

**THE BODY OF THE DISABLED:
EDUCATIONAL APPROACH TO PROTESIZATION
A READING THROUGH CASES OF PARALYMPIC ATHLETES**

**IL CORPO DEL DISABILE:
APPROCCIO EDUCATIVO ALLA PROTESIZZAZIONE
UNA LETTURA ATTRAVERSO CASI DI ATLETI PARALIMPICI**

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Abstract

The article raises the issue of the birth of malformed children during the time of a world emergency; how can we culturally deal with this issue? The focus is on malformations (hemimelia) of the lower limbs. The study discusses the cases of three currently or previously active paralympics athletes: O. Pistorius, J. Long, A. Mullins. Our main question is to understand whether the biomedical paradigm is enough for the use of prostheses in amputees and to analyze the validity of an educational support aid to increase the degree of resilience in emergency situations.

L'articolo pone il problema della nascita di bambini malformati nel tempo di una emergenza mondiale; con quale cultura affrontare questi casi? Il focus è sulle malformazioni (emimelie) degli arti inferiori. Si presentano tre casi studio riferiti ad atleti (o ex) paralimpici conosciuti: O. Pistorius, J. Long, A. Mullins. Nelle conclusioni si pone in discussione se il solo paradigma biomedico possa bastare nella protesizzazione di amputati e sulla validità di un ausilio di accompagnamento educativo che faccia crescere il grado di resilienza in situazioni emergenziali.

Key words

Disability, Hemimelia, Paralympics, Biomedical Paradigm, Resilience

Disabilità, Emimelia, Paralimpiadi, Paradigma Biomedico, Resilienza.

The men,
even if they must die,
they were born not to die
but to begin with.
Hanna Arendt

Introduction

The Italian population counts 60mlm317 thousand inhabitants on 1 January 2020. This data has been falling continuously for five years; indeed, since 2015 we have had a decrease of almost 551 thousand residents. In 2019 there were 420,170 registered in the birth offices, with a decrease of over 19 thousand units in 2018 (-4.5%). For 100 deceased people only 67 children are born (in 2010 there were 96). The balance of births and deaths was 212 thousand in 2019 (ISTAT, 2020).

According to the Italian Society of Neonatology (SIN), co-founder since 2015 of the World Birth Defects Day, -25,000 children are born each year in Italy with various types of malformation (worldwide about 8mln); these malformations, are responsible for about 25% of deaths before birth, and about 45% after birth particularly in the first year of life (Richmond, Atkins, 2005; WHO, 2004;2006;2008;2010; ISTISAN, 2011).

In the framework of malformations (different types, and not only physical ones), the focus that we discuss, concerns the congenital malformations of the lower limbs. The recovery of the data is extremely difficult. We found a reliable number from a report ISS, 2011 (ISTISAN n° 15/16). The report states that from a total of 21821 malformed newborn, 6122 showed lower limbs congenital defects.

In 2017 the WHO (World Health Organization) published the document “Leading the realization of human rights to health and through health”, in which it reiterates these concepts: *We all have the right to the highest attainable level of physical and mental health, without discrimination, wherever we are and whatever our circumstances. [...] Good health not only depends but is also a prerequisite for the pursuit of other rights. Human rights cannot be fully enjoyed without health; likewise, health cannot be fully enjoyed without the dignity supported by all other human rights.*

This document was preceded by the report “The Global Strategy for Women’s, Children’s and Adolescents’ Health 2016-2030”. During its presentation, UN Secretary General Antonio Guterres, said: *“In times of complex development challenges, the investments we make today in the health and well-being of women, children and adolescents will help build peaceful, sustainable and inclusive societies through the Sustainable Development Goals”.*

The Subject

Despite the COVID 19 pandemic orients our reflections on the use of the body and its care, it still remains an “emergency in the emergency”. Indeed, the management of subjects affected by congenital malformations, their educational direction and care approach, and the coexistence of both, is still a main issue.

A recent Italian conference has offered us the possibility of reflections with the curvature that we have offered previously. The first edition of the Festival of Paralympic Culture was held in Rome in November 2018.

During the press conference before the opening ceremony, the president of the CIP (Italian Paralympic Committee) Luca Pancalli, said: *“In recent decades we have gone from being handicapped and disabled, to being paralympic: not only has the terminology changed -which today no longer calls for bodily deprivation- but the way of perceiving disability in our country has changed. What is the mission of the paralympic movement has been accomplished, changing the perception of disability using the strength of the highest level athletes. [...] “The cultural revolutions take place for several reasons: We have used sport as a tool and not only as an end*

to set in motion a mechanism of cultural revolution in the country. It may seem presumptuous, but we want to do exactly that and that's what is happening”.

