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“If Pain Could Speak, What Would It Say?” Re-lational Inter/Intra-rogation of sickle cell disease: A Poetic ~~Inquiry~~ Insight.

Peace O. Anumah

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Abstract

If pain could speak, what would it say? If it could have a form, what would it look like?

I start with these questions to illustrate the line of inquiry I am reframing as *insight*. The insights come from a conversation with a *therapist warrior* battling sickle cell disease (SCD). I use the language of *therapist warrior* for multiple reasons. To protect the anonymity of my conversational partner; to obscure her name but *not* her identity or infinite resourcefulness; to work with an archetype in a way that is congruent with the model of engagement I use within our conversations - Internal Family Systems (IFS), (Schwartz, 2013).

I work with this model in my therapy practice. I draw on it in this paper to highlight the transformational power of externalising the pain experienced by the therapist I am conversing with. I will offer an overview of the model and an overview of the new language I am introducing in relation to methodology.

IFS offers a different lens through which to view pain. Pain can be externalised as a “part”, no longer within the individual. This helps to empower the individual and their experience of pain.

In this paper, I seek to highlight the resilience of the therapist I am conversing with and raise awareness of sickle cell disease. The paper actively examines the oppression and racialisation experienced by individuals with SCD from within the health *care* system. *Care* is contested.

I use “re-lational inter-rogation/intra-rogation”, a methodology I am developing, to examine this. This way of engaging with conversational material highlights the importance of intentionally exploring relational changes after every re-connection or newfound acceptance between and within a group and connecting those insights with wider political forces.

I use my embodied reflexivity for witnessing the impact, experiences, and happenings that occur during and after our dialogue. I illuminate my conversational partner’s resilience within the wider discourse of racialisation and marginalisation.

Keywords:

sickle cell disease,

poetic insight,

Internal Family Systems model,

pain,

re-lational inter/intra-rogation

Citation Link

Poems are transcribed from the conversation to add to the quality and aesthetics of the paper for the readers, as well as a reflexive process for me during and after my conversation with the therapist warrior. Poetry has a long history as a counter-narrative to the status quo and can be viewed as a decolonial, political act (van Rooyen and d'Abdon, 2020).

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Poetic insight

I listen with therapist warrior.
As she describes her pain.
We externalise that pain.
There's a pause as she speaks.

I notice a bodily reaction within me.
My heart races.
My breathing is intentionally deep and slow.
I am trying to regulate.

I sink deeper into my chair.
My mind wonders in the depth of her pain.
I see little gremlin-type creatures.
gnawing away at my own bones
their sharp teeth banging at my bones.

I wonder what that must feel like.
Acutely and chronically.
All the time, every time.
I respond, *"like gremlins?"*
Yes, she replied, *exactly that*.

An extract from our conversation:

"Evil little workmen, with their hammers and their chisels.
And all their tools banging away at my bones.
And their sharp teeth, gnawing away at my bones.
Breaking down my bones.
My legs, my arms, my back. They're inside my bones."

Introduction

I am a systemic psychotherapist and a doctoral researcher. In 2022 I put a call out to therapists living with sickle cell disease (SCD) to meet with me as part of an inquiry that speaks to my own interest in this important area that crosses over multiple domains- racial injustice, health inequality, the role of pain in people's lives, and the impact this has on people practicing as therapists. My inquiry that I am framing as *insight* speaks to my curiosity about resilience (a contested term, deconstructed later in this paper) and a strong pull, within me, to understand the experience of SCD more fully. Therapist warrior responded to the call. I imagined there would be more response, but I (perhaps) underestimated the role of stigma.

This paper illuminates our conversation and what we have learnt together though our connection. Our conversation is framed by the model of therapy called Internal Family Systems (IFS) and I introduce a new, emerging methodology to widen the context into therapist warrior's relationships with health *care* and racial bias.

Internal Family System (IFS) offers a model for co-constructing new understanding. Using IFS in our work together, I aim to illuminate therapist warrior's resilience and well-being. Additionally, I re-lationally inter-rogate/intra-rogate the systems at work in her life. Relational interrogation/intra-rogation is a method of inquiry/insight that I am developing. I offer further descriptions as the paper unfolds.

I have chosen to focus on the health *care* system and re-lationally *inter*-rogate/intra-rogate its relationship to therapist warrior, as well as within the SCD group to highlight the racial injustice inherent in the *care* provided to sufferers. I discuss the condition in more depth later.

Internal Family Systems (IFS)

Richard Schwartz developed the Internal Family Systems (IFS) theory in the early 1990s. This approach stemmed from his therapy experience, where clients would speak about having an inner *part* within themselves (Schwartz, 2013). This evidence-based theory asserts that we all have various "parts" or sub-personalities we need to embrace to achieve healing (Schwartz, 2013; Schwartz and Sweezy, 2020).

