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Illness representation in motor impaired children

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Abstract

The current study is interested to compare illness representation held by motor impaired children who comes from an institutionalized special school and those who live with their families and are enrolled in public schools. Fifty six children were investigated, all diagnosed with different motor impairments with results showing that the second group holds a more negative self-image, but also more knowledge about the illness including ways of treatment and information about the causes. In institutionalized children resignation was the predominant attitude on disability while the second group hold a more combative and active attitude.

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1. Introduction

Along the existence, stable, personal characteristics crystalized, forming so called “personal style of life” (Cucu, 1980, p.25), which in case of a disease becomes the personal style of being ill. The disease is an event that creates new condition of living, experienced both objective and subjective by any individual.

Motor impairments underlie visible morphological and functional changes, with long time consequences, mostly functional limitation, modified self-image, and sometimes challenging social interactions (motor impairments can be seen as a prove of mental deficiency by the laic population, that contributes to the rejection of those presenting motor disabilities). Illness representation was studied for decades and continues to be in the interest of clinical psychologist (Belar, & Deardorf, 2009; Pitts, & Phillips, 2003). One of the most useful models supports the existence of a cognitive schema that includes information about what causes the illness, symptoms and label,

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evolution, short and long term consequences and possible treatment (Cameron, & Leventhal, 2003; Leventhal, & Nerenz, 1985).

Maddux, Roberts, Sledden, & Wright (1986) also discuss the impact of any disease not only at biological level, but also psychological and social.

2. Methodology

The concept about one's illness determines how a person is able to adapt to it and constitutes the core of the intervention. The current study is interested to compare illness representation held by motor impaired children who come from an institutionalized special school and those who live with their families and are enrolled in public schools. The objectives were to determine the content of cognitive schema about illness in both groups of children (age 10-14 years old), body image, attitudes on disability, and the perceived quality of health. Schema about the illness refer to the beliefs regarding name of the illness and symptoms, causes, evolution, consequences and treatment.

Fifty-six children were investigated, twenty-nine of them coming from a special school for children with motor impairments. The special school is an institutionalized facility, appointed for education and housing of male students who have motor disabilities and very poor socio-economic status. Another twenty-seven children (eleven girls and sixteen boys) come from general public schools and live with their families, having an average income.

2.1. Instruments

Given the nature of the investigation, instruments were more qualitative in their nature, except from *Standard Progressive Matrices Test*.

Standard Progressive Matrices Test is a paper and pencil nonverbal intelligence test, contains 60 items of increasing difficulty, grouped in five series. Participants are required to select one from among 6 or 8 alternatives to complete a matrix problem. In order to give the solution one must operate with abstract figural stimuli, understand the gestalt and activate flexible strategies of solving. The test was administered in-groups with a time limit of 30 minutes.

Semi-structured interview was conducted in a one-to-one setting, asking about:

- Social identity of the child (age, background, family and school history)
- Self-concept: sense of personal value, interpersonal relations, attitude toward the illness, experience with hospitalizations (if applicable), action measures that contribute to improvement in daily living
- Physical self and body image: physical characteristics, functional abilities, physical appearance, health status
- Perceived threats or support for the present and future existence.

When was possible a short semi-structured interview was held with the parent (5 parents for first group participated and fifteen for the second group) with questions about:

- history of the illness;
- illness representation held by the parent;
- action measures and changes to address child's condition
- future expectation, threats and advantages perceived.

Pendula method is an instrument created by the author in order to measure the perceived quality of health. It consists in a pendula that can be positioned by the child in one out of nine positions that symbolized general health status from completely healthy to very ill.

Draw a Pearson test and a derived version of it *Draw a healthy and an ill person and a healthy and an ill animal*. These instruments are projective measures of self-concept and the idea of generating more than one drawing is to notice if consistency in perceiving the disease can be observed. No time limit was imposed for the drawing tasks.

2.2. Research hypothesis

Knowing that self-image and illness representation evolve with age (Bibace, & Walsh, 1980), but giving the narrow context in which the research was conducted we held constant the age of the participants and their physical

conditions, but we explored the relations with cognitive development and environment of the participants (institutionalized facilities or public schools, different socio-economic status, the presence or absence of family support). The hypothesis emerged are:

- Beliefs about the illness comprise all five elements that regards diseases, but differ by cognitive development of the child and his/her environment (presence or lack of family support and type of school).
- Attitudes on disability is different in the two categories of participants.
- Perceived quality of health is also different by the participants' background.
- Body image is altered in both groups, being more unfavorable for children coming from public schools.

