



BURKINA FASO Specific missions for prolapses

NIGER

Noma, a women's story?

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Hadjatou: a model of courage and resilience



Editorial

Women's resilience, a strength or a problem?

The term is omnipresent, repeated over and over again. It is used in politics, economy, ecology and health. Social programmes are also concerned by this phenomenon and resilience sometimes sounds like an injunction.

Women's ability to adapt in the face of adversity and their capacity to extricate themselves from a difficult experience are remarkable. They manage to call on their own resources, and to free themselves from their problematic situation with a high degree of responsibility, particularly when it comes to meeting the subsistence needs of their children. Nevertheless, resilience does not mean invulnerability. It is neither absolute nor ever to be taken for granted, and needs to be nourished through concrete perspectives, and by support that takes into consideration not just their personal situation, but also their environment.

What if it were injustice that gave resilience its lustre? Does this not reflect the disengagement of the State? The life stories that you can sometimes discover in this journal are not only individual. They become collective and symptomatic when they take place in the context of poor governance, an absence of opportunities and widespread insecurity. While it must be acknowledged that some governments make efforts to support women, women still face many obstacles. Access to maternal health, education and income-generating activities are still complicated and land law is hardly favourable to them.

The Sentinelles teams not only help women through their ordeals, whether they are abandoned, suffering from obstetric fistulas or else at the bedside of their sick child for several months, but they also look after them and offer them effective and lasting help.





Marlyse Morard Managing Director

INDEPENDENT OF ANY IDEOLOGY, SENTINELLES, FOUNDED 1980 BY EDMOND KAISER, WORKS TO RESCUE AND ACCOMPANY CHILDREN AND ADULTS IN DEEP DISTRESS.



| COLOMBIA

Access to treatment, an obstacle course

There is in Colombia a State health care and social security system which guarantees – at least on paper – access to treatment for all. To obtain their rights, the beneficiaries have to contribute to the treatment costs proportionally to their revenues and initiate the procedure with the health insurance themselves. Unfortunately, it happens that the latter does not respond adequately and/or refuses to assume the costs of operations or longterm treatments. In the face of the complexity of the administrative formalities, the most vulnerable people often abandon all requests.

It is the case of Santiago, aged 18 and afflicted with cerebral palsy. At the time we met him, the health insurance covered none of his basic needs. The financial situation of Santiago's family of eight being very precarious, we initiated legal and medical support in order to assist the young man in obtaining his rights. The steps taken got Santiago to win the case and today at last he receives the necessary medication and incontinence pads he needs, thus regaining some autonomy and enjoying a more dignified life. We are still working at getting him a wheelchair and the complementary therapies he requires.

| BURKINA FASO

Setting up of a network for the elimination of obstetric fistula

The obstetric fistula has been almost eradicated in developed countries, but in some parts of the world women and girls still live with this illness, even though it can be prevented or surgically repaired. At the end of 2018, a new United Nations resolution exhorted States to intensify their efforts in the field of obstetrics and neonatal care as well as in the treatment of obstettric fistula. Following up on that request, Burkina Faso has decided to set up a network for the eradication of this very serious and dangerous lesion involving the main actors working in this field (Ministry of health, regional hospitals and associations). Sentinelles takes part in the setting up of such a network and looks forward to intensifying its collaboration with its various partners in order to try and put an end to fistula in Burkina Faso.

MADAGASCAR

Surgical missions in times of a pandemic



Our programme of treatments continues to be impacted by the health crisis caused by the coronavirus. Surgical missions covering most of the orthopaedic operations on young patients could not unfortunately be carried out neither in 2020, nor during the beginning of this year. They are usually performed by a medical team from Reunion Island, the Association Journées d'Orthopédie. The latter will unfortunately not be allowed to go to the Large Island as long as the pandemic lasts. Pending resumption, the most urgent cases requiring immediate intervention are entrusted to specialists in various hospitals of the capital and covered by Sentinelles.



SENEGAL

Together for the well-being of talibé children

In order to better understand the talibé children phenomenon, the Sentinelles team embarked on a complex census exercise of the daaras in Mbour.