According to Richard Schwartz, these parts are natural. We are born with them. They are not products of trauma. Together they help us with life. But trauma injuries and experiences have forced them out of their natural state into destructive roles (Anderson, 2021; Schwartz and Sweezy, 2020). By learning how these parts function as a system and how other systems react to each other, individuals can effectively understand their conflict, find ways to manage these conflicts and develop healthier well-being.

The IFS approach divides parts into three roles. The roles the parts were forced into when the trauma happened. These are defined as:

- **Managers:** These are the protectors. They handle how individuals interact with the external world to protect them from being hurt by others and try to prevent further pain.

- **Exiles:** Shame, fear, trauma from childhood. The "managers" and "firefighters" attempt to exile these parts from consciousness to protect the individual from further pain.
- **Firefighters:** They work to distract a person from any hurt or shame experienced by the "exile", causing them to engage in behaviours such as addictions and eating disorders.

It is this idea of understanding our parts that I was interested in during my conversation with therapist warrior. The pain plays a role in her life and her systems. For example, her family, work, relationship, religion, and health *care* systems.

Critique

I am using the language of therapist warrior, a term we agreed upon to describe her identity but retain her anonymity. I have spent time and care attending to the ethics around this and I have struggled with the complexity of being a single author whilst drawing heavily on my conversations with (and learning from) therapist warrior. This comes with a degree of tension and conflict. I acknowledge that this invites criticism.

There have been criticisms too about the IFS model, for example, attachment theorists may struggle with the concept of the self being inherent rather than stemming from the relationships we form or do not form, with our primary caregiver (Schwartz and Sweezy, 2020). Another criticism is that it fails to consider any neurobiological underpinnings of mental health issues (Hodgdon, et al, 2021).

Nevertheless, I aim to use the pain as the part being explored within the IFS model. Looking at the roles the pain plays as a manager, exile and firefighter as therapist warrior relates and reconnects in a different way with pain. I will not go into detail about pain and the brain. However, studies have shown that pain can become traumatic in itself because of its impact on the neurological system and its associated triggers.

Preparations for the Conversation

I am conscious of adhering to ethical codes of conduct which frame my roles as both a therapist and researcher. Though this inquiry/insight is not part of my doctoral research and so has not been subject to organisational or university ethics procedures, it remains important for me to attend to ongoing relational ethics. I am organised by ensuring that our conversation causes her no harm or distress (adhering to practice and research ethics). I am as a therapist researcher aware of my axiology: my values, ethics, aesthetics, and biases that may influence my ability to listen and my ability to witness the relational process within the virtual room (our conversation took place through a virtual platform). I am reminded of the four domains for ethical consideration proposed by Tracy (2010) who outlines the importance of considering procedural, situational, ethical relationships, and the ethical issues of the study itself, in a qualitative research frame. These are issues I have considered and aim to weave in as a golden thread throughout this paper. The metaphor of "golden thread" was defined by Hornby (2018) as "an idea or feature that is present in all parts of something, holds it together and gives it value".

It is equally essential to be mindful of my philosophical stance and that of therapist warrior. Therefore, I will look at axiology, ontology and epistemology, which I have termed *axio-onto-epistemology*. I believe our axiology influences our ontology and epistemology (Deane, 2018; Patterson and Williams, 1998; McGregor, 2011). It is worth noting that informed consent was obtained prior to the day of the conversation. Therapist warrior agreed to have our conversation recorded and transcribed into poems. The poems created were shared with therapist warrior, and consent was obtained for the poems to be used in this paper alongside the transcriptions and my reflections. I consider my own experiences carefully.

Sickle cell anaemia (a severe form of sickle cell disease) runs close to home for me, as several family members and close friends are warriors of this blood disorder. I have seen the impact of this disease on their lives, the suffering and challenges that come with it. I have friends who have died from this disease.

I am aware of my experience and knowledge about the disease, and mindful of how this impacts my listening and witnessing. I am intentionally slow with our dialogue. Pausing and reflecting with therapist warrior on what I am hearing. Looking inwardly at the embodied impact of what I am hearing, (Jacobs, 2011). My interpretations of the words used, the translation of those words into images, or colours that form in my mind and what I allow myself to truly hear.

Reflexivity as a concept within qualitative research may be contentious (Patai, 1994; Pillow, 2003) but, for me, it remains an integral part. I view reflexivity as an embodied engagement. Several neurobiology researchers have shown that the body can know things that the brain has not yet realised (Azevedo, et al, 2017). Listening with my whole body being present, and witnessing its impact on my body, on her body, was a key component. Using a virtual platform had challenging aspects including making it harder to read the body language. I tried to describe what I was experiencing in my body to therapist warrior and ask about her own embodied experiences.

