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Remarkable lives: Lígia Cardoso Baldé in conversation with Jerome Carson

Lígia Cardoso Baldé and Jerome Carson

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Abstract

Purpose – *The purpose of this paper is to provide a profile of Lígia Cardoso Baldé.*

Design/methodology/approach – *Lígia gives a biographical description of her life and is then interviewed by Jerome.*

Findings – *Lígia talks about the stress of being a young single parent with a disabled son. She talks about how she built up her resilience over several years.*

Research limitations/implications – *The story Lígia tells is one of battling against all the odds. Her account shows how she had to manage without much external support, even from family.*

Practical implications – *Research has long demonstrated an association between life events and stress. Lígia tells us about the various stressors that confronted her at different stages of her life journey.*

Social implications – *All of us can make a difference in peoples' lives if we make the effort. Lígia talks about two doctors who knew the medical implications of her son's condition, but who also recognised her emotional needs and addressed those as well.*

Originality/value – *Lígia's story is inspiring at so many levels. She has successfully adjusted to a different culture, to a different language and has had to establish a new social support network. Now she is not just surviving, but slowly thriving.*

Keywords *Culture, Diversity, Stress, Resilience, Education, Cerebral palsy*

Paper type *Case study*

Introduction

Lígia is a mature student studying for a Masters in Positive Psychology. It was apparent both through her choice of topic in assignments and through her discussions that she was very interested in the concept of disability. She tells us in her story that interest has been hugely influenced by her experiences of caring for her own son, who was diagnosed with cerebral palsy. Lígia has had to overcome many barriers on her journey, but let her tell the story in her own words [...].

Brief biography by Lígia Cardoso Baldé

I was born and bred in Portugal, Lisbon, in May of 1979 but I have an African background. My parents were born in Guinee-Bissau and I have roots from Guinee-Conakry and Cape Verde. I am the middle child, and have one older brother and a younger sister. I remember my childhood surrounded by love and happiness from family and friends. However, my extended family was a little more reserved and this stemmed from the fact my parents came from two different religions and their marriage was never really accepted within their respective families. This also posed cultural challenges and it was quite a difficult experience in maintaining the African culture as well as adopting the Portuguese culture. I did not really have a close relationship with my mother, and was unable to share thoughts and feelings with her about relationships or other “girl-related” issues. This was particularly because my mother easily took offence at things that went against her beliefs and values and my father was someone who was far too respected to be able to talk to about personal matters.

One of the biggest changes in my life was the birth of my son when I was just 20 years old. The love I have for him is unconditional and he is an asset to me to this day. I have brought him up single-handedly since the day he was born, as his father is not in the picture. Both his father and I were young and we faced the difficulty of both having very different pathways in life and we were not able to handle or overcome these differences.

A year after my son was born, he was diagnosed with cerebral palsy. However, it was not until 2002, when he underwent his first operation, that I realised the extent of the disability or how much it was actually taking its toll on me. His disability had been discussed with me previously, and one of the earliest memories that I still remember so clearly is a meeting I had with multiple medical professionals. That is when it really hit me. They were talking to me about the operation, the procedure and all of the time they were using medical terminology that I did not understand. I felt instant fear for my son. There was one part where they asked me to leave the room whilst they were alone in there with my son, and I just absolutely broke down in tears. I feel like this meeting was a major trigger for my anxiety and social isolation that has remained with me to this day.

Around the same time of my son's operation, I had been offered a promotion at work. I had been told that my son would require 24-hour care for at least three months after the surgery. I was incredibly worried about how I was going to be able to fulfil my new job role and care for my son. I kept thinking it is going to look so bad for me to use up all my annual leave as soon as I was promoted. When my manager called me in, I was worried they were going to revoke the promotion from me, but they were incredibly supportive and gave me the time off, without me having to use my annual leave in order to care for my son. When I came back to work after three months that was when I found it incredibly hard. I felt really conflicted with my colleagues and their judgements and they were not very supportive. All of my colleagues were married and if they had kids, they did not understand what it was like to be a single parent and in particular of a disabled child. One of them even suggested that I bring my son in every day whilst I worked. I did not have the same social support as them and I just felt like I resented them, often becoming snappy around them and unconsciously developing a mean streak. This was a time in my life when I felt incredibly lonely, especially as a lot of my friends who were my age were all at university. We all had different interests too, and my priority was my son.

