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## ORIGINAL ARTICLE

### FOURNIER SYNDROME: PERCEPTION OF THE SUBJECTS IN RELATION TO THE EXPERIENCE WITH THE DISEASE

### SÍNDROME DE FOURNIER: PERCEPÇÃO DOS SUJEITOS EM RELAÇÃO À EXPERIÊNCIA COM A DOENÇA

### SÍNDROME DE FOURNIER: LA PERCEPCIÓN DE LOS SUJETOS EN RELACIÓN A LA EXPERIENCIA CON LA ENFERMEDAD

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#### ABSTRACT

**Objective:** to know the perception of the subjects who developed Fournier syndrome regarding their experience with the disease. **Method:** descriptive study, of qualitative approach. The information were produced from semi-structured interview guide with the aid of a tape recorder to four subjects. Data analysis occurred through the Technique of Content Analysis. **Results:** the subjects showed little content on the cause, progression of the disease and the performed treatment. They experienced changes in their daily lives, feelings of shame, disgust, and impotence, among others. **Conclusion:** a better approach is necessary between the subject with Fournier syndrome and health professionals so that, in addition to early diagnosis and treatment, they can understand their doubts and anxieties about the disease. **Descriptors:** Fournier Gangrene; Wounds and Injuries; Nursing Care.

#### RESUMO

**Objetivo:** conhecer a percepção dos sujeitos que desenvolveram Síndrome de Fournier quanto à experiência com a doença. **Método:** estudo descritivo de abordagem qualitativa. As informações foram produzidas a partir de roteiro de entrevista semiestruturado com auxílio de um gravador para 4 sujeitos. A análise dos dados se deu pela Técnica de Análise de conteúdo. **Resultados:** os sujeitos demonstraram ter uma pequena noção da causa, evolução da doença e o tratamento realizado. Experimentaram mudança em seu cotidiano, sentimento de vergonha, repulsa, impotência, entre outros. **Conclusão:** faz-se necessário maior aproximação do sujeito com Síndrome de Fournier e profissionais da saúde para que, além do diagnóstico e tratamento precoce, as suas dúvidas e anseios em relação à doença sejam compreendidas. **Descritores:** Gangrena de Fournier; Ferimentos e Lesões; Cuidados de Enfermagem.

#### RESUMEN

**Objetivo:** conocer la percepción de los sujetos que desarrollaron síndrome de Fournier en relación a la experiencia con la enfermedad. **Método:** estudio descriptivo de enfoque cualitativo. Las informaciones fueron producidas a partir de guía de entrevista semi-estructurada con la ayuda de una grabadora de cuatro sujetos. El análisis de los datos ocurrió a través de la técnica de análisis de contenido. **Resultados:** los sujetos tienen una pequeña idea de la causa, la progresión de la enfermedad y el tratamiento realizado. Experimentaron cambios en su vida diaria, sentimientos de vergüenza, asco, impotencia, entre otros. **Conclusión:** es necesario una mejor aproximación entre el paciente con síndrome de Fournier y profesionales de la salud a fin de que, además del diagnóstico y el tratamiento precoz, sus dudas e inquietudes sobre la enfermedad sean entendidas. **Descriptores:** Gangrena de Fournier; Heridas y Traumatismos; Atención de Enfermería.

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## INTRODUCTION

Described in 1883 by Jean Alfred Fournier, a French venerologist the Fournier syndrome or gangrene is an idiopathic infection with an acute onset, which affects, in most cases, the perineal, perianal and male genitalia regions, specifically involving subcutaneous tissue and fascia, causing necrotizing fasciitis. Cases may also occur in women and in individuals under 15 years, but in a significantly smaller number.<sup>1,2</sup>