As the conversation unfolded, I was aware of similarities and differences. For example, we are both therapists, same gender, ethnic background, race, and religion; but different family upbringing, and I do not have Sickle Cell Disease (SCD). I made the decision to communicate with her in an informal way, positioning myself alongside her, with her as the expert of her story.

Sickle Cell Disease

Of course, readers can research this disease, and I hope this paper encourages readers to do so. But how can you write about SCD, without writing about SCD? An overview here is required. Writing about it within the wider context of inequality may help readers to understand the systemic racism experienced by SCD sufferers. Sickle Cell Disease (SDC) is a group of inherited red blood disorders, most common in the African, Caribbean, and Hispanic regions (CDC, 2022). The human red blood cells contain a protein that carries oxygen called haemoglobin. They are round and move through small blood vessels carrying oxygen to different body parts. However, individuals with SCD do not have round-shaped haemoglobins (CDC, 2022).

The red blood cells have a C-shape, similar to that of a farmer "sickle tool". The red blood cells are hard and sticky and die quickly, creating a shortage of red blood cells in the body. When travelling through the small blood vessel passages to distribute oxygen to the body, they get stuck and clog the blood flow, because of their shape. This causes bone pains (commonly known as pain crisis) and other serious health problems such as infections, eye problems, stroke, organ damages, acute chest syndrome (CDC, 2022).

Sickle cell disease is a lifelong illness and, at the time of writing this paper, the only cure is a bone marrow transplant. Finding a well-matched donor is often difficult and, therefore, not everyone is able to have this. There are several medication and pain management protocol that can help ease the symptoms, but experiences of *care* and treatment varies.

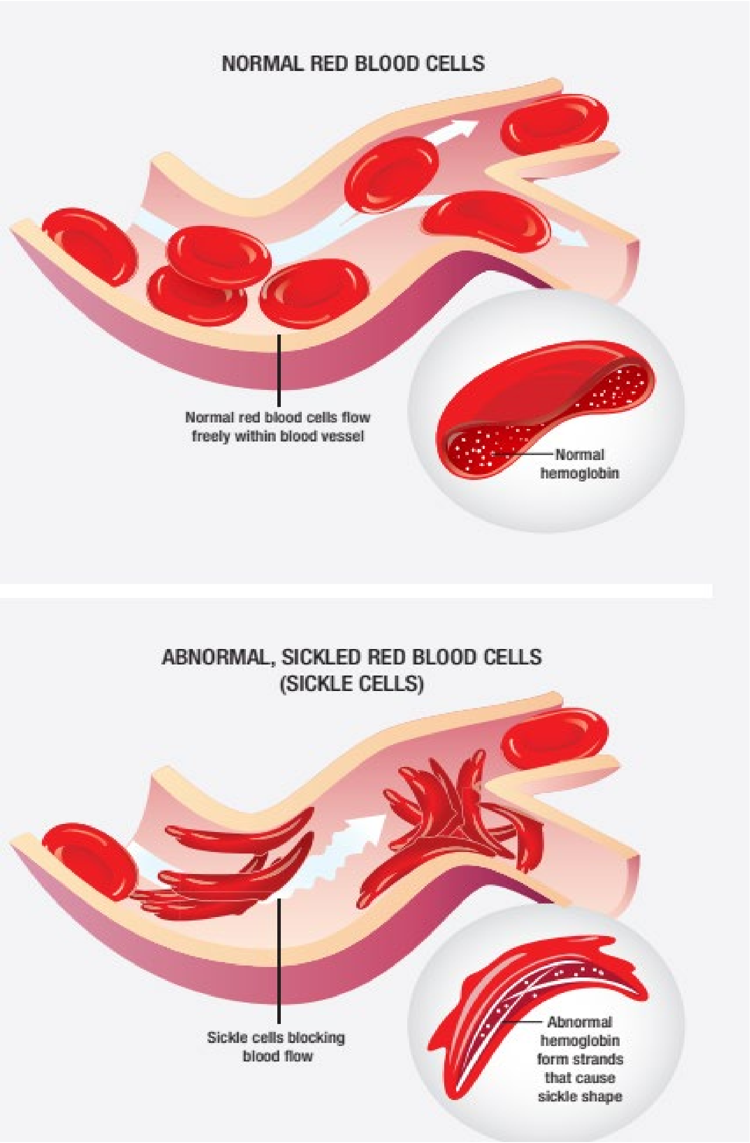

Image source: National Heart, Lung, and Blood Institute (2022)

Me and my sickle cell

Me and My sickle cell
I've known you my whole life, though we were never introduced.
You're always by my side, and yet I reject you.
Through thick and thin. The good and bad. You accept me.