To this end, it first met with the President of the district delegates of the commune to obtain his support. In Senegal each district and each village has a State appointed delegate. The cooperation of the about 41 representatives active in the commune has enabled the identification of 260 daaras. This census is only the first step in an important amount of typological analysis and observation work which will facilitate the identification of the more sensitive establishments and allow us to better protect the physical and moral integrity of the children. Recently a young boy died under the blows inflicted by a koranic master. The numerous forms of neglect and ill treat-

ment some talibé children are subjected to threaten their health and security. By associating the district delegates to our efforts in enforcing the respect of the rights of children will reinforce the social webbing and thus our own actions of assistance and prevention.



NIGER Women and the support for children suffering from noma

As a loyal reader of this journal, you know that noma is an illness that mainly affects children aged between 2 and 6 years old. Although the causes of noma are still not very well known due to the lack of scientific studies, some risk factors have been identified, such as malnutrition, a bad mouth hygiene and the immunodepression due to illnesses such as measles and malaria. If noma relates essentially to children, it is no less a story of women.

At the noma treatment Centre in Zinder, we welcome boys and girls in noticeably different proportions. For 25 years, we have welcomed a total of 1295 children, of which 55% are girls. This number does not help in knowing if noma affects more girls than boys, but it reveals that more girls are brought to the Centre. Where noma becomes a story of women lies in the care of the child toward recovery.

In Niger, the education and the health of children are handled by women. In our shelter, children are, for the most part, accompanied by their mother, their grandmother and sometimes their aunt. These women, who often stay with them for months, play a fundamental part in their recovery and their acceptation when they go back to the village despite the heavy consequences of noma. They see their existence highly impacted by the consequences of this illness.

Mariama, who is 5 years old, arrived at the Centre with part of her face necrotised, which ended up leaving her with a giant hole where her left cheek should have been. If Mariama is fine today, she nonetheless keeps scars that will not be repaired by reconstructive surgery for some years. Each morning, when she receives treatments for her wound, her aunt Zeinab who accompanies her almost always systematically faints. The sight of the wound is not easy to bear, but we understand later that the aunt is caught in a whirlwind of emotions: "Mariama is not my daughter. I lost 4 children and I only had one left. My sister who had a lot of children then entrusted her daughter



Mariama to me so that I could take care of her. This illness came as they entrusted her to me, and I am guilty of this."

Long talks between our nurse and Zeinab were necessary to try to free her of her guilt. These moments of exchanges allow us to soften the psychological effects the illness can bring, including the effects on the family and friends of the affected child.

If Zeinab soes not have to feel guilty of her niece's illness, who is to blame?

Niger is one of the poorest countries in the world. With two-thirds of its land being arid and without any access to the sea, it suffers from starvation, from recurrent droughts and this extreme climate leads to food precariousness as well as a total lack of means of subsistence for the population. 85% of Nigeriens work in agriculture where women are really active, particularly during the rainy season. During the peak of field work, because they have to help their husband, they leave their home and are thus less available to watch over their children. This is what happened to Mariama and her aunt Zeinab. The real culprit is the lack of means, the extreme poverty and hunger.

In the Centre's courtyard, these accompanying women talk between them during long hours. When they arrive at Sentinelles, they discover that they are not alone to endure their children's illness and they help each other out a lot. Some of them position themselves as true leaders. It is the case of Rekia, Aboubacar's mother, a 7-year-old child, who courageously gives a speech with strength and humility in front of 40 persons during a reunion.

"I came here once with my son Aboubacar. Back at the village, my tutor got seriously ill, and I was the only one who could take care of her. I left with her, leaving Aboubacar to my sister. When I came back home three weeks later, he had relapsed and was suffering from noma once again".

The lack of food, the bad hygiene conditions, the poverty, all of those risk factors that contribute to the contraction of noma are all too often gathered within Nigerien families that live in a state of utter deprivation. Women have to take care of their numerous children, of their ill family members, which can prove to be problematic.

