On how I got through COVID-19 lockdown:

An autoethnographic approach to resilience in disability

Abstract

I explore how I—a person born with a physical disability living alone in a foreign country—was able to cope with COVID-19 lockdown. I used the autoethnographic method (Chang, 2016) to scrutinize sources of my resilience. Through evocative autoethnography, I reviewed risks/coping strategies recalling the lessons drawn from my childhood in the care of two supportive women. Then, performing analytical autoethnography, I self-assessed my lived experiences through a social science lens. A theoretical validation of my personal story helped me to acknowledge how resilience in my life had been built and was mobilised in the face of the pandemic.

Key words:

autoethnography, resilience, disability, emancipatory research

Introduction

When the COVID-19 outbreak began, I found myself in an unusual predicament: I was a black English-speaking Caribbean woman with a physical impairment working towards a PhD in Spain, whose languages I did not speak. COVID-19 lockdown was added to the list of difficulties I was already facing. Support for people with disabilities vanished because of the collapse of healthcare services and the priority given to people with severe COVID-19 symptoms.

The social exclusion and isolation of vulnerable social groups and their consequences on mental health during global COVID-19 crisis have already been documented (Sabatello at all, 2020; Jalali at all, 2020; Chakraborty, 2020; Boyle at all, 2020; Lund & Ayers, 2020). The setbacks in the human rights of people with disabilities have also been denounced (Solomon at all, 2020; European Disability Forum, 2020). New forms of discrimination that have emerged during the pandemic, clearly showing the urgency for the improvement of health crisis management in the future. This autoethnography contributes to this corpus offering insight into the specific experience of COVID-19 lockdown of a person born with a physical disability.

I do not focus exclusively on feelings and meanings that emerge from experiences of discrimination, exclusion, or isolation. In line with the emancipatory disability approach (Oliver, 1997; Barnes, 2001; Berger, 2016), I resist reading disability as tragic or pitiable, focusing instead on self-care, agency, and resilience building. In fact, people born with a physical disability, being the only social group for whom restricted mobility is their normal, showed themselves to be prepared for isolation and mobility limitations imposed with the COVID-19 outbreak (Chou, Chen, & Kröger, 2021; Authors, et al., 2022).

I have no legs and an amputated hand, but I learned to move short distances with my prosthetic legs, and I like to use a scooter instead of a wheelchair to move around. I am the only one from my mates at the special school I attended who dared to do such a thing. I was the first person born in Guyana with a physical disability who got a job at the University of Guyana. I trained students with special needs during their final phase of research. And then I came from Guyana to conduct my research here in Europe. I came without a scooter, only with my prosthetic, which needed to be replaced with a better one. People asked me how I dared go alone to a different continent, to an unknown country where English is not spoken, while I don’t speak Spanish. I said: “Because I will learn.”

Long ago, I created my own routine to cope with difficulties (positive thinking, mindfulness, yoga, listening to instrumental music, mutual support networks, positive memories, humour, etc.), which showed to be useful in the COVID-19 pandemic lockdown. During Spain’s three-month stay-at-home order (in which people could only leave home for essential work, medical appointments, or the care of another person), I thought and wrote about the factors and tools (emotional, technological, and economic) that enabled me to continue working and socialising while confined, living alone in a foreign country.

I used the autoethnographic model (Chang, 2016), viewing my life experience as “meaningful data in its own right” (Berger, 2016; Ellis, Adams, & Bochner, 2011). In this endeavour, I crossed the research-participant divide by being a sample and a researcher at the same time. Two of my colleagues became co-authors on this project. Their insights helped me to keep distance from my “data” (that is, from the stories of my life) and avoid solipsism. On some occasions, they merely typed the memories that I dictated to them, annotating my associated thoughts and feelings. At other moments, we discussed relevant aspects of my life, and they held up a metaphorical mirror to me, allowing me to explore my subjectivity more fully in their company.

This study did not need any formal ethical approval since the main data that was reported and analysed was my own experiences. As a solitary autoethnography, this research did not include any additional data collection involving other human participants.

The first part of this study is evocative and performative, almost stream of consciousness. In it, I capture the moments of my childhood and early adulthood that surfaced in my memory as I thought about my experience of survival during COVID-19 lockdown. The second part of the article is analytical. I use the lenses of Resilience Theory and Disability Studies to make sense of my experiences.

Evoking past experiences of resilience through reflections on COVID-19

For 10 years I had regular physical therapy for my hand. But during lockdown, my appointment was postponed. Then it was postponed two more times before being cancelled. My hand started to swell, and after several weeks I had debilitating pain in my hand and shoulder. I sent an email message to a general practitioner asking for care. She couldn’t offer me an appointment, but she sent a prescription to the pharmacy for painkillers. They were so strong that they affected my stomach and I had to stop using them. Now I had pain not only in my hand and shoulder but also in my stomach.

