Illness narratives, dependence level and life satisfaction in post-polio syndrome

Narrativas sobre a doença, nível de dependência e satisfação pessoal na síndrome pós-polio

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ABSTRACT

Objective. The purpose of this study was to investigate the lifetime illness experience of four patients with Post-Polio Syndrome (PPS). **Method.** The empirical contents were submitted to a categorization process containing questions referring to: (1) the acute phase of paralytic poliomyelitis and recollection of past clinical pictures and syndromes; (2) physical rehabilitation, guidance as well as care at services for the disabled; (3) adaptation to a new lifestyle; (4) living with PPS and related prejudices and misconceptions; (5) apprehensions towards the future. The level of functional independence (autonomy) was measured using the Barthel Index, a questionnaire regarding several practical motor skills. **Results.** We have found that the symptoms in post-polio patients increased their day-to-day level of motor disability and sometimes decreased their overall level of life satisfaction. **Conclusion.** Rehabilitation processes as well as counseling have a positive influence on (PPS) patients.

Keywords. Post-Poliomyelitis Syndrome, Disabilities, Rehabilitation.

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RESUMO

Objetivo. A proposta desse estudo foi investigar a experiência de vida de quatro indivíduos com síndrome pós-polio (SPP). **Método.** O material empírico sofreu um processo de categorização com questões a respeito de: (1) fase aguda da poliomielite anterior aguda e memórias do passado; (2) reabilitação física, orientação e tratamento em serviços especializados; (3) adaptação ao novo estilo de vida; (4) viver com SPP e preconceitos sofridos; (4) apreensões sobre o futuro. O nível de independência foi avaliado pelo Índice de Barthel, um questionário de perguntas a respeito do desempenho motor em atividades básicas e instrumentais da vida diária. **Resultados.** Os resultados encontrados apontam que os sintomas apresentados pelos indivíduos aumentam seus níveis de deficiência em atividades funcionais e algumas vezes diminuem a satisfação pela vida. **Conclusão.** O processo de reabilitação e orientações influenciam positivamente na vida dos pacientes.

Unitermos. Síndrome Pós-Polio, Deficiências, Reabilitação.

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INTRODUCTION

In several countries, as well as in Brazil, polio-related virus disease disappeared completely as a result of universal immunization. Consequently, younger and middle-aged doctors and physiotherapists have had no experience encountering acute polio virus infection but instead have encountered its resultant impairments and disabilities. The acute anterior poliomyelitis (AAP) is a viral disease, which is characterized by headache, fever, pharyngitis, as well as signs of advanced meningeal irritation, followed by a lower motor neuron syndrome located to the spinal cord and consisting of an assymetric flaccid palsy of spinal muscles. People who had suffered the onset of poliomyelitis 3-4 decades earlier, may develop a new set of symptoms and functional declines, called post-polio syndrome (PPS)[1-3].

The criteria for PPS syndrome were identified and its impairments and functional disabilities described. Patients frequently complain of new onset fatigue, motor weakness, muscular pain, and/or joint pain. The combination in a post-polio patient of disuse of some muscles along with of overuse of other muscles, compounded by insidious weight gain and chronic weakness, can certainly contribute to the progressive loss of functional capabilities especially when the aging factor is included. These factors, taken together, may lead to further difficulties in performance of daily activities[3,4]. Despite the difficulties of becoming ill and slowly recovering from a life-threatening disease, some published studies indicate that patients with PPS lead satisfactory lives and achieve most of their ambitions in their work as well as in their personal life[5-7].

We describe four patients with PPS in regard to their past symptoms and practical problems faced as well as expectations. The Barthel Scale[8] gave us a general idea of the main functional disabilities presented by these individuals regarding certain daily functions.