The reflections we propose in this work are inspired by what it is stated above; the birth of a malformed child, raises the necessity to adopt new “emergency” skills. How do we have to deal with it? What are the tools? What are the results? We need an “emotional capital” as expressed by Mariavittoria Isidori, who says: *“culture, but also education, can perform various functions: through contact with people who have already experienced similar situations, cultural and educational systems can put the subject that for the first time is in that type of condition, able to understand, assimilate how much the crisis experience can “teach”.* (Isidori, 2012).

Our intent is to present case studies from which we can discern the best approach and implementation. We will do it using the stories of paralympic athletes with different malformation needs (cultural, physical, psychological). In this specific case, we will talk about athletes with lower limb malformations.

Case-History:

We present below the cases of three famous Paralympic athletes associated by malformations. We discuss the solutions adopted (by their parents), and the relationship with their prosthetics.

AIMEE MULLINS

Aimee Mullins was born on 20/07/1975 with a hemimelia peroneale and underwent amputation of the legs below the knee when she was one year old. She learned to walk on prosthetics, and then to run, competing nationally and internationally as speed champion, setting world records at the 1996 Paralympics. She graduated in “History and Diplomacy” at the prestigious Georgetown University, where she was the first double amputee to compete in the 1st Division of the NCAA, National Collegiate Athletic Association. Despite her prosthetics, she is a model, starting with a legendary runway show of Alexander McQueen; she then devotes herself to acting, playing the Leopard Queen, in Matthew Barney’s Cremaster Cycle. In 2008 she was the official ambassador of the Tribeca/ESPN Sports Film Festival. She is also known as a supporter, model and public speaker (TED Talks 5 million views) and her face becomes a symbol of possibility and human potential.

Athlete Model Actress (life history in www.aimeemullins.com).

JESSICA LONG

Jessica Tatiana Long is born on 29/02/1992 in Siberia; she was abandoned in an orphanage, because she had fibular hemimelia; at 13 months old, she was adopted in the United States by a Baltimore family and at 18 months old, she suffered an amputation of both legs at knee level. She started to play sports at an early age, with gymnastics, but at the age of six, she started swimming. At the age of 12, she became the youngest member of the Paralympic team in the United States, making his international debut at the 2004 Athens Games and winning three gold medals. She is one of the most decorated swimmers in the world with 23 medals, 13 of which are gold medals. She was appointed among the “Women of the Year 2011-12” by the US Olympic Committee, for the eight medals won in London 2012. To the question why this sport, she answered: “Initially I was fond of gymnastics, but because of the damage I had to my knees with prosthetic legs, I changed, also encouraged by the fact that I did not have to wear prosthetics” [www.paralympic.org/jessica-long].

OSCAR PISTORIUS

Oscar Leonard Carl Pistorius was born on 22/11/1986, with a fibular hemimelia; at 11 months he was amputated of both legs under the knees. He soon began to practice sports: at the

age of 11 he began playing rugby; he then moved on to water polo, tennis and then to wrestling. In 2003 he left rugby and moved to athletic particularly in the 400 meter run. After a long legal battle in 2012, he was admitted to the London Olympics to run with abled runners using special prosthetics “carbon fiber prosthetics” or “Cheetah”, for which he used to be called “Blade Runner”. He was paralympic champion in 2004 on 200 meter run and in 2008 on 100, 200 and 400 meter run. He was the first and only amputated athlete to win a medal in a world championship race for abled runners, with silver medal in the 4x400 relay at the Taegu World Cup in 2011.

Hemimelia-amputation-prosthetics, is the least communality of these stories. Although prosthetics are an important tool that can give a great possibility of change and improvement in life; amputees, because of cultural and social stigma, will always be considered different people. The two moments, amputation and prosthetization, are connected and will always remain intertwined. It is therefore very difficult to find a definition of self-acceptance in prosthetic people, but this concept is considered very important from a psychological point of view for the well-being of these people. How to encourage this self-acceptance? Are the three stories reported overlapping or are there similar ideas for good practices?