I could barely move my hand. I could no longer cook. I started to order food on Glovo and Uber Eats. It became costly, but I didn’t have any alternative. The pain got worse as the weeks were passing. From 2 to 4 a.m. I couldn’t sleep at all, even with painkillers. I became irritable and anxious. I couldn’t work. I couldn’t type.

I tried a voice typing application, but it didn’t understand my Caribbean accent. It was transcribing ‘co-creation’ as ‘creep-creation’, ‘recession’ as ‘receive’, constantly messing up my words. When I explained the situation to my PhD supervisor, she requested additional budget so that I could audio record my writing, and someone could transcribe it for me. This new way of working with an accent-friendly scribe allowed me to finish my work on time. But the pain was constant, and the isolation was killing me.

The COVID-19 lockdown in Spain started in March 2020 and lasted until July. I finally saw a physical therapist on October 20, 2020. But after so much time without exercise, the therapy didn't work. Instead, it worsened the situation. My hand and shoulder were injured, with inflammation and internal bruising in the muscles. It continued to be a torture.

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"Happy birthday, Karen!" They were jumping in a Google meeting, saying "Hello" and "Cheers" as they were waking up in different geographical regions and time zones to celebrate my fifty second birthday. It was my biggest and best-attended birthday party ever. My old and new friends, schoolmates and relatives from the Caribbean, the UK, the US, Canada, Spain, and Japan popped up on my screen cheering me, and the conversations with them lasted the whole day long. I was reunited with so many people, even my former neighbours after almost 40 years. Only the pandemic could have made such an event possible; it was organised online, and it took place in the context of restricted mobility, when everybody around the globe was home.

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The whole world became one in the lockdown and aligned in mobility limitations. Sometimes I felt like a veteran — mobility limitations aren't new to me. I felt like I had an edge over new members of this unique global community of limited mobility.

The 70’s: projecting disability stereotypes onto me

At the beginning of lockdown, I sank into despair and experienced constant headaches.

Then, I found myself turning to the pleasant memories of my family and parental nurturing. Laughing, cooking, and walking with my mother and grandmother.

When I was growing up in the 1970s, Guyana was a developing country and disabled people were systematically segregated in education and in life. It was difficult to launch my career. My family lived a very stressful situation in my early years: my mother needed to go to work, and I needed to go to school, but we had to wait for years for me to be accepted at a school. My physical disability meant that we had to depend on somebody’s good will to let me attend school. I was expelled several times because of my physical disability. But my family was determined to educate me.

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In Guyana, women must do the housework, procreate, and raise the children. Women must be fit and attractive. A woman’s highest achievement is to get married. But I had a different body, and I didn’t fit in that system. I didn’t care; I found relationships and children stressful, and I couldn’t do the housework.

My uncle used to say: “Oh, Karen is pretty! What a pity!” lamenting that I wouldn’t be able to marry. When I laughed, he questioned me: “Why are you laughing?” I just thought, “His expectations don’t match my expectations”. I told him that I didn’t want to get married; I wanted an education. And my uncle’s ironic answer was “Good luck with that!”

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When I was a child, the Church provided some support, but with strings attached. They wanted to control how my mother moved in her life.

I have a body that attracts charity. What charity had to offer me was a food hamper, but not a book hamper; they never gave me pencils or books. They gave me milk, sugar.

“Thank you very much for this. Can you give me a book next time?”, I asked.

They were surprised and offended: “How dare you?” they countered.

When the Church advised my mother to put me in an orphanage, she answered that she wanted to put her daughter at the same place that other Church members put their children: at school.

My family, we three, made our own plan, contrary to charity: my grandma, to have her tailoring business; my mother, to work in a laundry; and me, to go to school.

The 80s and 90s: old ablism and new laws

In the 80s and 90s, new legislation protected people with disabilities against discrimination. But attitudes are slow to change.

According to the rules of the scholarship that I obtained from the United States, I had to return to my country of origin and work for three years at the university. But the University of Guyana didn’t want to employ me. I heard administrators ask, “Why should we employ her? If she falls climbing the stairs, we will be in trouble”. I talked back: “I grew up climbing stairs on my knees and with my prosthetic”.

Under pressure from my scholarship administrators, the Department of Education at the University of Guyana University hired me to be a teacher trainer. This was the first time the institution to hire a teacher with a disability. The department head was not confident I was able to teach classes, nor was the administration. My department head told me that he and his team had been ordered to attend my first class. I answered with a smile, “Oh, everybody is welcome to my class!”. After I said that, nobody came to check on me. My first class went fine.

