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The hidden faces of sepsis, what do they tell us? Focal points for improving patient outcome



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Based on the patients' perspective Nutma sheds light on the hidden faces of sepsis, calling for more expertise on sepsis sequelae. She also offers recommendations to improve recovery and outcome.

It wasn't until 2007, after my illness that: *"I came to understand the extensive process of recovery after critical illness. Moreover, I came to realise that the need for explanation, support and advice, as well as the importance of providing the patient with a good start of the recovery process, was seriously underestimated. Having been a former nurse, I considered this an important eye opener"* (Nutma 2016).

Obviously, I was enormously grateful for having been given a second chance. When my recovery came to a standstill at a certain point, I learned that survival 'in itself' wasn't sufficient to measure 'outcome'. I'm very happy that the patient's perspective of quality of life is being taken into account more and more.

Sepsis: a critical illness in disguise

In 2007 I experienced the thin line between life and death caused by sepsis. I fell ill due to a septic shock, and spent 5 days in ICU. I was in critical condition and my family was informed that "it could go either way", leaving them between hope and fear. Fortunately, thank God, I turned the corner after having been ventilated for a few days. Sepsis is incredibly sneaky. Without warning and seeming to resemble the flu, sepsis strikes like lightning, devastating both you and your loved ones. In a few hours' time I went into shock and developed acute respiratory distress syndrome (ARDS) and disseminated intravascular coagulation (DIC), the meaning of which comes close to Death Is Coming.

Earlier that morning, just before ICU admission, antibiotic IV treatment because of pneumonia had already started. I tried to make sense of it all: how did my body lose control? It felt like some supernatural force was pushing me over the edge.... It started with dizziness when walking to the toilet, and soon it felt like my legs went wobbly. I made it back to bed just in time and called for the nurse. It became clear that I was very hypotensive. Shortly after that my feet and hands had turned ice-cold and I felt my heart beating very fast. I realised that I was going into shock. In less than 15 minutes my shortness of breath worsened and as I coughed, my mouth filled with bloody mucus and fluid. For a moment I was caught by the very fear of dying, and I thank God there was an ICU to turn to: it saved my life.

Being a nurse at the time, I tried to get a hold on things. The first few hours after my transfer to ICU I stayed very alert, and every now and again I looked over my shoulder on the monitor to see if my blood pressure was rising. It wasn't.... Sepsis, however, never crossed my mind! During my nursing education the word sepsis had been mentioned with regard to a complication of a wound infection or a peritonitis. Never ever had it been referred to as the systemic, dysregulated host response or organ dysfunction that was making my body react in this life-threatening way. Eventually I had to let go, due to exhaustion. Breathing was hardly possible, and after a moment of saying goodbye—"for better or for worse"—I was given ventilatory support. Sepsis nearly killed me, but no one ever mentioned the word.... A few months after my discharge I noticed the

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word sepsis in my medical record.

As said earlier, sepsis really caught me by surprise. Many patients don't realise what's going on, because the brain has already lost control. As a matter of fact, when patients do stay alert and experience life slipping through their fingers, they often don't get the chance to fully realise the impact either, because intubation makes sedation necessary. On top of all this, lots of patients don't realise 'what hit them', because, just like me, they hadn't been informed. Hence it became my mission to communicate about sepsis and to literally spread the word. Fact is, that even when patients are not admitted to the ICU (with treatment sometimes carried out under the supervision of an ICU physician) sepsis remains a critical illness. Actually, it seems to be the most common critical illness outside the ICU, for one main reason: sepsis is not often promptly diagnosed at the general ward. There's one more important aspect of disguise: when things go wrong in terms of prompt diagnosis and consistent implementation of protocols, sepsis is generally referred to as 'a complication', whereas it should actually be regarded as a calamity. The report on 'collateral damage in Dutch hospitals', published in 2007 (de Bruijne et al. 2007), led to the Security Management System implementation in hospitals, including protocols of the Surviving Sepsis Campaign. The importance of compliance was illustrated by van Zanten et al. showing a decline in the mortality rate of 16.7% (van Zanten et al. 2014). When it comes to consistent compliance and alertness, a lot of work still has to be done in hospitals and other settings, in the Netherlands, but in the rest of the world as well.

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Recovery after sepsis and critical illness: from no man's land to a mission

- Given the fact that sepsis is a critical illness in disguise, extra effort is also needed to spot it proactively, including concentrating funds and scientific research to develop biomarkers.
- Raising the red flag on sepsis remains very important, just as important as communicating the word 'sepsis'.
- The same applies to creating more awareness of long term sequelae, although significant progress is being made by the Global Sepsis Alliance and many others.

My recovery took a long time and there was no aftercare whatsoever, nor information about what to expect and how to cope. It was also hard for my husband and children. My energy level was terribly low. I was readmitted three times because of an infection during the first few years, and I had problems with 'ordinary' things like planning, multitasking, remembering appointments, etc. Mentally I suffered from mood swings, a short fuse, and the quest for the explanation of the 'void'; I had no factual memories of the crisis I'd gone through. Actually, the struggle *for* life had turned into the struggle *with* life. Nowadays we know that critically ill sepsis patients are more likely to develop PTSD (Johns Hopkins Medicine 2013). Fortunately, the definition of postintensive care syndrome (PICS) has highlighted the impact of critical illness in general (Needham et al. 2012). At the time, however, I blamed myself for having these feelings. Finally, after 8 months I found some fellow-sufferers. They also felt like they had been dropped in no man's land: deserted and facing rehabilitation all alone.