Discussion

The human being in the first years of life is extremely dependent on relationships (food, care, emotional shelter, etc.) and, in feeling safe in the world. Parents naturally assume the role of caregivers which often creates a strong emotional bond although sometimes in a possessive and/or absolutist way. In this sense, the birth of a premature child, sick or malformed is a highly traumatic and intolerable experience. The outcome of this event often opens painful scenarios: the malformation, directly affects the health of the child, but indirectly affects everything that revolves around the family. Couples that have always been considered solid, can enter in a deep crisis due to a feeling of guiltiness, anger, or the conviction of having been punished and wrongly injured (Woolf et al., 2016; Castelli Gattinara & Pallini, 2015). The Theory of Attachment (Bowlby, 1982)¹ argues that failure to process the grief of a trauma has devastating effects on the caregiver’s ability to properly care for the child (Solomon and George, 2011; Main and Hesse, 1990). In addition, the approach of the parents to congenital malformation is determined by the looks of others, becoming a matter of aesthetic suffering and not only of functional use (Didierjean et al. 1997; 2006). This multifaceted problem offers fundamental questions in an effective and efficient society that penalizes physical deformity. In the beginning of the article already presented by Isidori (2012) we find a quote that we find very adherent also in this work:

“How unfortunate is the one who does not know how to have patience! What wound heals if not little by little? You know that we work with ingenuity and not with magic; and intelligence needs time.” (W. Shakespeare, Othello, act II, scene III).

Emergencies induce to make choices under socio-cultural pressures generally dominated by the cultural paradigm²; in this case the bio-medical paradigm. This paradigm offers the flank to the dichotomy: do we need to take care of the person, or of the pathology? Emergencies often indicate the choice of the *primum vivere deinde philosophari*. It is not a questionable error, the decisions to amputate/ prosthetize; rather, it is the second phase, the one inherent to the human-

¹ John Bowlby, a famous psychoanalyst, with the observations verified in children, and with mammals during the first years of life, will believe that “attachment is an integral part of human behavior from cradle to grave”

² A paradigm is “a set of examples of effective scientific practice recognized as valid” by a community of experts, who “comprehend globally laws, theories, applications and tools”, providing “models that give rise to particular research traditions with their own consistency”. The paradigm includes not only theories, observational and experimental techniques, problem solving methods, but also the most speculative beliefs and values that underpin research. (Kuhn, 1962)

ization of the emergency, the one that could be deficient. Speaking about the emergency should refer, at the first instance, to the foundational dimensions of: emotions, feelings and affections. (Isidori, op. cit.)

We further analyze the cases mentioned: they can offer reflections in this regard:

AIMEE MULLINS

Born in the USA from Irish parents, themselves children of very large families. The father, a plasterer-worker forced to emigrate, had a strong conviction of the effectiveness of a degree to rise in the social elevator: the thing becomes a mantra for all his children. The first surgery, Aimee will have it on his first birthday, followed by three others; the last at 8 years old. Her early prosthetics were crude, like rounded plaster casts. With two brothers and 24 cousins, she developed a strong character; *she became a tomboy*, her father said in an interview (Leffler, 1998). Thanks to a scholarship for disabled people given by the Department of Defense, she attended the Georgetown University; in that context she realized the value (including the economic one) of the sport-Paralympic. In mid-1995, she decided to train for the Paralympics, despite missing just over a year at the games. She asked the famous Frank Gagliano to train her and so her sports career took off. Participation in the paralympics attracted the media attention to prosthetics (1996), the manufacturer then proposed a sponsorship agreement. Mullins often appears with her legs covered, but never forgets her prosthetic condition. The designer of Givenchy, Alexander McQueen, perceiving the personality of the (former) athlete, created wooden legs which looked like boots. She walked the catwalk without warning the media before. It was in this way that the *Wearable Sculptures* were born.

She will become even more famous in a TED talk titled “12 pairs of legs” (www.ted.com/talk/aimee_mullins).

Prosthetics are her added value.

JESSICA LONG

Tatiana Olegovna Kirillova was born in Bratsk, Siberia and was left in an orphanage; at thirteen months she was adopted by a couple in USA. At eighteen months she was amputated/prosthetized. At six years she began swimming, a kind of liberation from prosthetics. At the age of twenty-one, accompanied by her adoptive parents, she went to Russia to meet her biological parents: “*I really dreamed of this moment. My parents in the U.S., they always told me I was adopted. It has never been a secret to me*”(dailymail.co.uk,16/12/2013; siberian-times.com, 7/12/2013;). In the most successful year she takes a break (three months) from competitions to train the women’s swimming team in his first pool in Baltimore: “*Seeing how excited they were to train in the sport I’m passionate about was incredible. I took a step back from the sport while continuing to be part of it, and it really helped me to fall in love again at swimming and I confirm that I still want to be part of it.*” (teamusa.org, 03/28/2018). Prosthetics are an aid you can use.