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Years earlier, I worked as part of the secretarial and accounting staff in a community-based rehabilitation programme. I remember a day when my mum’s sister stopped by my office. She had been told I had an office, and she had come to see if that was true. She saw I had four computers, an appealing office… but she didn’t enter. She was peering through the window, checking to see if it was real. She did not enter saying, “Hi Karen, congratulations! You are working, best wishes”.

When I told her that the office was funded by the EU and run by an Italian group whom I was working for, her eyes got large. She couldn’t understand that her sister’s child born with a disability could manage such a fine office.

Building ability through care

“Barbara, why do you have to take Karen everywhere?”, relatives and friends used to ask my mother.

“Because I am her legs!”, my mother answered.

She never made me feel unloved.

My mother was brilliant at numbers, but she chose to abandon her professional life because I was born with a physical disability. She worked hard to grow me up as an ordinary person and not as a disabled person. Therefore, she didn’t have time for herself, and she gave up her own life to look after mine.

Church members and our relatives viewed me as a burden to my mother. I was specially seen as a major hindrance to her marriage prospects. So, they withdrew support to punish her because she did not take their advice regarding me.

My mother took me everywhere until I was 15 or 16 and I got my first prosthetic leg. Then I started to move on my own.

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My mother had a bad marriage, she was married to a man who later started to hate her and didn’t want to see her happy. I grew up in the middle of that disgrace.

But my mother and I were happy. “Look at me, I can laugh!”, she used to say.

We laughed together despite the bad circumstances. And our relatives were surprised: “Oh, you are so happy!”

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“If I die today, you should be able to cook alone and do everything alone”, my grandmother used to say. She showed me how to do things for myself: how to light a gas stove, how to cook using gas bottles, how to bake bread, how to make coconut biscuits, and how to sell them. Sometimes there were people in front of our house waiting for our biscuits to come out of the oven, “They smell so good!”. We used to sell biscuits on Sunday.

My grandmother taught me how to use Mentha oil to improve my health. She instructed me how to make a Caribbean lemonade, a Mauby drink, in the proper manner.

She showed me not to act pitiful or disabled. She showed me how to build my ability. I grew up making things, contributing to the family.

“You know, Karen, the world will not be fair to you…. You need some skills to increase your chances of surviving the prejudices you will face”. She was reading me self-help books and used to ask me to read her the same motivational books and the Bible, and then we used to comment the texts and learn lessons from them.

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My grandmother was a minister of the Church of Silent Unity, a metaphysical religion whose beliefs centre around positiveness, expecting good things, and providing faith, courage and strength to people who seek it.

“Create your opportunities.”

“Don’t focus on negatives.”

“Don’t let negatives overwhelm you.”

She believed in affirmation. Your statements nurture your soul. She knew the value of nurturing. Our house was decorated with posters, such as one that read, “Divine order is in my mind, body and soul”. Divine order is about a purpose. My grandmother believed that I was there for purpose, and I had to find my purpose in life.

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As a little girl, I was bothering people, asking them to teach me. I wanted to know things, but they tried to distract me with food: “Give her an ice cream”, ‘Give her a Coca Cola”. Only my mother and grandmother understood my enthusiasm for learning.

I have had a lot of gaps in my education due to the lack of rights for children with disabilities in the 70s in Guyana. I started attending the mainstream school at the age of 12. Everybody was surprised how quickly I caught up, and that happened because I used to read and analyse textbooks with my mother and grandmother. From them, I learnt early how to read, speak with people, ask for feedback, and share my views. Although I started my schooling several years later than others, I always had the best grades in my class.

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When I was little, my mother’s relatives referred to me as “that child”.

Today they praise my mother: “Oh, Barbara… she did a good job!”

“If you would see Karen now, you would not recognise her!”

“She achieved what she said she wanted to achieve”.

Moving in the world without my mother

My mother died when I was 29. My relatives told me, “Karen, you are not in a position to make choices anymore because your mother died”. And I said, “I am not opening the door for abuse just because my mother died!” I decided not to accept any name-calling, humiliation, criticising, control over me, terrorisation or anything else that would harm my ability to function or my mental well-being. I was confident that I would find a way to finish my university studies, get a job, be independent, and have a decent life.

One of my cousins once said, “I don’t like Karen. She is too positive.” I was too positive given what my position was supposed to be at that time.

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I was homeless after my mother died. I had a part time job, I volunteered, and I had to find a new way of living.

