)	0,45773(0,0424)	0,37341(0,1049)
Domain 3	0,68356(0,0009)	0,56345(0,0097)	1	0,69051(0,0008)	0,27871(0,2341)
Domain 4	0,75378(0,0001)	0,45773(0,0424)	0,69051(0,0008)	1	0,53958(0,0141)
Overall	0,53508(0,0151)	0,37341(0,1049)	0,27871(0,2341)	0,53958(0,0141)	1

Source: Prepared by the authors, 2013

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coefficient of correlation greater than 0; the highest between the domains 1 and 4 have a correlation coefficient of 0.75378.

DISCUSSION

This study observes that participants were more satisfied with regard to life quality and health status, and more dissatisfied with respect to the physical factors. This body dissatisfaction, although increasingly common in society in various age groups, is higher among adolescents and possibly a result of the biological and psychosocial changes, characteristic of this life stage[10]. Corroborating this finding, a study performed with adolescents found a high prevalence of body dissatisfaction amongst the participants, without a difference between genders[11].

Another finding was that the relationship between pain and discomfort in terms of the psychological domain. This showed that the perception of pain may have some psychological basis. This relationship emphasizes the subjective aspect of the condition of each individual, this changes the way adolescents see their disease, pain and its consequences. This situation is heavily dependent on what perceptions each patient has concerning the trauma they are suffering. Likewise, there is an association between energy and fatigue in terms of the psychological aspects of patients, reinforcing the idea that adolescent's worldview influences their approach to adversities in life.

A relationship between patient's participation in and opportunities for recreation/leisure was found with the environment and the psychological domain. This indicates that the opportunity for and participation in leisure activities are closely related to the patient's environment. They also relate to one's motivation to participate in these activities, which directly involves psychological aspects. The way an adolescent perceives and deals with their problems is strongly related to the development of their resilience. Resilient individuals are people who can reframe feelings and negative experiences, minimizing their impact and building some aspects of their character from these experiences[12]. There was also a statistical relationship between the availability of financial resources, life quality and health satisfaction. A lower socioeconomic status may be considered a risk factor demonstrating the possibility of problems related to drug use, violence and the maintenance quality of life[13]. However, the impact of social status is possibly determined by the perceptions of each individual. Thus, a specific event can mean an experience full of negative feelings for a person or lead another person to mature and grow as an individual.

A study conducted in Brasilia, DF; with 852 young people and adolescents, found that despite a low socioeconomic status; the presence of support networks involving family, school and friends contributes to an increase in resilience. Minimizing the impact of this risk factor[13]. It is noteworthy that some factors widely described in the literature as being important in facing adversity were not statistically significant. This may be due to the fact that although the instrument was effective it was not powerful enough to recognize these aspects.

Another possibility is the participants may have not entirely understood the ques-

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tions posed by the questionnaire. This is possible as some of the youngsters in the sample were only at the elementary level of school.

Issues discovered not to be statistically significant in this study comprised: self-esteem, physical environment, ability to accept physical appearance, ability to get around, work capacity, support received from friends and spirituality, religion and personal beliefs. Self-esteem was not discovered to be a statistically significant factor; however, its relation to the process of resilience is widely accepted in the literature. Studies indicate that the development of resilience is linked to an ability to self-regulate and control levels of self-esteem[14]. The patient's physical environment also determines how the individual confront adversity, as resilience can be defined as an interaction between genetic and environmental factors[5]. Despite the fact that its relevance is not confirmed in the tests, the patient's ability to accept their physical appearance, their ability to get around and their capacity to work may influence the development of resilience directly or indirectly.

Some authors state that the more resilient adolescents feel more competent, value themselves more, are happier about themselves and are more accepting of their bodies. The same authors also claim that self-respect is closely related to enjoying the life you lead; and that girls and boys who are more resilient have more pleasure in life[4]. Thus, these ideas confirm the importance of the variables described.

As for the support received from friends, its importance is indicated by different studies concerning resilience in individuals which consider the influence of relationships with

significant people. This may relate to the provision of support in overcoming adversities in life, which refutes the results described[2,5]. It is also important to emphasize, that spirituality and personal beliefs, despite not having been observed as statistically significant, may be important for the development of resilience.