3. Results

One of the first findings showed significant difference regarding IQ levels in the two groups with children coming from special school having a mean intelligence level of 86.71 IQ and those from general public school with 95.93 IQ ($t(55) = 3.98, p < .000$). No children with intellectual deficits were included in the groups still, the significant difference was notice and can be explained mainly by less cognitive stimulation in the case of institutionalized children and possible more severe physical impairment that required more focus on being able to move and to solve physical challenges than cognitive ones. These results are in agreement with some of Tottenham findings (2012) regarding risks in early institutionalized children. Another important difference between the two groups is represented by socio-economic status, again, those coming from special schools having a more scarce background, with very poor parents or no parents at all (one third of them being abandoned children). Also, one third of children from general public school comes from families with single parent (mostly the mother), but their socio-economic status is still better than children from the other group.

An interesting finding reveals that in the institutionalized group 32.78% are last born in the family and only 14.22% are first born. In the public school group 40% are first born and 17.3% last born. Interviews with the parents uncover some explanation for these findings. Every time when there is sufficient financial support, the child with motor disabilities is held in the family, regardless the birth order of child, with members making adjustment in order to help him with his suffering. When financial resources are insufficient, parents decide to institutionalize the child with motor disabilities more frequent if he/she is the last born compared with the first born. When the first child has a physical impairment parents are filled in with guilt and trying to compensate this they concentrate on caring for the child sometimes including self-sacrifice. Until they decide to have another child, longer time has passed and a stronger bond between child and parents was formed, giving the parents less readiness to consider institutionalization later, when difficulties emerges. On the other hand, when the sick child is the last born, and parents have more than one healthy child, it is easier for them to consider institutionalization, especially when they also confront with financial burden.

The results concerning illness representation and cognitive schema upon the disease revealed interesting differences between the two groups (tab. 1).

Nonparametric Kruskal-Wallis/ Mann Whitney tests shown significant differences for all five components of illness schema, with children coming from public school holding a more comprehensive and coherent representation of their illness.

Table 1. Illness schema in institutionalized children compared with children attending public schools

Component of illness schema		Institutionalized children	Public school children	Mann-Whitney/ Kruskal-Wallis
Symptoms	Pain, functional limitation, physical appearance, limited capacities	58.15 %	80 %	$z = 2.93, p < .001$
	Unspecified	41.85 %	20 %	$z = 2.76, p < .001$
Causes	Real	10.71%	26.66 %	$\chi^2 = 9.482, p < .001$
	Faith	21.74%	20 %	$\chi^2 = 1.102, p > .05$
	Unknown	68.75%	53.34 %	$\chi^2 = 8.576, p < .001$
Evolution	Better	32.24 %	39 %	$\chi^2 = 6.576, p < .001$
	Same	39.28 %	40 %	$\chi^2 = .733, p > .05$
	Uncertain/unknown	28.58 %	21%	$\chi^2 = 5.921, p < .001$
Consequences	Restrictions	35.72 %	80 %	$z = 2.97, p < .001$
	Unspecified	64.28 %	20 %	$z = 2.95, p < .001$
Treatment	Physiotherapy/massage/exercises	9.71 %	33.34 %	$\chi^2 = 16.902, p < .001$
	Medication/surgery	20.34 %	20 %	$\chi^2 = .434, p > .05$
	Unknown/unspecified	70.05	46.66	$\chi^2 = 18.022, p < .001$

Concerning the attitude toward the illness, children from public schools are driven by a more combative and involved attitude, often with tendency of overcompensation such as: immersion in intellectual activities, value placed on facial appearance and special attention given to cloths and dressing rituals, and emphasis on other desirable characteristics (altruism, generosity, compliance). Special school children have a more resign attitude toward the disease with comments such as "it can be worst then that" "at least I can walk", giving that they don't have healthy peers around them, and they need to adapt in a rather homogeneous environment choose by their parents to represent home for months and years to come. Apart from these two main attitude, some special manner of reaction were noticed:

- Lack of trust in peers, tendency for solitude, especially in children with an IQ above average that lost their naïve perspective upon life.
- Ambivalence in communication with others: openness to relate, desire to make friends followed by drifting apart and indifference. It is almost like a self-protection strategy in case of any betrayal.
- "Masked coolness" trying to convince others that the disease he/ she encounter doesn't impose any limitation, sometimes risking accidents or difficulties.