Eventually, having gained strength from complementary medicine, I decided to assemble all the information on sepsis and recovery after critical illness I could find, and write a book about it. Moreover, it triggered me to turn my mission into a new job: teaching, giving lectures, information and guidance, from the patient's perspective.

I sincerely hope *Sepsis and Afterwards* provides former patients, relatives and professionals from all over the world with a better understanding of the impact of sepsis and all that may be helpful during recovery. Information about the book: <https://www.sepsis-en-daarna.nl/english>

The hidden faces of sepsis – some focal points

Sepsis leaves a trail of devastation to many survivors and/or relatives. A few months ago I received a phone call from a woman whose sister had just passed away in ICU, due to sepsis. She told me that in a few days' time her sisters' legs had turned purple and black, and how she had witnessed her sister literally leave this life bit by bit. It's terrifying and one of the horrible physical faces of sepsis, causing death or great *visible* impact due to disseminated intravascular coagulation (DIC). However, I'd like to shed some light on the more invisible, let's say *hidden* physical faces of sepsis: neuropathic disorders, neurocognitive sequelae and the effects on the immune system.

□

An important aspect of my job is to provide guidance to former patients (and/ or their relatives), and it strikes me how often they report some form of neuropathy. This also applies to those who were not admitted to the ICU (meaning they were not ventilated and sedated), emphasising how sepsis itself can affect the peripheral nerve system. They may suffer from tingling, pain or even numbness. When these symptoms occur during and after ICU admission they are described as ICU-acquired weakness, but actually this expression doesn't cover the sensory aspects mentioned above. Critical illness neuropathy is a comprehensive expression for various disruptions of the nerves. This may also include autonomic dysregulation (as reported by some clients), combined with hypersensitivity to all kinds of stimuli, together with an auto-immune disease or a hyperactive immune system in general. This suggests a possible (complex) link and interaction between the brain/the central nerve system and the immune system. Many of these patients are confronted with the knowledge gap with regard to these after effects, because the expertise about sepsis among physicians is often limited to the acute phase of the illness.

A (research) centre specialised in sepsis sequelae would really be a major step forward.

As to the neurocognitive sequelae, it is important to realise that sepsis is an independent risk factor for delirium, making patients vulnerable to neurocognitive disorder: they are facing problems with their short-term memory, mental processing speed and multitasking, and returning to work. Smith and Meyfroidt stated that “the brain is always in the line of fire” and that:

“a brain-oriented approach should be a unifying concept in the management of all critically ill patients” (Smith and Meyfroidt 2017).

More focus on neurocognitive rehabilitation(facilities) is needed.

Protecting the brain is reducing neurocognitive sequelae and the effect on the immune system as well. What applies to the brain applies to PICS in general: you don't have to repair what can be protected and secured. Furthermore, especially after sepsis, the immune system is totally out of balance, giving way to all kinds of 'intruders', among other things, due to a heavily disturbed intestinal flora.

“According to a study published in the Journal of Hospital Medicine, about onethird of the survivors of sepsis or septic shock were readmitted within 30 days (Zilberberg et al. 2015). This all lays a heavy burden on the lives of the survivors and their family members, but on society and healthcare as well” (Nutma 2016).

And who shows those concerned the way to build up their immune competence again?

Patients should be provided with recovery tools to build up their immune competence.

In organising the workshop 'Recovery after sepsis' I try to make a contribution and give tips about good nutrition and dietary supplements which I found to be very helpful myself.

Conclusion

Serious attention to rehabilitation right from the start can make the difference between the downward spiral and climbing up. Fortunately the general focus on the impact of critical illness and ICU admission (which concerns many sepsis patients) has improved. Quoting *Sepsis and afterwards*:

“Investing in getting the ex-patient in better shape and teaching how to deal with impairments can mean a lot in terms of prevention. The so-called Balance Training for adult former ICU-patients was started up in the Netherlands in 2016, initiated by Hanneke Oonk, “Gezondheidszorgcoach” (health care coach),” together with the author of this article. “It supports survivors in dealing with longterm sequelae, by means of mindfulness, peer support and psycho education, aiming at (re)gaining the balance in body and life. [...] 'Family and Patient Centred Intensive Care' (FCIC) was founded in the Netherlands in 2015, aiming at reducing the impact of ICU care. This foundation seeks to combine expertise and experience of (health care) professionals, researchers and former patients and relatives” (Nutma 2016).

Still, aftercare tailor made for the needs of sepsis patients, like the workshop mentioned above, and reducing long term sepsis sequelae require more attention.

Therefore I'd like to call for more expertise and education on the hidden impairments of sepsis and to provide patients with more specific recovery tools, thus preventing readmissions and help them to improve their quality of life; the life that was so hard-won.

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