The Fournier syndrome is a polymicrobial infection with the presence of aerobic and anaerobic bacteria, acting synergistically under different mechanisms, with the gateway located into the urogenital tract, digestive tract or skin disorders. There are at least four microorganisms in each lesion, and the most frequent are *Escherichia coli*, *Pseudomonas aeruginosa*, *Staphylococcus aureus* and *Streptococcus fecalis*. Those microorganisms act synergistically with a rapid spread in disease progression with an infectious process by an obliterating endarteritis, leading to thrombosis of cutaneous and subcutaneous vessels and consequent necrosis of the affected area by local ischemia. It may extend quickly to the anterior abdominal wall, the dorsal region, the upper and retroperitoneal members, and may lead to sepsis, multiple organ failure and death.<sup>3</sup>

Subjects with Fournier Syndrome usually develop a typical clinical condition: two to seven days of fever, with redness, skin necrosis and crepitus, sometimes, pain and chills.<sup>1,4</sup> One may observed as predisposing factors for the development of the disease diabetes mellitus, alcoholism, urinary tract infections, malnutrition, hypertension, smoking and immunosuppression, in addition to advanced age, mechanical trauma and prolonged hospitalization.<sup>5</sup>

The diagnosis bases mainly on physical examination, but imaging methods contribute to confirmation, assessing the extent of lesions, detecting a subjacent cause and monitoring response to therapy using radiography, ultrasound, and others.<sup>1</sup>

It is very important that the person with Fournier syndrome has an early follow-up by multidisciplinary health teams in order to reduce complications and, consequently, to avoid death, since the mortality rate due to the disease is still high.<sup>6</sup> One states that mortality by Fournier syndrome is around 40-67% of affected subjects and that this index decreases according to early diagnosis and treatment.<sup>3</sup>

Besides all the physical changes - loss of skin integrity of the perineal, perianal and genital regions with the emergence of wounds - the person with Fournier Syndrome also has the psychological damage resulting from his/her state of health. At various times, that subject deals with negative thoughts about the pain, the disease, changes in relation to the self-image and the hospitalization process. Thus, the treatment of a wound - like lesions from Fournier syndrome - is a complex and dynamic process, and the development directly relates to the intrinsic values of the subject. Health professionals need to value the psychological aspects of the subject, stressing the importance of a multidisciplinary, integral and humanized approach, in which guidance and monitoring should be individualized, taking into account the personal and social aspects of the individual.<sup>7</sup>

The prognosis improves when the assistance is immediate to clinical suspicion and the health professional focus his/her care on both the individual as his/her family, responsible for the care, later, in the home environment. Recalling that psychological support is as decisive as the diagnostic and therapeutic conduct.<sup>8,9</sup>

Therefore, considering the peculiarities in the care to the subject with Fournier syndrome and the importance of health staff in his/her rehabilitation process, the objective of this study was to know the perception of the subjects who developed Fournier syndrome in relation to the experience with the disease.

## METHOD

Descriptive study, of qualitative approach, conducted with subjects with diagnosis of Fournier syndrome and treated at a public hospital in Itabuna/BA. That institution has 154 beds and provides services of clinical care, surgery, outpatient, psychiatric and emergency care.

Among all users served at the hospital, the subjects were selected, from the records in the medical charts, according to the following inclusion criteria: aged over 18 years old, having confirmed diagnosis of Fournier Syndrome and who received health care in 2011 and 2012 and being man.

Thus, at first, eight subjects were selected; however, after contact of the researchers by phone, two subjects were excluded for having died after discharge and two had addresses different from the ones in the hospital records. Therefore, four subjects participated in the study.

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The information were produced in September and October 2012, from semi-structured interviews with the aid of a tape recorder. All interviews were conducted at the subjects' residence subjects, chosen by themselves as desired.

The study complied with the ethical guidelines for research on human subjects contained in Resolution 466/12. The survey was conducted after favorable opinion of the Hospital Ethics Committee and the Research Ethics Committee of the State University of Santa Cruz, CAAE number 04959012.5.0000.5526 and opinion number 128,029. The subjects formalized participation in the study by signing the Informed Consent Form with free withdrawal and anonymity guarantee in relation to their identity.

