

Francesca Fedeli

Although stroke is often perceived as occurring primarily among the elderly, it also strikes infants, and can even occur before birth. It is one of the top ten causes of death for children, yet public awareness is extremely low, early detection is limited, and rehabilitation is inadequate. Francesca has applied some of the most pioneering research on the human brain to improve care for young stroke victims using technology while empowering families to play a greater role in their children's healthcare needs.

The New Idea

Unlike stroke affecting older people, whose incidence can be prevented through a healthy lifestyle, the causes of infant strokes are largely unknown. The phenomenon is more widespread than perceived, with 2-3 every 1000 newborn affected. Through her organization, Fight the Stroke (FTS), Francesca Fedeli is developing a holistic approach to the issue of pediatric stroke, which has far reaching implications for the treatment of a host of other illnesses. She provides families with a coping mechanism to understand what has happened to their children, to feel supported by an international network of parents who share the same situation and to engage in their children's rehabilitation at home.

Francesca has designed a rehabilitation toolkit which marries technological games and tools with face-to-face home rehabilitation. By applying the latest scientific findings on the brain cells responsible for imitation and empathy (known as mirror neurons) she created a wholly new approach to rehabilitation using wireless videogame technology (based on Microsoft Kinect system). Children get better while playing games, and crucially, the software collects data on each body movement, proposing an *ad hoc* rehabilitation based on each child's progress. The collection of data in the long run could also provide a scientific foundation to better understand child stroke and improve its cure, and create a new, integrated model of illness care. By moving rehabilitation from the hospital to the household, parents are also feeling the therapeutic benefits of being directly involved in their children's improvement. Francesca is harnessing the healing power of empathy –the parent/child bond – to accelerate health outcomes among patients, and empowering parents to rehabilitate their own children. Her combining of video game technology and harnessing the power of empathy has the potential to profoundly transform rehabilitation and cure for all types of traumas.

Francesca began her work in Italy, but after a fellowship in the United States, she is mobilizing an increasing international community of parents to raise awareness on the issue and connect them to the scientific and medical sector. FTS has increased its scope internationally with families engaged through the International Alliance for Pediatric Stroke and the first advocacy and support group in Italy, reaching today more than 200 parents.

The Problem

Blood must flow to and through the brain for it to function; if the flow is obstructed then the brain loses its energy supply, causing permanent damage to tissues, leading to stroke. The consequences are motor, cognitive and behavioral problems. Data on infant stroke is scarce, but

statistics confirm that 2 million young people under 35 are affected by stroke every year. Many of them are children. Of 1,000 newborn children, at least 2-3 are born with a perinatal stroke. Without a global registry, the incidence rate may be 2 to 4 times higher than published estimates. Signs of a perinatal stroke may go unrecognized for months or years because the symptoms can be subtle in very small babies who do not (and are not expected to) walk or talk. Late diagnosis leads to late intervention, missing the highest peak of brain plasticity and thus the biggest chances for the child's full recovery. Francesca and her husband discovered that their son, Mario, had been affected by a stroke only by chance: the hospital where he was born was undertaking an unrelated research trial that involved a brain scan of all children born in a given period.

Once a pediatric stroke is detected, rehabilitation can be time-consuming, expensive, stressful and ineffective for families. Current rehabilitation efforts follow adult physiotherapy and occupational therapy procedures, which are carried out in hospitals or clinics by doctors. As a parent of a child with stroke, Francesca experienced first-hand the struggle to be part of her son's rehabilitation process, which involved frequent visits to the hospital and repetitive, ineffective rehab activities. She understood that her own confusion was a problem of world magnitude—in areas far beyond stroke -- and decided to do something about it.

Francesca also addresses the needs of the parents of young patients. Lack of information on the causes or the consequences of stroke leaves many of them feeling lost, depressed or often guilty that they may have done something wrong during pregnancy. Support groups are a starting point for making them feel less lonely and more confident. Being actively involved in their children's therapy at home also seem to have therapeutic effect on them.

These issues of early diagnosis, rehabilitation and parental involvement fit in a wider problem of misperception of stroke, both among the public and in the medical community, where there is almost exclusive emphasis on adult stroke. As a result of low global public awareness, the resources dedicated to research in infant stroke are insufficient. Francesca believes that information technology has provided many parents, even without a medical background, with the opportunity to understand in depth their children's condition and to help hospitals to devise better healthcare solutions. She calls this open medicine, a new system in which the relation between patients (or their parents) and the doctors is rebalanced. This, combined with the development of advanced technology available to more people as well as promising scientific research, could provide a possible turning point in the role that families play in healthcare, whether they are affected by stroke or a variety of other diseases or conditions.

The Strategy

Francesca's life changed when her son Mario was born. 10 days later Francesca and her husband learned that Mario had suffered a stroke. Doctors told them that neurons are the only human cells not to be replaceable and there was not much that could be done, except for engaging in the same rehabilitation that is offered to adults which usually yields modest results. Unconvinced and uninspired by the traditional rehabilitation practices, Francesca began to study the issue independently and came across the research of Professor Giacomo Rizzolatti on mirror neurons. These neurons, first discovered in primates twenty years ago, are thought to be responsible for learning through imitation. They are also the scientific basis for the human capacity (shared with