In a study involving adolescents exposed to situations of psychosocial risk, it was found that 62% of young people consider religion as being very or extremely important. In addition, 77% usually ask for help in their struggle and 68.3% usually thank God (alot or intensely). Thus, we highlight how individuals invest in their spirituality and how this contributes to their self-esteem and therefore to their resilience[13].

Thus, religion, spirituality and personal beliefs can be used as a support in difficult times. This also contributes to the development of other factors such as hope, comfort and safety[13].

Another relevant factor is the possibility of a correlation between all domains studied; reinforcing the notion that resilience is not just a catalog of the qualities of individuals. It seems to be a multifactorial process that binds the individual to the environment around him from birth to death[15].

It was found that only the domain 1 (physical) is not significant, that is, all other domains were quite significant compared to the total obtained for each patient. The physical domain, which only explains the variable 8 (physical safety and protection), may not have been significant due to the fact that all adolescents who participated in this study were hospitalized. This meant they were limited to the ward and were surrounded by doctors,

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nurses and other health professionals.

Nevertheless, it is important to remember that domain 1 has a strong relationship with the domain 4 (environment), which was significant in the sample.

Despite the fact that the domains 2, 3, 4 and *overall* are significant, domain 2 (psychological) and *overall* were the ones that most influenced the quality of life and the resilience process when compared to the others. The psychological domain, as discussed earlier in this study, explains the issues of positive feelings, memory and concentration and negative feelings. This is in addition to pain and discomfort, energy and fatigue, participation and opportunities for recreation/leisure.

The *overall* domain explains the perception of life quality and satisfaction in terms of health and financial resources. Furthermore, the question concerning the activities of everyday life can be explained by two domains (psychological and *overall*).

Thus, it is observed that most of the protective factors found in this analysis are ones based on individual characteristics and factors related to the support of the environment.

The individual protective characteristics refer to the qualities that assist in the patient's ability to cope, making the individual less susceptible to certain situations. These characteristics are the result of the relationship between the person, the environment in which they live and their personality traits[4].

The individual's characteristics and their convictions about their own capacity to handle the challenges of life can also play a protective role for individual[5].

In the case of a disease, the cognitive ability to cope and accept the reality of their

health status are possible protective factors, as they are associated with a better quality of life and a lower amount of stress[16].

Thus, protective elements based on the individual have a positive association with the ability to confront adversity, they are directly linked to the environment in which the adolescents live and their life trajectory.

The environment surrounding children and adolescents is never perfect, but when the balance is greater, it can reduce the damaging effects of adversity[4]. In this context, individuals in the family, school, health professionals and the community itself, in which the teenagers are inserted, can provide help and support in difficult times. When the community is able to provide public services such as education, health, safety and quality housing, a clear protective effect may be perceived [4]. The ways in which the protective factors found in this study influence the resilience process are not clearly defined in the literature. An understanding of the combination of these factors is considered essential to better understand the development of potentialities and strategies for coping, and thus organize effective actions for promoting resilience and reduction of vulnerability of individuals.

CONCLUSION

It was found that domain 2 (psychological) and *overall* were the domains with the lowest p-values, so there is evidence that these domains influence the quality of life of adolescents to the greatest degree.

Thus, the protective factors in this analysis are those based on the individual and fac-

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tors related to support and the environment. These findings reinforce the idea that life experiences and the way teenagers see the world around them strongly influences how they confront adversity.

Therefore, it is essential that health professionals are sensitive and are prepared to identify the peculiarities of the individual adolescent and the illness process of each patient. This is in addition to minimizing, as much as possible; their negative experiences in order to enhance the hospitalization experience ensuring a constructive direction for teenagers. Therefore, from the perspective of resilience, care allows assistance to be focused on the integrality, valuing both objective and subjective elements. This new paradigm aims to develop the personal and social skills of the patients and healthcare team, emphasizing methods of coping with illnesses and adversities instead of just pathologies. It is proposed that the state and health professionals are directed towards comprehensive care and that issues related to resilience in general, particularly during adolescence and chronic illness are addressed. This should be discussed in an emphatic manner both in undergraduate health courses, in hospitals and the healthcare network in order to motivate further research in the area and to improve care quality.

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