Data were analyzed by the method of content analysis proposed by Bardin<sup>10</sup>, following the phases of pre-analysis, material exploration and treatment of results, inference and interpretation.<sup>10</sup>

Thus, besides the characterization of the subjects, the following categories emerged: "It started with an itch": the onset of the disease", "Comprehension on the disease and its treatment", "Perception related to healing" and "Nursing and home care".

In order to ensure and preserve the subjects' identity, the statements were identified by names of "Olympians", namely: Zeus, Apollo, Dionysus and Hermes.

## RESULTS AND DISCUSSION

### ♦ Characterization of the subjects

The participants were four men, aged from 45 to 75 years; as for their occupation, two were retired, one, seller, and one, trader. As for associated diseases, three had diabetes mellitus and one, hypertension.

Wound healing time ranged from two to four months, with papain, in the injured area during the course of healing for the period they were hospitalized and in home care. It is noteworthy that papain consists of proteolytic enzymes and peroxidases, produced from unripe papaya (*Carica papaya*). It has bactericidal, bacteriostatic and anti-inflammatory action, used in the treatment of wounds, removing necrotic tissue quickly and in a nontraumatic way. Moreover, another advantage is its low final cost. Trained professionals should perform the indication of the use of papain, improving patient's care and outcomes. Its use occurs associated with cleaning technique and subsequent application of the product, with dressing

change according to the needs of the patient and his/her wound.<sup>11</sup>

### ♦ "It started with an itch": the onset of the disease

Fournier syndrome has fulminant onset and presence of hyperemia, subcutaneous crepitus, bubbles formation, genital hypersensitivity, also occurring with severe and progressive pain, swelling, and subsequent wound by tissue necrosis. The higher the degree and extent of necrosis, more important are the systemic effects, and, thus, the greater the mortality.<sup>8</sup>

The disease associates with the presence of fever and chills, being also important the presence of fluid secretion of dark brown color with strong and repulsive foul odor at the injury site.<sup>3</sup>

Subjects reported numerous symptoms, consistent with those observed in the literature, highlighting the itching as the first symptom, followed by swelling and pain - reported unanimously. They referred to the syndrome as insidious, occurring with progressive pain, characterized as unbearable:

*It started with an itch. I kept scratching, and a little lump began to appear. This lump got to the size of a marble. [...] It hurt so well. (Zeus)*

*[...] a lump over there, I scratched, then it became an abscess. I felt pain. (Apollo)*

*It hurt like this, here [...] this part, then, it started to swell up, and then a secretion exploded. (Dionysus)*

*I was already feeling it swollen. I didn't feel anything. I felt only a soccer ball on my buttock. It increased, but I can't remember when it started [...] the fever I felt here, at home, until I got to the hospital. (Hermes)*

### ♦ Comprehension on the disease and its treatment

Being a relatively uncommon disease and having no determined cause, sometimes the Fournier syndrome is unknown by the subjects, including, say some authors, by those who have gone through the experience of developing it.<sup>3</sup>

The statements allowed observing that all the subjects mentioned lack of knowledge about its name and some terms related to the Fournier syndrome, even after the treatment period. Some subjects classified also as "abscess" and "boil" in an attempt to explain the signs and symptoms:

*No. I've never heard of it [...] I thought it was a boil. (Zeus)*

*No [...] It's an abscess, it was an abscess. (Apollo)*

*It's the Fournier bacterium. I got to know it over there. (Hermes)*

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In addition, the subjects showed a vague notion of the cause, progression of the disease and the performed treatment.