Rekia explains to us: "I hesitated a bit to come back to the Centre because during our first stay, we had been explained the risk of relapse and I was ashamed to be back with my son to see the caregivers. But the hesitation was short-lived, and my husband supported me a lot. It is he who gathered the required money so that I could travel with Aboubacar to Sentinelles". Rekia talks openly and without discomfort. She is a very respected voice within the group of women in the Centre.

Another voice that is also very respected, a true example for all of them, is the one of Laouré, our cook.

Laouré arrived at the Centre in 1998 with a complete constriction of her jaws because of noma. She was 2,5 years old at the time. Today, she is a 25-year-old young woman that shines and she has come a long way under Sentinelles' supervision. Although her two maxillofacial surgical operations did not allow for a complete recovery of her mouth opening, she was able to be schooled and benefitted from a professional formation; and she was finally hired where she was healed 20 years ago. Laouré gives hope to all women that are in the Centre with their children. Not only does she take part in the numerous discussions, but she is also the proof that having noma is not a curse.

Each of these women demonstrates the major part they play in the education and the health of future generations. This role must be taken into account in the establishment of policies fighting against poverty on a national scale and it is by inte-



grating the improvement of women's rights that the major objectives will be seen through. The Nigerien state and its non-governmental partners have clearly understood the issue because the women are as much the actors as the beneficiaries of the recent changes. Recently, two laws were for example adopted to protect and support the young women being schooled as well as to reinforce the fight against early marriage. An important advocacy led by the female population will also allow them to fight actively against violence based on gender.

Within its means and focusing on the person itself, Sentinelles contributes to the fight against poverty by tackling the illness of noma through prevention, the raising of awareness and the treatment. And for the accompanying women, they are the biggest actors in the recovery of the children, and they will play an essential role in raising awareness in their community when they return to the village. We also look after them for that!





Prolapse : long years of suffering that could be avoided

- **Bladder prolapse or cystocele:** this is the most common (80% of pelvic prolapses). This is the externalization of the bladder into the vagina by the collapse of the anterior wall of the vagina
- Prolapse of the uterus or hysterocele
- The prolapse of the rectum or rectocele.

Women suffering from prolapse regularly ask for our help in order to regain their health. Where possible, we offer access to surgery as part of our obstetric fistula programme. The demand and the waiting list increase every year.

Prolapses of the different pelvic organs are often linked. It is a common condition that is clinically diagnosed quickly, but the surgical management can be complex.

Milder cases can be treated with pelvic floor muscle rehabilitation. In the more advanced stages, the organ(s) protrude outside the vagina and an operation is then necessary. Symptoms experienced by women include abdominal or pelvic pain, pain during sexual intercourse, protrusion of the organs into the vaginal opening, bleeding or bladder weakness.

The most common cause is trauma during childbirth, during which severe musculoskeletal disorders can occur. This is particularly true for multiple births, large or heavy babies, complicated deliveries or deliveries that are too close together. It is most often seen in women who have had several children, who have had complicated deliveries and who are menopausal. The prevalence of prolapse in Burkina Faso is far from established, but due to earlier, closer and more numerous pregnancies, this condition occurs more frequently and earlier in Burkinabe women than in western women. They come to us for help, often many years after the prolapse has occurred, due to lack of knowledge or lack of access to care. We take care of them during the surgical missions organised as part of our obstetric fistula programme. However, we can only help a few women per year, as surgical operations, apart from obstetric fistula cases, are not financed by the United Nations Fund for Population Activities (UNFPA).

The waiting list is getting longer, and we would like to be able to organise specific prolapse missions. The testimonies that we have collected from certain women at the time they were referred and after having undergone surgery clearly demonstrate the needs, the suffering they have endured for too many years and, above all, the happiness with their regained health!

AFSA, 44,

had been suffering from prolapse for 15 years. She has had 13 pregnancies, including 10 deliveries. She has 7 children still alive.