other primates) for emotions, in particular those such as empathy that require putting oneself in somebody else's shoes. Francesca contacted Professor Rizzolatti, who had been awarded the Brain Prize, and began to actively use what she had learnt to devise a rehabilitation system that went beyond mechanical imitation but would use the full potential of mirror neurons. She experimented this method with Mario and noticed that by having his parents engaged in the rehab, rather than stranger medical staff, the child would progress much faster than other kids with similar conditions. The mirror neurons were activating a lot more than imitation reactions: as the "patient" and "health professional" were indeed parent and child, many more human emotions were also transmitted. Empathy was at the core of his treatment. These led to remarkable progress in Mario's health. It also shook Francesca and her husband away from a dark period of depression into a new phase of life. They began to consider what they had as a gift, and what they did not have as an opportunity. Francesca decided that it was not sufficient to try new ideas with her own son: other children and other parents had to be given a chance to experience her joy and satisfaction and created *Fight the Stroke*. The loneliness of her first year as a mother turned into the desire to speak up about what had happened to her family. She began by telling her story during a [TED conference](#) that suddenly reached a global audience. As more and more parents contacted her, she created an online forum for them to share their experiences, learn new facts and acquire new coping methods. This online group quickly grew internationally and offline. There are now over 200 parents involved who meet locally as well as in an annual Italian Family Gathering in Milan. As their voices grew stronger, infant stroke began to be discussed more widely in the media.

Francesca then turned her attention to improving rehabilitation for pediatric stroke – an area where she saw significant impact could be made, also thanks to a wiser usage of technology. Upon being the first Eisenhower Fellow for Innovation from Italy in 2014, Francesca began to map the issue of rehabilitation care, conducting interviews in USA and Europe with over 100 doctors and experts. She realized that it was not just in Italy, but across the West that rehabilitation practices for young stroke survivors were inadequate and had not been renewed or innovated in years.

Taking her insight on the healing power of empathy, she began to match it with existing therapeutic methods and tools, turning her attention to technology that was already available. She noticed that modern videogame consoles, such as the Wii or Kinect, consist in advanced wireless tools that scan a player's movement and instantaneously transform it into an action on the screen. She approached Microsoft in Italy and began to study with them a toolkit for dynamic rehabilitation exercises for children. She is now working on a final toolkit based on the feedback on the experts and is planning to run a clinical trial with families. Further product development include the usage of Azure, Skype Translator, 3D Printers and HoloLens. This new toolkit would allow peer-to-peer learning through remote connection, that is promising to be even more effective than parent-to-child learning. This can be effective for children who live far away from existing support groups or hospitals and can engage in rehabilitation as if it was a game played with a peer.

By allowing rehabilitation to be moved out of hospitals and into the hands of households and families, hospitals can be alleviated from in-house therapies, parents can be empowered and children could recover faster. This method would also allow the collection of big data for future

research and be applicable to other forms of rehabilitation from different types of traumas and motor disabilities. To secure scientific evidence on her method, Francesca is aiming to test her innovation in a double blind clinical trial, beginning with selected Italian families.

Francesca is in the process of making FTS into social enterprise in Italy. She plans a cross-subsidy model, where she might sell the toolkit for adult orthopedic patients (through insurance companies or hospitals) to enable her to offer the toolkit to families affected by pediatric stroke free of charge. Francesca is also working with local and intl health insurance agencies to set up an agreement to pilot a first program with adult rehabilitation.

Looking to the future, Francesca is planning the next technology innovation in the area of early detection of stroke. She has plans to create a head cap that will increase early detection, leading to the quicker implementation of rehabilitation therapies and ultimately the faster recovery of any child who suffers a stroke or any other traumas that requires rehabilitation. Putting children through MRI scans is extremely difficult, as the child is not supposed to move and the experience can be frightening for children. Francesca has already partnered with local Universities to begin research and development and is in the process of securing a financial partner.

Francesca is working on the issue of infant stroke in its entirety, from early detection to rehabilitation, from parental involvement and co-creation to community building and is innovating every aspect of its management. She has involved all necessary stakeholders and is ready to revolutionize the way pediatric stroke is approached. This could lead to innovation, both in terms of processes and tools, in several other areas of healthcare and applied to the treatment of a host of other illnesses. Potential of her approach can be foreseen even out of the health system (ie. learning platforms) and in developing countries (ie. through specific training modules for parents).

The Person

Francesca has always shown leadership in making change happen. She then began a career in marketing, communications and corporate social responsibility. Starting in several food companies, she then moved to American Express to build from scratch its first corporate marketing department in Italy. She then moved to ING and was instrumental in developing the first model of direct bank in Italy. Her life changed profoundly when her son Mario was born. Through her journey dealing and managing her son's stroke, Francesca grew stronger, more determined and began to think bigger. Four years later, Mario is in an entirely different place than his doctors originally predicted – he is walking, talking and taking part in FTS's awareness campaigns. Francesca was determined that other parents have access to her experience, and she founded FTS in 2013. In 2014, she left her marketing job with ING to fully dedicate herself to this mission.

Over the years, Francesca has established herself as an international thought leader and influencer on the topic of pediatric stroke, open medicine, citizen science and crowdsourced solutions in healthcare. Following her TED Talk, which has received more than 900,000 views, she was invited to sit on the Board of Directors of the International Alliance for Pediatric Stroke.

Most recently Francesca further solidified her position as global thought leader by publishing a book translated to *Fight and Smile: A Story of Love and Science*.

In June 2015 Francesca has been selected as the First Ashoka Fellow in Italy, entering a network of leading social entrepreneurs, as the Nobel Prize Kailash Satyarthi and other 3000 professionals with unrivaled commitment to bold new ideas, who have innovative solutions to social problems and the potential to change patterns across society.