When I eventually managed to study and find work, my able-bodied colleagues often had prejudices about me, as my mother had warned me. For example, when something went wrong at work, they automatically assumed I was the cause. On one occasion, I heard a co-worker defend me, “But she was on vacation when that happened”, thus silencing my critic.

From evocation to analysis: resilience in disability

Scholars argue that resilience is one of the most profound constructs across disciplines (Rutter, 2006): psychology, psychiatry, anthropology, sociology, amongst others. “It is a biopsychosocial phenomenon, linked to life stress and people’s unique coping capacity (…) expressed and affected by multilevel attachments, including family, school, peers, neighbourhood, community, and society; consequently, resilience is a function of micro-, exo-, mezzo-, and macrofactors" (Green, 2002).

Most definitions of resilience include the overcoming of stress or adversity, or a relative resistance to environmental risk (Bowes & Jaffee, 2013, cited by Hornor, 2017). Evidence shows that some individuals have a relatively good psychological response despite suffering risk experiences that would be expected to bring about serious consequences. They exhibit relative resistance to environmental risk experiences, as well as the capacity to overcome adversity. Thus, resilience is seen as "the ability to bounce back from adversity, frustration, and misfortune (Ledesma, 2014), the ability to adapt positively when confronted with adversity or stress (Luther et al., 2000). This adaptation process can sometimes result in thriving, where people broaden their perspective, learn something positive, develop new coping skills, or expand their social relationships as a result of a stressful experience (Afifi et al., 2016; Carver, 1998; Feeney & Collins, 2014; Park & Fenster, 2004)."

Resilience is, thus, concerned with the combination of, on the one hand, traumatic risk experiences, and on the other, a relatively positive outcome despite those negative experiences (Fergus & Zimmerman, 2005). Traumatic risk experiences combined with a positive outcome describes my own experiences of COVID-19 lockdown and the memories from my childhood that it conjured (see Luthar et al., 2000).

Scholars have highlighted that being part of a relationship with at least one stable adult during childhood is one of the most significant sources of resilience (Afifi et al, 2016). The Theory of Resilience and Relational Load (TRRL) acknowledges how family members' communal orientation and maintenance of their relationship influence appraisals of the stress and thus personal and relational health and adaptation. As I have shown, within my family, I felt validated and secure, loved, and affirmed. My mother and grandmother were always there for me, and we acted together as "a team" resisting numerous stressors such as marginalisation and stigma.

However, it seems that resilience is not only about protective factors. It has also been stated by scholars that "central to resilience is a controlled exposure to risk (rather than its avoidance)" (Rutter, 2006). Our family team (composed of my mother, my grandmother and me) was exposed to different risks in a controlled manner, as we used to calibrate and regulate the situation analysing the origin of each harmful situation, learning positive lessons from hazards, and designing our coping strategies together. The importance of gaining knowledge from hardships has been highlighted likewise by psychiatrists and psychologists as a significant protective factor (Luthar, 2006; Csikszentmihalyi & Nakamura, 2011). The experience of coping successfully seems to lead to greater psychological strengths later, "probably the key element is some form of successful coping with the challenge or stress or hazard" (Rutter, 2006). The role that my grandmother played as a metaphysical minister was precisely to show people how to learn from difficulties and overcome them through faith, love, goodness, and bravery. This way, while we were going together through numerous hazards, I received a sort of professional training in overcoming difficulties during my childhood.

According to the Theory of Resilience and Relational Load (Afifi at All, 2016), the relational context is one in which important uncertainty-management work is done. TRRL argues that long-term relationship maintenance moderates the impact of uncertainty-producing events on people’s personal and relational health and builds resilience (Afifi, 2020; Afifi & Afifi, 2021). My experience shows the huge influence of past long-term relational experiences (developed in my childhood) on resilience. On the other hand, it showcased the role that online communication tools played in maintaining meaningful relations in the age of technology. My experience of lockdown in a new country at a new university where I was just arrived made it difficult for me to have local relationships during the first COVID-19 lockdown and the period afterwards. The ability to rely on my previous long-term relationships from my country of origin by means of internet technology empowered me substantially, providing me with enough social and emotional support to cope with this unpredictable situation.

Moreover, scholars argue that resilience is concerned with “a variety of cognitive and behavioural acts linked with happiness, including planning and goal setting for the future” (Dunn, Uswatte & Elliot, 2012). Interestingly, the data extracted from my autobiography reveal more than two decades of building positive emotions with my mother and grandmother, and later with peers. Positive emotions are acknowledged by researchers as a sort of enduring resource that help people live well (Fredrickson, 2004).