Me and My sickle cell
I'm in pain. No! In agony! The pain I know you didn't mean to cause.
Why don't you just leave? I wish you'd just leave.
No, don't leave. You're all I've known. What would life be like without you here?

Me and My sickle cell
I'm a burden. I'm weak. I'm sick. I'm broken. Who would want me?
Oh, the pain! The agony. My bones! My legs, my arms, my back!
I'm tired! I'm tired. They don't understand, I'm tired! Why don't you just leave?e and My sickle cell

Look at my scarred arms. Look at the needle marks.
Blood transfusion is my lifeline.
I hide my scars. They mustn't see. One less thing to judge me with.

Me and my sickle cell
You are me, but only a part of me.
I am more than my sickle cell.
My daily battle.
I rise. I fall. But I rise yet again!
I'm a warrior. A soldier. And my scars? My badge of honour.
Me and My sickle cell
I've known you my whole life, though we were never introduced.

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I created the above poem by transcribing therapist warrior's description of her experience with Sickle Cell Disease (SCD). I asked her to imagine her pain as living outside her body. What form does it have? What shape? By externalising and objectifying the pain, I witnessed the therapist giving the part a form, its own beliefs, feelings, and characteristics.

Therapist warrior: *I feel like it actually doesn't want to be around. But it has no choice.*

Me: *I'm wondering why that is. Why does it feel as though it has no choice? What is its role?*

Therapist warrior: *I think it has different roles. Its role has changed throughout my life. But somehow, I believe its role is to warn me. And so, it has no choice but to be around me. It's constantly following me. There in the background and then it makes itself known to* ***warn*** *me? I think. Maybe it feels I am doing too much. When I do too much. For example, if I work long hours and become very tired, sometimes that would trigger my "pain crisis". It's trying to warn me that I am stretching myself too much and I need to rest. Maybe.*

Me: *That's interesting. So, it shows up and makes itself known to warn you (**Manager role**). To protect you. Right now, as we're talking, I feel a sense of calmness within me.*

Therapist warrior*: That's funny because I feel uneasy. My heart is racing slightly. Faster than before. It may feel like it's here to warn me. But at the same time, I'm struggling with feeling grateful. I feel like I'm supposed to be grateful. But why does it have to be so intense? Why does the pain need to feel so intense?*

Me: *Why don't you ask it? Do you think if it wasn't so intense, you'd still notice? Do you feel there's no need for it to warn you?*

Therapist warrior*: "laughs" … probably not! I just remembered a memory from when I was a teenager, and I would rebel. I wanted to fit in so badly that I would go out drinking, smoking, not eating properly and then I'll have a pain crisis and repeat these behaviours again the next weekend. I really wanted to fit in, I wanted to feel "normal", so much that I ignored so many warning signs (**exile and fire fighter**).*

Me: *The memory you just brought up, what do you think the "part" would have needed back then?*

Therapist warrior: *I've never really looked at it like that before, but I guess it needed me to take better care of myself. The pain is always there, and I can manage it with pain medication. I know the right things to consume. I just didn't do it. This is an interesting way of looking at my pain. I've really hated it for many years. I felt shame and like I was a burden. But I can see how it has tried to keep me safe, making its presence known. Warning me that things are getting to an extreme level in my body.*

Now, I feel sad for it…

Therapist warrior was able to witness herself alongside her pain. Her position. Her experience. Its role. Its significance. This caused her to develop a level of empathy for her SCD that she had never thought of.

Therapist warrior*: I've never really considered sickle cell pain as something outside my body because it's always been part of me- if you know what I mean.*

Me*: what does it feel like to experience sadness for it? To have it outside of you?*

Therapist warrior*: I'm not sure. I need to think on that. But having it outside of my body is freeing. I feel light. I feel strong. But at the same time, I feel strange. It's all I've ever known. I don't want it to be outside of my body, but at the same time, I do. Very odd!*

Pause…

Therapist warrior: *I'm now wondering, those times I get tired. It must feel very tired too.*

Me: *How do you mean?*

Therapist warrior*: It's been here with me since I was born. It's been doing this role from the start. To have those gremlins show up all the time? That must be exhausting for it. I know that because I feel the impact all the time. The pain itself (pause) must be tired, just like I'm tired.*

Me: *Why don't you sit with it for a moment and ask it, is it happy with its role? I wonder how it feels about those gremlins?…*

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My intention here was to support therapist warrior to challenge her thoughts and beliefs about Sickle Cell Disease (SCD). Beliefs and thoughts she had held for several years. I was mindful of my position, knowing that I do not have SCD and that I could perhaps never truly understand her experiences. I am very mindful of my empathy and sensitivity levels (Holmes, 2020). As our communication continued, I noticed that she had strong beliefs, values, and ethics. She questioned why she obeyed certain social norms; what it is to be a human with SCD in society, and how society views you. Furthermore, she had never really questioned how she came to know she had sickle cell disease. One can argue that these areas of discussion tie into her Axiology, Ontology and Epistemology.