It is necessary to mention that, after the completion of early diagnosis, treatment may be an urgent surgery, with debridement of devitalized tissue, performing a new surgery if necessary.<sup>12</sup> Allied to surgery, support measures are available for water-electrolyte, acid-base and hemodynamics disorders, and administration of broad-spectrum antibiotics.<sup>1</sup>

From the statements on the perception of before or after the treatment, the subjects reported the "scraping" and withdrawal of "rotten meat" as measures used to treat their disease, as follows:

*[...] I thought I was getting to the hospital on basis, that they would "burst", [...] taking that thing out of me and I would get better [...] firstly, I underwent a surgery and after, they performed a "scraping". (Zeus)*

*I thought it would be simple [...] it started to ache, then the doctor performed a scraping. (Apollo)*

*I can't remember. He performed the surgery, then I bandaged it [...] (Dionysus)*

*[...] when he put the knife into it, it got a lot better. He took off all the rotten meat. (Hermes)*

#### ◆ Perception related to healing

After surgical treatment, the subject with Fournier Syndrome starts living with the dressing at the injury site, which is subject to constant changes.<sup>13</sup> The regulations generally indicate the completion of the dressing twice a day, or more often, if necessary.

Subjects with Fournier syndrome, trying to explain what it feels like to go through this experience, report many feelings. For this, the nursing professional can intervene in order to bring success to treatment, playing a key role while helping the subject to cope with his/her disease and acceptance of the image of the wounded body.<sup>7</sup>

Although the lesions initially manifest it in the biological body, they reverberate in the psycho-emotional and social plans of the people. The characteristics of lesions (necrosis and odors) hinder or limit social contact, leading to isolation and suffering.<sup>14</sup> Family, friends and health professionals can help them to accept their body image, now modified. Thus, approaches focused only on the wound does not reach the individual, which is unique in his/her pain.

The needs for dressings and other forms of treatment, performed either in hospital or when in home care, indicate a change in the routine of the subject and his/her family:

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*[...] there were two (dressings) if I didn't go to the bathroom. If I went to the bathroom, three or four times [...] I always had to have someone to change it [...] (Zeus)*

*Three times. Every day, there were three times. (Apollo)*

*Twice. In the morning and in the afternoon. (Dionysus)*

*[...] the dressing every day [...] It was once, twice. (Hermes)*

Interviewees also reported the pain, characterized as unbearable, as a symptom present both at the beginning of the disease as in the treatment period, especially in the execution of dressing:

*[...] it hurt so much [...] 25 hours a day, it hurt. And I wasn't anymore [...] the worst part was the cleaning with the serum [...] (Zeus)*

*[...] I felt pain before the surgery, I went there because of pain. After that, I felt no pain no more. (Apollo)*

*[...] it was pain [...] just pain. (Dionysus)*

*[...] nothing. I've never felt pain. (Hermes)*

During the course of healing - when there is manipulation of the wound - the intensity of pain may vary according to the administration of analgesics and evolution of the disease. That combination of drugs with humanized care aims to improve the therapeutic efficiency and to provide greater comfort to the patient.

The absence of pain is a situation rarely observed in Fournier syndrome. Only one subject of this study reported feeling no pain, which can be attributed to the fact that he had spent the first few days after surgery in an intensive care unit under sedation.

The interviewees referred also feeling repulsion to see or touch the bandage, not expressing the will to even observe the wound after debridement:

*I put my hand on one day and I saw that hole; that disgusted me. I couldn't see anything. I didn't want to, right? (Zeus)*

*[...] I tried not to look at it. (Hermes)*

Thus, the body conception, in body-mind and body-soul, where the health professional should enhance the subject's body as part of a whole human being, which has history, rights and duties. Therefore, the subject must be informed about the procedures so that they understand their reasons; avoiding, sometimes, the feeling of disgust and ignorance of his/her state.<sup>15</sup>

It is important to consider the combination of the severity of the health status and the proximity of death that the patient makes due to his hospitalization brought by Fournier syndrome. Sometimes, the patients with that



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disease lose their identity and autonomy, privacy; they experience the feeling of fear, isolation, and their self-image is modified.