METHOD

The patients had been questioned concerning facts related both to the episode of previous acute polio as well as to the PPS. The questions were given sufficient time for response, the time being approximately 30 minutes (Table 1). The interview was later recorded and the relevant content extracted after consensus was reached by the researchers. The environment in which the questions were applied was both quiet and private. Private comments were not reproduced. Immediately afterwards, the Barthel Scale[8] was applied and eventual doubts that had appeared while the patients pondered were clarified (Table 2). A Term of Free and Clarified Consent regarding the purpose of the study was signed by all participants. The study was carried out in the neurology services of Universidade Federal Fluminense (UFF).

We took into consideration the vulnerability of these PPS patients when performing the interviews. In addition, the individuals of the present study had the possibility to contact us if they needed to discuss any experience that was related to the interviews. There was also a follow-up meeting for all the individuals participating in the study at which the results of the study were presented.

Table 1. Questions about the lifetime illness experience.

	Questions
1	To comment about the time where you presented the polio and important moments that had been marked.
2	Did you receive orientation regarding the kind of specific activity, equipment of aid (orthoses, walking sticks, crutches, walkers) or service specialized for the service of patients with neurological injuries?
3	Were you attempting to conserve energy and to only use it in with priority activities?
4	How it was your adaptation for a new reality, habits and strategies created for one better management of the picture? What was drastically changed?
5	Which alterations and damages had occurred with the appearance of the post-polio syndrome?
6	Were you oriented to use some medicine for the illness?
7	Which are your perspectives, hopes and fears in the future?

RESULTS

CASE (1)

A 41-year old male, caucasian, tax auditor, reported that at age five he began presenting with the clinical picture of acute anterior poliomyelitis (AAP) that subsequently resulted in upper right limb and lower left limb paresis, difficulty in walking as well as in carrying out some of his basic daily activities. His infancy was marked by the fact he considered himself different from others of his age. In order to overcome, he tried to carry out activities with a very high degree of difficulty as, for example, climbing up walls and trees, running for long distances overcoming strong muscle and joint pain, and using a skateboard. He considers not to have suffered any form of prejudice during his infancy, although he did receive embarrassing nicknames. He faced such commentaries natural-

ly. He went through rehabilitation from age 5 to 13. However, past events from this period are not recollected by him with much clarity. At age 19, he entered the Air Force Preparatory School for Air Cadets, even though he had in mind that he would fail in the physical examination. He had passed the written exam for an administrative area of the Air Force, even though he could not enter due to his physical deficiency. He returned to his activities and he was subsequently enrolled in a regular exercise program. He does not comprehend the relation of his physical weakness of the legs and arms with any intellectual competence. He considers this the most frustrating aspect of his life. He returned to his activities normally and later was enrolled in to regulate it exercise program. He has always practiced sports of various kinds, but never received any guidance whatsoever on the risks that such activities involved. He says that the first physician who evaluated him stated that his recovery would be directly related to the frequency as well as intensity of the exercises. The physician then suggested a premature ingression into a program of regular physical activity. After 3 decades of clinical stability, he began referring weakness, muscle aches, and cramps in muscle groups not previously affected during his first bout of polio. In August of 2005, at age 39, he was diagnosed with PPS. He would eventually receive a disability pension, reducing drastically his level of physical activity as well as initiating a strict diet. He has alternated bouts of depression as well as anxiety and prefers not to ponder the future. He believes that he could still benefit from stem cell research as well from new types of treatment available for his kind of disease. He considers the support he has received from health professionals, friends and family fundamental. He feels well-received by his peers in general. Despite possessing at present a score considered good to adequate on the Barthel Index, he is unable to carry out such activities for long periods of time, mainly because of muscle and joint pains as well as fatigue. He does not customarily walk for long distances. Currently, he has acquired more discipline concerning his daily activities, selectively carrying out those often relatively higher priorities. This patient obtained a 90-point score on the Barthel Scale, with functional loss demonstrated in climbing and in walking down stairs as well as in walking upon unstable surfaces (Table 2).