Axio-Onto-Epistemology

I have grouped all three of these philosophical stances because they are interconnected and should not be separated (Deane, 2018; Patterson and Williams, 1998; McGregor, 2011). Axiology focuses on the role of values, and value-based judgements, which include ethics and aesthetics (what it means to be good, right, or wrong), what beauty means and the notion of worth. Axiology is interested in questions such as, why do we obey social norms? I believe that an individual's axiology will influence their ontology. Because ontology is concerned with what it means to be a human being. Are we free agents? Or are we controlled? Ontology is concerned with the relationship between different social realities and social structures, the nature of the world and what we know about it (Crotty, 1998; Ormston et al, 2014; Berryman, 2019). At the same time, epistemology is concerned with how knowledge is acquired (Crotty, 1998). How do we know the world, how do we know what we know? Values form our thoughts, beliefs, and perception. They are embedded in everything we do, say, how we behave and what we create (Hart, 1971; Hofkirchner, 2004).

Me*: At what point did you know you had sickle cell disease?*

Therapist warrior*: That question has really stumped me. I don't think I can pinpoint a time where someone sat me down and said "you have sickle cell anaemia". I just remember being a poorly child. I know I was diagnosed at three months. I spent most of my childhood in and out of hospital. I don't remember a moment when someone said, "you have sickle cell". I've just always known that it's been part of me. It's just always been with me.*

Me*: When did you know that the illness had a name "Sickle cell anaemia?"*

***Therapist warrior:** I had a nurse specialist. She was amazing. Being a Black woman, I was inspired by her. I looked up to her. She was instrumental in telling me about it, as was my mother. From an educational standpoint the nurse specialist was key. When an ambulance would be called 10 out of 10 times, they would not know what sickle cell was. So, the blue lights will be going off and my mother would be telling them about sickle cell whilst I'm being rushed into hospital.*

***Me:** What difference did naming it make?*

***Therapist warrior:** Having all that information really helped me. It empowered me. But at the same time, I felt like I had to wear this label. I remember when I was twelve years old, I was crying to my mother saying "no one would want me. I'm broken, I'm damaged", and she would try to reassure me and say what mothers would typically say to encourage their child. As a young teenager, I rebelled against the illness.*

Smiles.

I smile now, but cringing at the thought of some of the things I would do. Like I said already, I would go out drinking, smoking, and waking up the next morning in pain and repeating the cycle every weekend. Just to fit in. Then in my mid-twenties, I found my faith and that's when everything changed. My whole outlook on life changed. Before I felt shame, I felt like a burden. None of my friends knew I had Sickle cell. I kept it hidden. It was important to me to be liked. My Sickle cell was the focal point of my identity, I didn't know other parts of me. My faith gave me a different look on my values, how I see myself. How I relate with people. Now I talk about my sickle cell whenever the topic comes up. Before, I felt like I was annoying, a burden, because I was always sick. Now, I still feel *like I am annoying, but a type I am proud of. I use my voice to challenge the system, especially the health care system, because of how they treat us. It's wrong. It's riddled with racism. They probably find me annoying! But I'm happy about that…*

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This dialogue with therapist warrior encapsulates all three philosophical stances. It shows how the acquisition of knowledge (epistemology) about her illness and her newfound faith influenced the values she held (axiology) and, in turn, changed the way she viewed herself in society (ontology). This amplified her voice, empowering her to speak up against social injustice and embrace being a member of the Sickle Cell Disease community by getting involved and advocating for better care and treatment as well as the Black and ethnic minority community. Mignolo (2010) talks about the need to be epistemically disobedient. She talks about it as a way of diverging from a euro-centric epistemology, "de-linking from the illusion of the zero-point epistemology" (Mignolo, 2010). I use Mignolo's term "epistemically disobedient" to highlight how this therapist was attempting to "de-link" herself from the knowledge and narrative of what it means to be a *human* with SCD—fighting against the oppression that has riddled the health *care* system, the systemic racism and racialisation. Swimming against the tide in the pool of oppression, not just for herself but for others. She decided to no longer view her world through the lens her oppressors had given her. To be epistemically disobedient takes courage to swim away in a different direction, away from that which tries to assert itself as the primary way of knowing (epistemology) – which then translates to the primary way of being (ontology) – which further influences your values (axiology).

Re-lational Inter-rogation and Intra-rogation

Systemic racism

According to the CDC (2022) there are an estimated 300,000 children a year born with SCD. The World Health Organisation (WHO) recognise it as an important public health problem (C.D.C., 2022) but there is still very little funding for researching this blood disorder, compared with other genetic blood disorders (Matthie et al, 2019; Lee et al, 2019; Coleman et al, 2016). Several researchers have argued that this lack of funding is due to systemic racism and racialisation (Mahase, 2021; Bulgin et al, 2018; Redhead, 2021).