Alongside this, I also felt my family turned against me. Another memory that stands out for me was when my cousin told people about my son having cerebral palsy. People used to come up to me and be like "Oh my gosh Lúgia, you've got a son who's disabled" and to me, it felt like they were basically saying he's dead. This was something that definitely changed my personality, I became less talkative and less empathetic towards others, again cutting myself off from the world.

In 2009, I took an E-learning degree course in education in Portugal, and this helped enhance my purpose in life. However, due to the economic situation in Portugal, particularly, the recession, once I completed my degree in Portugal, I opted to move to the UK for a better quality of life (having extensively researched this). My son was also in a school where they did not understand his disability and they did not accommodate this very well. One of the main issues I faced was the staff and school's lack of understanding about intellectual and physical disabilities, particularly in the context of the public schooling system, where my son was to spend most of his days. Unfortunately, my son was also subjected to bullying and I felt that there was a constant fight between me and the school, making me both physically and emotionally tired. I also felt I was failing in my duty as a mother to protect my son and how this situation was going to affect his future, both in the short and long term. At that time, I could see that he was not happy and effectively this also made my decision to move much easier.

Moving to the UK is something that I do not regret at all though I faced some additional difficulties. With my son's disability, I had to go through the whole diagnostic process again in the UK and it took almost three years for my son to be diagnosed with cerebral palsy again, despite medical notes from Portugal. It was a tough time having to go through examinations, tests and scans all over again. The support systems in the UK, especially schools, have proved to be so much better and I feel that my son is happier. I now feel as though I have done my job as a mother.

I opted to go back to education with my move to the UK and started with a psychology degree course accredited by the University of Central Lancashire. The course in itself was very good,

but I had bad experiences because of the language barriers I was faced with. I isolated myself away from colleagues because I felt that I was incredibly incompetent compared to them and their language skills. This in turn reduced my self-confidence and self-esteem and I really did not want to talk to anyone. I felt myself going into a negative spiral and my grades were even affected by this, further decreasing my confidence, motivation and trust. When I look back and remember this moment, I can now really understand how you can lose your identity so easily.

Despite this, I managed to complete the course, and on my final year I was blessed to meet a tutor who was really supportive and encouraged me to enrol on an MSc in Positive Psychology. I am now in the second year of the course, and although I have faced some tough times, I feel that in myself as a person I am becoming the individual that I truly want to be. I take opportunities as they present themselves and I like to challenge myself in the subjects that I am passionate about. Alongside this, I have been working as a support worker with young people with mental health problems, although ironically facing my own mental health problems. The role has allowed me to gain great experience in this field as well as provide me with support and structure in my life. It has also helped me to build my self-esteem in order to support others. Witnessing their positive outcomes has certainly developed my skills and confidence.

I feel that there is still a lot to learn and improve in myself, but I am more realistic about my weaknesses and always striving towards self-improvement where I can. The Master's course has taught me to focus on my strengths and I have come to realise that my weaknesses are diminishing in significance.

I used to be ashamed to be a single parent and today I am proud about the person who I have become and the choice that I made 18 years ago in becoming a single parent. I have changed the way I think and today I do not feel that I have lost anything or missed opportunities. On the contrary, I feel like I learned and gained experience with everything that I have been through. Every single day I am grateful and thankful for everything and especially seeing my son's smile each day.

Lúgia in conversation with Jerome

Jerome: Lúgia, several times in your life you have felt family or work colleagues have turned against you, sometimes because of your disabled son. How have you coped with this?