CASE (2)

A 52-year-old, caucasian, female teacher related that in 1952, at 12 months of age, she presented the first symptoms of AAP. During the first two years of disease evolution, she was unable to walk. She does not recall the events from this period of her life clearly. Soon afterwards, she had begun a regular program of rehabilitation therapy. While still an infant, she had been advised by health professionals to practice some type of sports. Her parents as well as relatives had always treated her as a normal child and constantly sought not to reveal any concern with the disease, lest she come to feel emotional trauma regarding the incident. She rode a bicycle, ran and swam regularly and did not present any muscular and/or joint pains. In adolescence, she started to get afflicted due the pain as well as regarding daily motor functions and on account of this tried not to do things that could increase the damages and deficiencies caused by her illness. Due to the socio-economic difficulties faced by her family, she began working at age twelve. At this time, it was perceived that patients with AAP isolated themselves and many could not come to accept the illness. Until the onset of the year 2000, she led a normal life, full of motor tasks. In the second semester of this year, she began presenting with a new set of motor symptoms, mainly muscle weakness and intense fatigue. Upon at 50 years old, she had been diagnosed with PPS. This would be considered the most difficult period of her life. The association of depression, fear and generalized pains compelled her to severely curtail both her professional and personal activities. Activities formerly carried out with easy and climbing up and down a stairway and walking across a smooth long floor long became tremendously difficult. In 2007, she sought medical as well as physical therapy and resumed fighting the formidable obstacles and limitations imposed by the disease with strong will and perseverance. She was later advised to also curtail some habits considered detrimental to her health and motor performance. The prescription of an orthoses for the ankle reduced her pains. She also carried out therapy with intravenous immunoglobulin and subsequently referred improvement in both motor symptoms as well as fatigue. However, she does not consider the future promising as far as newer treatment options are concerned. The patient received a 90-point score on the Barthel Scale, with functional loss primarily related to walking (Table 2).

CASE (3)

A 49-year old, caucasian, female relates that in the first semester of 1975, at age of 9, developed AAP. Unfortunately, she presented with severe impairment in walking, due to extensive destruction of lum-

bossacral spinal cord neurons. Flaccid paralysis of the lower limbs was another presenting symptom. Despite the damage provoked by the illness, her infancy was marked by times of great happiness and pleasure. She went through rehabilitation for 10 years since the beginning of symptoms. She never received any guidance or advice concerning the activities she would have to go through in order to achieve a better management of the illness. In March of 1997, a new episode of muscular weakness along with fatigue and generalized pains forced her to seek medical assistance. She was later informed that such symptoms represented a delayed effect of the acute form of the disease. She then received the diagnosis of PPS. She proceeded to drastically reduce both the frequency and intensity of her domestic activities, dedicating herself almost exclusively to painting and pottery, and has no hope of improvement of her clinical picture. She is aware that these symptoms are delayed manifestations of the disease and prefers to well on the present. She had never been advised to receive drug treatment, and only received physical therapy during 2007. She has referred a reduction in pain in her back and limbs since beginning physical therapy on an outpatient basis. The patient achieved a 45-point score on the Barthel Scale, showing complete lack of autonomy for bathing and other care related to hygiene, clothing herself, walking, as well as in climbing up and down stairs (Table 2).

CASE (4)

A 53-year old, caucasian, male and a Brazilian Marines official, relates that at age 7, after an intense fever, headache and throat pain, he presented acute motor weakness of his right lower limb that remitted gradually over the years. As an infant, he was able to carry out all motor activities and was never advised as far as the conservation of energy was concerned not regarding heroic means of compensation. By mid-2000, he was referring worsening of his weakness as well as worsening of the fatigue, as well as the appearance of new symptoms such as lumbar pain. In 2002, after being submitted to a series of complementary exams, he received a diagnosis of PPS. He has continued to carry through his daily activities with professional guidance. He receives physical therapy only eventually. After obtaining orthoses for his lower limbs, he has referred a marked reduction in pain. Despite the maximum score on the Barthel Scale, the patient referred joint and muscle pain after performing the majority of activities, especially those related to walking and transfer (Table 2).