"I got this disease about 15 years ago, after giving birth to Baby, my third child. I had very intense pain in my lower abdomen and a mass came out of my vagina. The health centre informed me that I needed an operation, but as I could not afford an operation, I took cheap painkillers. The lump only grew over the years as I gave birth to my other children during my illness. It would come out, go in, and I often had to push it in. The worse it got, the more my husband and family moved away from me. These were psychologically and physically difficult years. One day, when I was in severe pain, my sister-in-law gave me the telephone number of Sentinelles. I had no idea that this was the contact that would open the door to recovery after fifteen years of physical and mental suffering. Today I am completely healed in my flesh, in the depths of my intimacy and in my spirit, and I have come to express my gratitude to Sentinelles and to the people who cared for me, and to bear witness so that other women suffering from this disease know that they can be healed! "





KADIDIATOU, 46,

had been suffering from prolapse for 17 years. She has 5 children.

"My illness started in 2003 as a result of pelvic pain. I consulted several times without success and then recently I went to another health centre where they gave me your contacts and told me that you would take care of my illness. That is how I came to meet you and ask for your help. Before the operation I had severe pain in my lower abdomen and dizziness. I could no longer work like the other women and the co-wives thought it was due to laziness. It was eating away at my heart because in the village you have to be able to work in the field for the whole family's ration. I didn't want my husband to come near me anymore. After the operation I am no longer in pain or dizzy. I know that I will be able to take part in the work in the fields this year and not be totally dependent on others. I will be able to welcome my husband with open arms at the end of my recovery period. I am very happy, and I have no words to thank those who have helped me. »

Help women in Burkina Faso benefit from an intervention that restores their health.

We would like to organise specific missions for prolapse patients at St Camille Hospital in Ouagadougou.

The cost of a surgical operation required to heal a woman with advanced prolapse amounts to around **CHF 500**, or **CHF 5,000** for a mission of ten women.

This includes pre-operative consultations and examinations, surgery with the operating kit, post-operative medication and a four-day hospital stay.

Sentinelles already covers the costs of transport and the stay at our Convalescent Centre.

SWITZERLAND

A long-term treatment

Hadjatou just celebrated her 11 years. She arrived in our country from Burkina Faso at the end of January 2020 for the reconstruction of her face which was severely damaged by noma. Such surgery cannot be performed in her country, hence the organisation of a transfer to Switzerland.

Treated in the Geneva Teaching Hospitals, Hadjatou has already undergone three surgical interventions consisting first in the reconstruction of her left cheek, destroyed by the illness, with a flap from the serratus anterior muscle (on the left side of the thorax, under the armpit) and the reconstruction of the bones of the left eye socket and the nose.

In the course of the last operation an expander was placed under the skin of her forehead. It is a sort of balloon that will be inflated little by little in the course of several weeks with the introduction of some liquid by means of a little valve placed on top of her head. Such technique allows the progressive increase of the skin surface, which will later be used in the reconstruction of the nose also destroyed by the illness. Thus, the skin of the nose will be the exact same colour as the rest of the face.

Hadjatou bears this heavy treatment with great courage and resilience. Unfortunately, it is often interrupted because of the ongoing health crisis, and then extended because of some medical complications. In addition, the delays between the various operations are lengthy. Though she has adapted remarkably well to her life in the Massongex Shelter where she is very well treated and supported, Hadjatou is beginning to find it hard to be separated from her people. When the nose has been reconstructed by two separate operations there might be a need for some additional small finishing touch interventions, and then Hadjatou will finally be able to return home and rejoin her family with a new face.

We are accompanying her on this long road to healing and always marvel at her joy of living and her capacity to adapt, a real lesson of life!



GRAND PREMIERE: A LIVE CONCERT IN FAVOUR OF SENTINELLES



On Tuesday 27 April, from 7.50 pm, Stéphane Wild (www.stephanewild.net) will offer his talent and songs live on Facebook from our offices, with interviews with Christiane Badel, President, and Marlyse Morard, Director, as well as videos presenting some of Sentinelles's actions.

To share these unique moments of music and solidarity, visit the Sentinelles Facebook account.

Scan the QR code to access the account www.facebook.com/ sentinellesfondation



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