Lúgia: When it first happened with my colleagues, I felt unable to cope. It affected my relationship with them, I became cold. When they were offering advice to me it felt unrealistic then I stopped talking to them about my issues. In a way, that was a coping mechanism for me – I stopped talking about the issues with colleagues. I became quieter. With family this was the worst time for me. Especially with my cousins who were the same age as me, but we all took different pathways. To avoid them, I stopped socialising with them and became distant, isolating myself. I tended to avoid talking about my life. I had an understanding they weren't going to help me. I was fearful they were going to judge me if I was to disclose my honest feelings to them. So, like in my professional environment, I coped by creating a distance, so I wouldn't feel hurt any more.

Jerome: What hopes do you have for your son's future?

Lúgia: When my son was young and he was just diagnosed, I was very unsure about his cognitive development and this was a major concern for me. But from Primary school age I realised he was okay intellectually and I began working with him on his strengths, such as his memory. There were other times when I had big worries in terms of him being bullied in school, whilst while we lived in Portugal. I know he is capable of getting a job, obviously something that is not physically straining for him. I think that he is a fighter and he is tough and when he puts his mind to a task he will accomplish it. Overall, I would like my son to be happy in himself and with his life.

Jerome: You mentioned that one of your tutors on your UCLAN accredited course supported you. What difference did their support make to you?

Lígia: Well it was during my UCLAN course that I sought out a tutor. They were not affiliated with UCLAN and it was a personal tutor, but they were incredibly supportive in my third year as I was feeling really down and depressed. The personal tutor I had provided support to enhance my confidence and build up on my strengths, something that I really needed to do. I started to believe in myself again because of this support and in turn it gave me the confidence to apply for the MSc at Bolton. Not only that, I feel that their support has made me a better person in terms of my work ethics and organization, that has allowed me to succeed in my education at a higher level.

Jerome: You are now in the second year of an MSc in Positive Psychology. What has the course taught you about yourself?

Lígia: Although I studied Psychology for my undergraduate degree, the difference in the course is the emphasis on positive psychology, where I have come to view the subject slightly differently. Most importantly, this course has helped build my personality, and I actually view my life differently. I feel proud to have a child with disability, I feel proud of my resilience and the fact I can speak another language. I feel that I have really found myself with this course to live a life that is meaningful and fulfilled for me personally, without having to please everyone.

My relationship with my MSc tutors is very different from other academic relationships before. The way that I can talk to them. I feel that they know me very well and they are so supportive and always have the right words to say to me in the times I need it the most e.g. "You should be proud, you're an excellent Mum"; "I know you are going to graduate next year"; "Wow, I am really impressed about your resilience". They are able to empathise with my life and sometimes it's good for me to be in that environment away from situations where I have to put everyone else's needs first.

Other tutors have helped me identify with my resilience. Some of the modules that I have undertaken on this course have allowed me to reflect upon my own life and uncover traits and elements of positive psychology that I have been able to implement in my own life. My current dissertation is something that is "close to home" to me and I have received lots of support from multiple tutors, who have encouraged me to conduct research in an area that I am passionate about as well as giving me advice.

Jerome: What does the concept of hope mean for you?

Lígia: Honestly, hope for me is something that I relate to my faith. One of the reasons for this is because I was brought up with two religious backgrounds which allows me to have a balance between the two. All my goals I wish to achieve, I always believe that something, whatever it is, is going to give me the strength to be able to achieve them. Hope is a stimulation for me, it's like I am feeding my unconscious and conscious mind with hope in order to accomplish what I set out to do. Hope for me has a positive connotation, instead of putting me down, it is a source of optimism.

Jerome: What changes would you most like to see in mental health services?

Lígia: From one of my experiences, I really think they need to be more aware of cultural issues. The UK has a large and diverse population. Some people have different perceptions about mental health and some people don't take into account the backgrounds of individuals who have mental health issues. This is something I see a lot in my professional work as a support worker and languages interpreter. So, treatments and services need to be aware of the differing cultural backgrounds of individuals to support them in the best way that they can.

I am aware that there has been some research on black and minority ethnic groups' access to mental health services and indeed one of my MSc assignments reviewed some literature on this. However, with the growing population as well as some of the taboos around mental health, I still feel that mental health services need to adapt to meet service users' needs as much as possible.