Table 2. The Barthel Index - Mahoney FI, Barthel D (1965).

Functional Activities	Score
FEEDING 0 = unable 5 = needs help cutting, preading butter, etc., or requires modified diet 10 = independent	Case 1 (10) Case 2 (10) Case 3 (10) Case 4 (10)
BATHING 0 = dependent 5 = independent (or in shower)	Case 1 (5) Case 2 (5) Case 3 (0) Case 4 (5)
GROOMING 0 = needs to help with personal care 5 = independent face/hair/teeth/ shaving(implements provided)	Case 1 (5) Case 2 (5) Case 3 (0) Case 4 (5)
DRESSING 0 = dependent 5 = needs help but can do about half unaided 10 = independent (including buttons, zips, laces, etc.)	Case 1 (10) Case 2 (10) Case 3 (5) Case 4 (10)
BOWELS 0 = incontinent (or needs to be given enemas) 5 = occasional accident 0 = continent	Case 1 (10) Case 2 (10) Case 3 (10) Case 4 (10)
BLADDER 0 = incontinent, or catheterized and unable to manage alone 5 = occasional accident 10 = continent	Case 1 (10) Case 2 (10) Case 3 (10) Case 4 (10)
TOILET USE 0 = dependent 5 = needs some help, but can do something alone 10 = independent (on and off, dressing, wiping)	Case 1 (10) Case 2 (10) Case 3 (5) Case 4 (10)
TRANSFERS (BED TO CHAIR AND BACK) 0 = unable, no sitting balance 5 = major help (one or two people, physical), can sit 10 = minor help (verbal or physical) 15 = independent	Case 1 (15) Case 2 (15) Case 3 (5) Case 4 (15)
MOBILITY (ON LEVEL SURFACES) 0 = immobile or < 50 yards 5 = wheelchair independent, including corners, > 50 yards 10 = walks with help of one person (verbal or physical) > 50 yards 15 = independent (but may use any aid; for example, stick) > 50 yards	Case 1 (10) Case 2 (10) Case 3 (0) Case 4 (15)
STAIRS 0 = unable 5 = needs help (verbal, physical, carrying aid) 10 = independent	Case 1 (5) Case 2 (5) Case 3 (0) Case 4 (10)

DISCUSSION

The objective of the study is to widen the comprehension of the natural history as well as complications of the acute anterior polio syndrome in general, and the post polio syndrome in particular. Although diverse systems of classification have been proposed, the best definition of the polio syndrome in general refers to the physical, psychological as well as social and economic limitations imposed upon polio patients[9-11]. After the conclusion of this study, it was observed that these polio patients presented with numerous complications and physical impairments, as well as strategies aimed at overcoming these very limitations and impairments[11]. The level of physical disability among these patients must be a central concern in matters of public health, at a time when the day-to-day difficulties of the patients tend to be manifold.

The term functional incapacity is commonly used to signify a restriction of the motor capacity of individuals to perform day-to-day activities and serves to quantify the extent of definitive illness[12]. The four case studies demonstrated distinct degrees of functional incapacity that caused specific limitations in the performance of socially defined tasks of a particular sociocultural and physical background. The performance of basic and instrumental activities of the daily life (Table 2), the working aspects of the non-occupational roles and the recreational aspects of leisure were discussed and analyzed. The deficiencies/incapacities had exerted a negative need for informal and formal aid and in long term care. We also consider the self-evaluation of individuals regarding the limitations imposed upon them by polio and PPS and individual forms of reaction. To understand how individuals become "incapable" on specific occasions, it is necessary to consider, additional factors (medical care received, rehabilitation and the physical and social environment involved), the risk factors (such as sociodemographics characteristics and lifestyle) and individual factors (such as psychological and social characteristics and lifestyle)[13]. While some individuals of the present study fight tirelessly against the barriers imposed by the illness, others prefer to passively accept their resultant problems and disabilities.