The quality in health state also shown significant differences between the two groups: $t(55) = 4.51, p < .000$ in favour of children included in special school. They seem to perceive their own health as stronger and more satisfying compare with the other group.

Both drawing and the interview disclosed negative feeling regarding reduced capacity for physical activity or effort, walking deficiency, low strength in limbs and visibility of the defect. In the drawings the projection of the defect is present in 71% of institutionalized children and 81% in the case of public schools children. The rest of the drawings either present some other interests (e.g. computer games - a person sitting in front of the computer, with very schematic representation of ill person and ill animal, or sexual preoccupation, with emphasis on chest, hair, make up), or the quality of the drawing is very poor.

4. Discussion

In the current study we compared illness representation (motor disability) in two groups of participants: one group coming from special school, being characterized by lower intelligence level, lack of family support and low socio-economic status and a second group of children coming from public schools, children who lived with their families and coming from average socio-economic background. The second group is more aware of the consequences of their disease: know more symptoms, can specify the real etiology of their illness and can offer proper treatment measures as examples. Regarding the symptoms a large percentage of children coming from the first group were not able to list appropriate signs of their illness (they either mentioned headaches or stomach aches or even fever, which have nothing to do with their motor impairment or didn't mention any specific symptom).

Causes of the disability is better acknowledged by the children that live with their family, have a higher IQ score and a better socio-economic status. The fact that prognosis of the illness is seen rather optimistic, is an anchor for support intervention and a positive fact. But some rather alarming explanation can also be offered: only a small percentage of the respondents know the real etiology of their impairment, percentage that is relatively close to the one of the respondents that offers physiotherapy as a treatment measure, which is more appropriate than medication in the majority of the cases, and this is the reason why children have an optimistic view about their illness. It is obvious that the children need to be informed about the origin of their disease and what is the suitable intervention for recovery in order to obtain an active involvement from their part (Maddux, Roberts, Sledden, & Wright, 1986).

Popa-Velea (2010) mentions several possibilities as reactions to a chronic disease: *acknowledgment and acceptance* followed by appropriate involvement in the treatment, *neglect and ignorance, non-combative/resignation attitude and combative, active commitment for the recovery*. The study exposed more combative attitude coming from children that have their parents present and a more submissive one, appearing on the side of institutionalized children.

Giving the circumstances, both attitude serve the interest of the children, allowing them to perform and to experience a sense of belonging and similarities with their peers (Cameron, Leventhal, 2003). In line with this finding is also the one referring to the perceived health status, children living among sick children being more satisfied with their own health, while those who encounter healthy children on daily bases being more dissatisfied with it.

Meeting people means to reveal your exterior, to allow others to see your look and to be assessed by it. The participants of the study are already at an age that allow them to comprehend the importance of their physical appearance, and motor impairment may transform the body in an enemy, being held as the source of all problems. Even more, the healthy person can feel embarrassment in their company, and may have difficulties to communicate, enhancing the negative perception about the body (Falvo, 2014; Quick, 2014). Social comparison processes to some extent explain the development of negative or positive body image in young people, and a more careful attention should be placed on how children see themselves in order to empower them to live fulfilling lives.

Overall, the results shown differences between the two groups, with children leaving with their parents and being enrolled in public schools, holding a more negative self-image, but also more knowledge about the illness including ways of treatment and information about the causes. Interview disclosed more negative self-representation than the drawings. In institutionalized children resignation was the predominant attitude on disability while the second group hold a more combative and active attitude.

The findings suggest the urge to inform children about their condition and to motivate them to play a more active part in the rehabilitation. Also, is important to anticipate the negative self-image that emerges in association with motor impairment and to offer counselling. The study holds some limits: first, there was a significant difference in IQ scores between the two groups that could moderate the results. Second there are limits drawn by the qualitative measures used and the reduced number of participants.

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