Jerome: What are your views on the use of medication for mental health problems?

Lígia: I know medication can be good, but for mental health problems, it should complement therapy. Your body is telling you something is not right, you need to work it out in your mind and acknowledge that your mental health is not okay. You need to work out whether it's your environment, thoughts, beliefs or behaviour and deal with it. Sometimes medication is not the

answer (e.g. medication cannot change the environment). Medication can become addictive and may not work in the long term. Although research has shown the biological and neuroscientific nature of mental health problems, such as neurotransmitter deficiencies or structural changes in the brain, psychological research has made breakthroughs to treat certain disorders without the need for medication, for instance with some types of depression.

Jerome: How do you think mental health services can best help promote recovery, which is said to be the goal of many services?

Lígia: Although there are many mental health services and providers, they are often understaffed or have limited places. Although they may want to treat everyone, it is not always possible. Therefore, their goal is to provide support and treatment and to prompt receiving care in the community. However, this may lead to relapses. If services wanted to promote better recovery, more time would be needed with each patient on a case-by-case basis. Moreover, if they have a good experience with services and they suffer a relapse, they may be more likely to access services earlier in the future, which is good as early intervention has been found to lead to better recovery.

Jerome: Have you been inspired by any mental health or healthcare professionals you have come across?

Lígia: In Portugal, the two doctors that used to see my son were important for me at the time as they gave me the right support. They allowed me to talk a lot, because I was only 20 at the time. They were really there for me. Instead of just teaching me straight away to deal with a disabled child, they talked to me a lot about how I felt. They were inspiring because they were both medically able and provided emotional support. I think this is something that is important in any healthcare professional. The way they made me see my son's condition was really positive and gave me courage to cope with his condition. They were proud of me and this also gave me strength.

Jerome: In terms of people with lived experience of mental health problems, have any specific individuals impressed you?

Lígia: One of my friends was on holiday and she was acting very strange and her parents took her to the hospital and she was admitted to the psychiatric unit and diagnosed with schizophrenia. She was in the hospital for six months. I was impressed by the way she challenged this because she never accepted the medical diagnosis of schizophrenia. Even with the prescribed medication she still fought against the diagnosis and on her return home from her holiday she got a second opinion and the doctor confirmed she had been misdiagnosed. She did in fact have bipolar disorder. Because of this, she has now changed her life and has more motivation and determination. She became more confident, got married, found a good job, has started a family and is living her life as normally as possible. It was impressive to me because she fought her misdiagnosis and got on with her life as best as she was able. I think the biggest challenge for her was overcoming the stigma of the original diagnosis and the fear attached to it. I am impressed with the way she has coped with her mental health problems.

Jerome: What challenges lie ahead for you? What do you most want to achieve in the future?

Lígia: All of my professional life I have helped others and I want to carry on doing this as this makes me happy. I want to use what I have learned from my MSc to help people in a different way, as the MSc in positive psychology has changed the way I view my life. I feel I could help others in very different ways from what I do now, potentially through research and counselling, things I have been inspired to do by my course. One of the things that I have considered is recording my own videos on YouTube that will help people in different ways. Maybe to target single parents who have a child with a disability, bringing in my own experiences with language barriers, and talking about the resilience I have developed and the support I have gained. I want to be able to show people that they are not alone and give them encouragement that things can be better.

Jerome: What would you most like to be remembered for?

Lígia: Honestly, for me it's being a single parent of a son with a disability. Mainly, to show how much I have achieved and especially to show that I have the resilience to adapt to different countries and cultures, as well as still doing things I am passionate about in my life.

Conclusions

Lígia is a remarkable woman. A young single parent with a son who has a disability. She made the very difficult choice to leave Portugal for the UK in the hope it would lead to a better life for her and her son. It has not been an easy transition, with many upsets along the way. With each passing year, Lígia has got stronger. In the last couple of years she has started trying to fulfil her educational potential. Having completed an undergraduate degree, she is now enrolled in a Master's programme. Always trying to secure a better future for her and her son. She is slowly succeeding. Her efforts can be an inspiration to many people in similar situations.

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