Illnesses that cause deficiencies cause with great disgust and inconformity because, in additional to the suffering inherent to any pathological process, they are many times accompanied by prejudice as well as social isolation[14]. Although some episodes involve matters of prejudice as well as moments of depression, the individuals of the present study can handle these hardships and consequently face them with natural aplomb. Certain social activities have been marred mainly by problems involving locomotion.

Religious beliefs and spiritually related practices can, in some cases, mobilize extremely positive energies and initiatives, with limitless potential to improve the quality of life of the individuals. In the particular case of physical deficiency, this can have a significant impact on their rehabilitative process that true "miracles" may come to be spoken of[14]. In a study with 442 patients whose course of illness evolved with pain, discovered that religious practices helped reduce pain as well as help increase their control over[15]. It was perceived, in our study, that soon after the episode of AAP, the patients enrolled in physical activities and rehabilitative programs with goal to improve their motor performance as well as their muscle power. Unfortunately enough, such individuals had not received adequate orientation concerning the risks inherent to extreme exercise, "overuse". Coincidently, after decades of clinical stability, these patients later went on to develop PPS. None of our patients mentioned religious experience as an aid in confronting to physical, clinical and psychological damages caused by the illness. Guidance, regarding the type, frequency and intensity of the activities had been delayed. The muscle and joint pains had been considered by all as the main problem caused by the illness. All patients had mentioned medical support as well as physical therapy support, even though late, as fundamental in modifying the natural course of their illness as well as in their lives in general. The possibility of medical treatment associated with the use of equipment of assistance and support was not always presented as treatment option. While some patients believe that they will benefit from newer therapeutic modalities, others do not believe in newer possibilities of treatment[7].

SUGGESTIONS FOR PATIENTS WITH AAP AND PPS

Functional limitations, psychosocial factors, and symptoms associated with post-polio syndrome can present a significant impediment to work. Symptoms of PPS may cause deficits in daily life activities such as getting in and out of bed, bathing, washing, and shopping (i.e.: activities of daily living)[7].

Support through rehabilitation medicine and occupational health services may be valuable for people with PPS seeking and/or maintaining employment. Examples of options that may help a person with PPS to obtain and maintain employment include frequent rest periods, shortened workdays, accommodations for

mobility impairments (ex: wheelchair accessible workplace and/or use of vehicle to help reduce time spent walking), individualized dietary and exercise regimens, and change to more sedentary work. Ergonomic computer equipment and proper seating may assist in reducing effects of neck strain and upper body fatigue. Low impact exercise such as yoga, bicycling, tai chi or water-based activities may be combined with dietary modifications to improve fitness for those experiencing PPS symptoms. Dynamic exercise therapy in heated water appears to be an appropriate way of exercising as overuse of existing motor units and muscle fiber can be detrimental. A careful balance must be considered in physiotherapy so that fatigue and pain are minimized. Exercise can improve muscle strength and overall fitness if prescribed individually and carefully evaluated[16].

In conjunction, referral to a Vocational Rehabilitation Agency may be necessary for vocational services including vocational assessment, transferable skills analysis, career exploration, retraining, placement assistance, and equipment and workplace modification. Although symptom variability appears central to PPS, the majority of individuals with the late effects of polio seem to demonstrate similar symptoms, most commonly weakness, fatigue and joint pain. It may be especially important for professionals assisting persons with PPS to carefully assess each individual given that PPS symptoms can vary in severity and distribution of damage in the anterior horn cells[17]. Timely, early diagnosis and prompt job accommodation interventions, along with medical treatment and counseling, may be indicated to help individuals with PPS to maintain existing employment.

CONCLUSION

We have found that the new symptoms in post polio survivors, increase walking and climbing stairs disability, increase the disability to perform daily activities and also decrease satisfaction with life. Physiotherapists and other health care professionals must therefore be aware of the potential vulnerability in this patient group when approached by them to alleviate their PPS symptoms.

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