Berghs et al. (2022) found evidence of systemic racism and unethical care in treating those with Sickle Cell Disease (SCD). They also found that healthcare professionals' knowledge of sickle cell disease was lacking. This same comment was echoed by therapist warrior. I am reminded of a BBC news feature (2021) covering the death of a young man with sickle cell disease, age twenty-one, who rang 999 from his hospital bed because the healthcare professionals failed to recognise the significance of his symptoms. Link and Phelan (2013) found that individuals with SCD are often stigmatised and labelled which leads to negative consequences such as devaluation, judgement, and social disqualification. Bulgin et al. (2018) and Wakefield et al. (2018) added that individuals with SCD also experienced perceived racial bias, discrimination and negative treatment because of their racial identity.

Blind to my Pain

You see my pain, my tears, my shivers.

You hear my cries, my groans, my moans.

Sickle Cell? You're confused. I can tell.

Through my pain I explain, as plain as I could.

Still, you're confused.

Paramedic, I might be, but medical care I do not have for you. You say.

Gas and air are all I need. I say. I plead, just gas and air, for now.

You resist, still confused.

I sigh!

You don't see my pain. My tears. My shivers.

You don't hear my cries. My groans. My moans.

Your judging eyes are all I see. The colour of my skin is all you see.

Go on, leave! Look away!

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As I make note of my conversation with therapist warrior captured in the above poem, I feel an immense sadness wrap around my heart. To be visibly in pain, in agony and yet invisible. To not be seen as human, even when displaying extreme human emotions, causes me to feel a deep sadness. I remember my family members, my friends and those that have died. Knowing that this has been and continues to be their personal experiences. Dehumanisation of Black people remains visible in our health care systems. Humans being seen as less than human or subhuman (Goff et al., 2014; Jardina and Piston, 2021). Kteily et al. (2015) described this racial dehumanisation as a process where people are stripped of their emotions and cognitive ability. I argue that this directly contributes to people with sickle cell disease being denied adequate care, with their pain being minimised or ignored. I use an approach I call *re-lational inter/intra-rogation* to examine this system of oppression for therapist warrior.

Re-lational Inter-rogation/Intra-rogation – (purposefully separated and hyphenated). I provide a working definition as a process whereby an individual makes an intentional decision to re-connect with a person, place, organisation, or religion (human and non-human entity) after an acquired knowledge about that human and non-human entity that shifts the way they relate, interact, perceive, that human or non-human entity, as well as themselves. This can be between the individual and several groups and/or the individual within a group.

Inter-rogation/Intra-rogation is hyphenated in reference to Mignolo (2010) to acknowledge "de-linking from the illusion of the zero-point epistemology". I am using this term in a relational sense, extending Mignolo's "epistemic disobedience" to extend the curiosity to what *follows.* Regardless of the agenda, vision, aim, or quest to obtain the “ultimate grounding of knowledge” (Mignolo, 2010) I believe a *re-connection* of some sort should follow, through a different lens. Re-lational Inter/Intra-rogation is a process that needs to happen to re-connect the re-lational link that was de-linked. Creating, co-creating, and re-negotiating what the new link could look like, feel like, and be like.

Re-lational Inter-rogation

Therapist warrior: *There have been times in hospital where I have had to wait for pain relief. The excuse I was given was that they had to wait for a doctor, even though they could see I was in pain. That used to frustrate me! Before I would accept however they treated me. Because I didn’t know any different. But I think my faith plays a massive role in how I view things today.*

Me: *If there was a theatre of oppression, who would be the main characters?*

Therapist warrior: *I think I will need to start from the ground and work my way up. I’d say the paramedics, then the hospital managers and directors, then the hospital trusts (the powers that be).*

Me: *Ok, and in this theatre of oppression, what is your role? Or what part do you play?*

Therapist warrior: *I’ve been cast as an annoying/whining person, claiming she is entitled to something, but it’s not meant for her- there is a feeling of, “if we must give you… here’s a little bit”.*

Me: *Almost like a reluctance to give you. How do you feel about this role?*

Therapist warrior*: I feel angry and sad. But, more sad than angry.*

Me: *So, you’ve been given this role as an annoying person, and you are sad to be in this role. Is there any other role you find yourself imitating? Or do you find that you’re adopting a different role for survival, and rebelling against the role they’ve given you?*