Furthermore, the scientific exploration of strengths indicates that strengths such as gratitude, kindness, hope, and bravery have been shown to act as protective factors against life’s adversities, helping us adapt positively and cope with difficulties such as physical and mental illness (Fletcher & Sarkar, 2013).

Apart from protective factors that operate on a micro level, broadly studied by psychologists, that I localised in my biography, I identified other protective factors that are not inherent to my subjectivity. They stem from societal development. In

Michael Rutter's theory (2006), resilience is not related to the individual's psychological traits, but rather seen as the ability to adapt when given the right resources. In this sense, I have highlighted the concrete resources I used during the lockdown. I did not use only my psychological assets, but also tangible assets such as friends, my health card, the online health app, my computer connected to the Internet, and, perhaps most importantly, the scholarship that allowed me to advance my career and live free of economic difficulties.

Specific grants for people with disabilities are the crucial asset. I was substantially empowered with the possibility to continue my higher education when scholarships for people with disabilities emerged. Grants I have been awarded allowed me to work within academia and provided meaning to my previous struggles to achieve an education. They acted significantly as boosters of my resilience. During the COVID-19 lockdown, although I found myself isolated and excluded from health services and feeling physical pain, I felt happy to be able to dedicate myself to my PhD.

Conclusions

In line with *emancipatory disability research* (Oliver,1997) a non-stigmatising approach to exploring disability, I aimed to shed new light on my own experiences as a person with congenital physical impairment, contributing this way my voice to the research of resilience in disability. It was not my intention to construct narratives of "overcoming disability", but rather to highlight the functional diversity, different ways of being embodied in the world, drawing attention to people with disabilities who also may stand for a valid example of resilience.

It is evident that, being born with a physical disability, I did not do anything on my own without the help of my family, mentors, and other social support I received, including scholarships that enabled me to work in the field of education and research. Importantly, the contemporary disability rights movement (the social model of disability) has provided me with the right to study, travel, work and perform research. This movement, which represented a huge cultural change in the 90s and that today in the 21st century strongly impacts both developed and developing countries, ultimately made it possible to voice this affirmative experience of disability.

Far from conventional assumptions about disability in line with traditional medical and academic concerns and interests (charity model), disability research that works within the social model promotes research agendas that are focused on the emancipation and empowerment of disabled people. These need to engage with innovative methodologies that can facilitate a sharing of personal experiences and creating debate (Hodge, 2008; Barnes & Mercer, 1997; Oliver, 2004; Barnes, 2004), including disabled people's voice in the leadership and design of research (Arstein-Kerslake at all, 2020). A development of emancipatory, participatory, and inclusive research methodologies is broadly suggested in the last decade, and this study provides a substantial contribution to that end.

Using an autoethnographic method, this research illustrates the value of self-narratives (Chang, 2008; Kendal at all, 2013) for learning about self and others. A writing process evokes self-reflection and self-analysis through which self-discovery of people born with physical impairment becomes a possibility. As I tried to demonstrate, self-discovery *per se* is appreciably concerned with agency and empowerment, that is, resilience. In turn, writing this autoethnography has brought me not only the understanding of building blocks of my strength in light of theory of resilience, but also has been a sort of “self-therapy”, as going through painful and sad moments in my life again has been a way to overcome them and feel somehow relieved.

As stated by many scholars, the effect of autoethnographic study is concerned with bringing “self-transformation to the writer in healing, catharsis, and broadening their conception of life experiences based on cultural and scholarly exposure” (Cavanagh, 2019; Ellis at al., 2011; Snyder, 2015). In my case, I traversed my own memory to perform this emotionally exhausting enterprise. This process invoked so many emotions that I began to struggle with depression and eventually I lost the will to continue writing. Then I was advised by a friend, “Do it for the science, you need to assist others on how to survive similar experiences”.

In parallel, I used analytical autoethnographic approach through which I self-assessed my lived experiences through the lens of Theory of Resilience and Disability Studies. The theoretical understanding provided me with a path to evoke and extract from my memories the most relevant details that helped me to acknowledge the building blocks of my own resilience. The intellectual growth has been another remarkable outcome of this research enterprise based on the combination of evocative and analytic autoethnography that alternated inward and outward gaze (Holman Jones, 2013).

The most compelling and most consistent finding indicates the centrality of my family relationships and social support as a critical component to building my individual resilience, as suggested by the psychological literature about resilience. But, from the perspective of disability studies, there are other resources that are worth highlighting, especially relevant for people born with physical impairment. Factors connected to social development that took place in the last decades, such as grants for professional growth and acquirement of technological skills and resources, have played an important role in our empowerment. And they, in combination with my memories of the support I received from my family team, are how I got through COVID-19 lockdown.

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