One cannot forget that, for it is a disease that affects the genital region, the patient with Fournier syndrome also experience the feeling of shame in relation to the health, but that can be overcome by the healing will:

*[...] I felt no shame anymore [...] I had always been a man who never liked to pee in front of anyone, when I traveled, I'd prefer to go into the bathroom, I've never defecated even in front of my wife; when she was in the bathroom, I waited until she left for me to get in. And there, I've lost the shame [...] with open legs, five ou six ladies got in, looked, looked at me naked. (Hermes)*

The feeling of shame may be accompanied by the feeling of helplessness that the subject feels about the disease: the job is interrupted - of both the subject, as the family member accompanying him - the economic difficulties increase and concerns become constant.<sup>16</sup>

#### ♦ Nursing and home care

For assistance to be complete, components of a multidisciplinary team must join forces in an attempt to heal, in a broader view of human beings, integrating expertise. In this group, the nurse plays a key role in assisting the subject with a wound and should be aware of his/her responsibilities. Thus, nurses have knowledge on treatment of wounds, being updated on the prevention and having extensive experience with the covers and products on the market. In addition to body treatment, the professional has great importance in the emotional support of that subject and should provide care, perform procedures, but, above all, provide humanization and receptiveness.<sup>7</sup>

Respondents indicated the importance of the service provided by the nursing staff, being possible to observe that the assistance of those professionals can bring resoluteness and comfort to the subject, but leave them dissatisfied and even more fragile in hospitalization:

*[...] there were loving nurses, but there were others who were "butchers". (Zeus)*

*[...] I felt no pain, the nurse was very good. (Hermes)*

Regarding home care, Ordinance No. 2529 of October 19, 2006<sup>17</sup> states that it must be a care modality inserted in local health systems in the Unified Health System (SUS), integrating actions of the various levels of care in a shared responsibility. After going through an inclusion criterion, the subject rely

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on a team of the closest Family Health Strategy (FHS) and on the family care.

The caregiver stands out as an essential actor for the effectiveness of home care, as an articulation element and intermediation of resources and efforts for the realization of the treatment plan.

Therefore, the family is no longer seen just as one that must comply with the provisions of health professionals; they must be heard in their questions, their opinion should be taken into account and their participation should be encouraged throughout the care process.<sup>18</sup>

It is possible to observe, in the reality of all respondents, the presence of a wife or sister that are caregivers, highlighting the female figure as one that promotes care. Unanimously, the subjects counted on the presence of a woman to carry out the dressing and the development of daily activities:

*[...] my wife started to bandage. Then, she did it at home; she's done all the dressings. (Zeus)*

*[...] I came back with a bandage and also bandaged here [...] It was my wife who did it. (Apolo)*

*[...] it was my sister. (Dionysus)*

*[...] my wife was the one who took my to the places and who bandaged. (Hermes)*

## CONCLUSION

This study allowed understanding the perception of subjects who developed Fournier Syndrome regarding the disease, treatment and changes in their daily lives. Its development has specific signs and symptoms that trigger feelings and lifestyle changes.

With the research results, it also became evident the lack of information about the disease available to the subjects and the clarification of its situation. This is certainly due to the distance between patients and professionals, which certainly contributed to intensify the difficulties of those individuals and their families, especially after hospital discharge.

It is important to mention that, after receiving treatment and being discharged, the subjects of this study received only family care (wives or sister). Nevertheless, when the patients are discharged and return to their community, they should receive assistance from the FHS, but the interviewed subjects did not even receive visits of any health professional. The subjects were accompanied by their caregivers, but they have not received guidance or training for care after discharge.

A further approximation between subjects with Fournier syndrome and health

professionals is necessary in order to develop actions that enhance health care, going beyond assistance to the wound, trying to minimize the physical and emotional damages caused by that disease. It is essential to promote proper planning assistance including psychological support and popular education in health. Therefore, the nursing professional can help the subjects develop skills for self-care, which contribute to improve their living process.

It is noteworthy that Primary Health Care develops great importance in the continuity of treatment and prognosis of the subject with Fournier syndrome, but it is necessary to invest in good working conditions and availability of resources so that the FHS can work and perform actions in a comprehensive manner to all users of SUS.

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