Therapist warrior: *I didn’t really understand much back then. I allowed a lot of things go by, by ignoring it. Turning a blind eye. But now I fight. I’m in a fighting role. But not with my fist. Back then I just wanted to get out of the hospital, I wanted to be pain free. Now I am in a different place. As a therapist, I work for a mental health charity that support the Black community. It’s such a big part of my world now. I hear people’s stories every day. I hear their struggles. I fight for their voices to be heard as well as mine. I didn’t know I was entitled to fight and have a voice back then, but now, I know my rights. I know who I am.*

Me: *Wow. What a transformation. Growing up, you had one type of knowledge that said “behave this way” but you have rebelled against that knowledge and acquired a different knowledge, and now trying to re-connect back to the system of oppression with this new perspective, with a louder voice, advocating for others as well. That’s amazing!*

Therapist: *(Smiles…) But I’d like to think I’m not a whining/annoying person. There have been many occasions where I have brought my concerns to the hospital regarding medical negligence. And threatened to raise complaints. They hate it when I say, “I can stand here and raise this negligence I experienced, what about those who can’t stand up for themselves?”*

Before, that wouldn't have been me. Now I use my voice. Maybe I am still annoying. But in a different way. It's an annoyance that I am proud of.

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Through this re-lational inter-rogation, my dialogue with the therapist highlights how she had "delinked" herself from the knowledge that she had acquired previously (epistemology). A knowledge that impacted her views on what was acceptable, her rights (her axiology), and how she behaved. How she used her voice and felt about herself. The impact on how she showed up in society (ontology). She ignored hospital negligence, remained silent and did not know she could fight. Her views changed. But for the system to change, she needed a different connection to it. In recognising this *disconnection*, she is attempting to *re-link* herself to the system with her newfound knowledge and understanding of who she is. Interrogating the oppressive system in being a *proud annoying advocate* for the Black community, but most especially for the Sickle Cell Disease community.

Re-lational intra-rogation

Therapist warrior has always had Sickle Cell Disease (SCD) but has not always seen herself as part of the SCD community. She had distanced herself from it. Seeing herself as a sufferer of this disorder and as a "burden; broken; weak". With a newfound acceptance of SCD she re-connects to the SCD community.

***Therapist warrior**: Growing up I didn't really see myself as belonging to a SCD community. Not many of my friends knew I had Sickle cell. I wore a mask every day just to fit in.*

***Me**: How does it feel saying that out loud?*

***Therapist warrior**: Not great! As I think about it now, I think the health care system had a massive role to play. I wasn't believed whenever I said I was in pain. So, I would wear a mask. I didn't want to be judged. Having SCD back then wasn't something I felt comfortable talking about. There was a stigma, and in some areas the stigma is still present.*

***Me**: But now things are different. What would you like to say to society?*

***Therapist warrior:** Yes, very different. I feel very much a part of the SCD community. I talk about SCD at any opportunity I get. I challenge the health professionals and advocate for others like me. It feels good. But society needs to know that we (Sickle cell disease sufferers) are all different and it is harmful to ignore us. I'm speaking to the health professionals, the government, the powers that be. But even families and close friends. If you have a relative with SCD that says they are tired, their "tiredness" is different to your "tiredness". When my husband is tired, that's me at my best.*

I'd like to say to them to sit down, understand and listen. And although we may try to do everything, we possibly can to feel normal, we are not capable and sometimes support is welcomed.

Sickle cell disease is like a spectrum. I've always considered myself one of the lucky ones. Some people within the SCD community are in awe that I am married, I have a child and I work. I feel sad that some feel that these things are unachievable or unattainable for them.

Me: *As you reconnect with the SCD group, what role do you play?*

Therapist warrior*: I'm still an annoying fighter. It's good to be "proud and out" there advocating for SCD sufferers. I'm proud to be annoying for their benefit.*

Me: *what's happening within you as you say those words?*

Therapist warrior*: I feel joy. I'm listening to what I am saying, and I believe it in my heart. It's not an easy task. But every time you try to reconnect with the oppressive system using a different way, they try to pull you back into the oppressive dance. It's exhausting. A constant fight…*

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Resilience – But I'm not resilient.

Resilience? Don't call me resilient.
I'm only doing what I'm supposed to do.
But I don't know how you do it all?
Don't say that. Really, it's nothing.
I'm only doing what I'm supposed to do.
Good God! How did I do it all?
But I'm only doing what I'm supposed to do.
I rise each day. She's my rock, that daughter of mine. My special girl.
I rise, each day, for her. She needs me. Doing what I'm supposed to do.
I rise each day. Doing the best, I can.
Doing better than expected.
If that's resilience, then you can call me resilient.

****

The term resilience has been around since the early seventeenth century stemming from the Latin verb resilire which means to rebound or recoil (McAslan, 2010). The decades that followed revealed that resilience was initially used to measure the strength and durability of inanimate objects (Gere and Goodno, 2012; Merriman, 1885; Holling, 1973; Bonanno, 2004). If the original intent for the word resilience was meant for inanimate objects that can be stretched and yet bounce back to its original form, is it right to attribute such characteristics to human beings?