OSCAR PISTORIUS

He is the second of three children from Sheila and Henke Pistorius. Born in 22/11/1986, in the province of Transvaal in South Africa, he is an Afrikaner, descendant of Dutch settlers living in rural areas (former settlers carefully used to defend themselves). In his autobiography, Pistorius tells the story that led his parents to the choice of amputation:

“*decisive was when my parents asked to meet some of the boys already operated [...] and realized that the boy they were waiting for, It was the same one they saw running in the garden!*” (Pistorius, Merlon, 2008).

The parents’ divorce took place when he was six years old. He had a strong influence from the mother who kept repeating him the same thing: “*The real loser is not who crosses the finish line last, is who sits down to look at the others*”. The mother (Sheila) used to wake the children up every morning and without a twist, ordered Oscar’s brother “*put on your shoes*” and Oscar

“put on your legs” (Buccini, 2013)

The mother died when Oscar was fifteen years old and he tattooed the event on his arm. He switched to athletics around sixteen years old, after several knee problems resulting from rugby. In 2017 he was sentenced by the Supreme Court of Appeal of Johannesburg to thirteen years and six months in prison for the murder of his girlfriend Reeva Steenkamp in 2013 (Buccini, 2013; Riotta, 2013) At the trial he shows up with no prosthetics.

Conclusions

“Resilience” is a commonly used term nowadays. The word is borrowed from metal technology and indicates, the breaking strength following a stress. The term contains a set of personal, family and environmental characteristics that promote a good process of adaptation and transformation, despite the risks and adversities. This expression finds great success thanks to the work of Boris Cyrulnik, in which he indicates this neologism, *which allows even the most abused to find autonomously the psychological resources to react and then structure a healthy personality* (Cyrulnik, 2000).

According to Marcel Manciaux, famous author in the themes of child abuse, it is: “the ability of a person or group to develop well, to continue to plan and project into the future, in the presence of destabilizing events, difficult living conditions, sometimes very hard traumas”. (Manciaux, 2001)

How do you educate in resilience? According to Canevaro (2016) you have to leave open a mental space with three questions: What is the truth? What is good? What is beauty?

It is called *kalokagathia*, which in the world of classical Greece also indicated the ideal of sport. Training/education is the only way to achieve it.

A scientist's work is to proceed in the dark with a candle in his hand: it means to see little of what is around; a scientific method is a method that seeks risk.

This is more or less the concept that Bachelard proposed in the famous treatise “Epistemology” (Bachelard, 1975). In this case, the bio-medical paradigm, and the subsequent choices, shed light on the problem only in part. Out of the three cases proposed, one is “accompanied”, “educated” by actions following the trauma; in the case of Jessica Long, in which the adoptive parents lead the girl to develop resilience with both prosthetics, as well to life in general. In fact, thanks to swimming, she understands that she must “use” them without depending on them; accompanied by his adoptive parents she makes peace with her birth origins; she finally manages to break away from his matrix of success showing autonomy. Differently Mullins cohabits with the prostheses, that became the reason of her existence, indeed they are her successful multiplier, However, her resilience is totally dependent on them which she worships like a totem (twelve pairs of legs/prostheses). Finally Pistorius is not accompanied/educated because of the rigid culture of origin, because of the divorce of the parents, as well as because the loss of the mother; his resilience is limited by the only approach he received, the biomedical one. In his second life he realizes that he is disabled (without being accompanied/educated), and the prosthetics remind him. Paraphrasing, being in prison, becomes free from prosthetics.

Taking care of the person or the disease? The problem does not arise: the human person is a psycho-physical unit. The problem in question has as a frequent reaction, the implementation of ruminative thought styles: parents wonder why and seek a solution. This reinforces a dysfunctional purpose of loss avoidance focusing on the abilities of the child while ignoring his affective world and who he really is with his limits and skills (Mignani , 2019). Therapeutic amputation of the affected limb or a part of it should be considered only after assessing the functional and psychological implications of limb loss and/or when amputation is necessary for implant placement (Boyadjiev, 2018). All types of treatment must be accompanied/ educated to rebalance the disorders of the disease. This applies to all parents who have to make choices towards their children.

This applies to all emergencies that arise in emergencies.

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