As human beings it is our nature to adapt and change. It's part of the evolution theory. We are not objects that can be stretched and pushed to a limit with the expectation to bounce back to our original form prior to being stretched. The inevitable will happen in that there will be a change that will occur within us. I believe that the systemic process of being stretched to our limit and what that involves will cause a change within us and around us, as opposed to a "bouncing back" process.

The word resilience carries an expectation of returning to a prior state of existence. However, sometimes this is not always possible. For example, towards the end of 2019 and early 2020 the whole world was hit with a deadly pandemic virus – COVID 19. The systemic process that followed caused a shift in the way we functioned- relationship formation, work, communication through a mask, or virtual screens, travel restrictions and regulations, etc. Life as we knew it changed. As much as people longed to go back to what was before the pandemic, this was not possible. Accepting the "new normal" and adjusting accordingly became a new, resilient approach. To force a person to "bounce back" to their prior state of existence when it is not possible, would cause an impossible bind.

***Therapist warrior**: I've been on a massive journey of getting to know myself, but from a different perspective and different lens. With an acceptance of my illness. And I'm still on that journey. But the word resilience makes me uncomfortable because I feel I am just doing what I'm supposed to do be doing. It's not until someone says something about how much I have done, I realise "good God, how am I able to do all those things?" I would describe my resilience as doing what I'm supposed to be doing. Whatever that is in the moment.*

***Me**: And who sets the expectation of what you are supposed to be doing?*

***Therapist warrior**: I think I do for the most part. My biggest motivator is my daughter. She's seven and has additional needs – and non-verbal. I often say "God, I grew up with SCD and I was a poorly child and now my daughter is non-verbal and, on the spectrum, how is that fair?" But I guess He gives us what we can bear, and He feels I am the chosen one that can look after this special girl. I have to draw strength to look after my daughter. She is the reason why today; I keep on going. She inspires me. I don't want to look back 10 or 20 years from now and wish I had done more or have any regrets because of fear.*

***Therapist warrior:** I have an expectation for myself, if I do better than expected for the day that feels like I am resilient….*

****

Van Breda (2018) defined resilience as a multilevel process that systems engage in to obtain "better-than-expected outcomes in the face or wake of adversity". He implies that resilience has multiple levels, meaning that it can span across different domains and not just within an individual. His definition resonated within me in my conversations with therapist warrior. Not the process of "bouncing back" from adversity but doing better than she expects herself to do daily.

Amo-Agyemang (2021) directly confronts the western, Eurocentric epistemology that have negatively positioned "vulnerable" Africans. He states that resilience experienced by the western world is not the same experience in other parts of the world. And to assume so, can be said to be "epistemically violent" (Spivak, 1988; Brunner, 2021).

We also run the risk of further oppressing marginalised communities if there is pressure and expectation to "bounce back". The assumption that the sickle cell disease community, and any group that are being oppressed, can bounce back from adversities can lead to the continued oppression they are experiencing (Amo-Agyemang, 2021). Resilience is not universal, it is not a" one size fits all" (Amo-Agyemang, 2021). People's lived experiences are not equal.

Final thoughts

To my oppressors
You tried to knock me off my feet.
But look, I’m still standing.
Tried to steal my voice.
I now know, I have a choice.
I have rights. I know my rights.

I looked away before, I could’ve fought.
But I was silent. Ignored by you, my oppressors.
Now I stand, amidst my oppressors.
And now I fight, against your oppression.
Your injustice. Your malpractice.

I’m a survivor! A warrior
I have a choice! I have my voice.
You tried to knock me off my feet.
But look, I’m still standing!
I stand for myself, and the community for which I stand for.

****

In closing, therapist warrior reports feeling stronger emotionally and physically and the last time she was admitted to the hospital was in 2019. She describes her experience with sickle cell disease as a journey. A journey that ebbs and flows, with good days and bad days, some very bad days.

Summary

I have set out to capture the relational power present when chronic and acute pain is externalised, using the concept of parts from the Internal Family system theory (IFS). Additionally, adopting an axio-onto-epistemological stance enabled me to sit alongside, being aware of my values, biases, ethics, embodied impact of what I was hearing and the impact this newfound knowledge has on the happenings occurring in the virtual room.

The lens of "re-lational inter/intra-rogation” shows the importance of intentionally exploring the relational changes that happen after every re-connection between and within a group.
This type of reflexive work enhanced the relational aspect of our conversation, the connection we experienced. I felt I had known therapist warrior my whole life, though we had just met. There is something about being vulnerable that invites trust into the room, into the spaces which the vulnerability occupies. There are also some things which language doesn't have words to describe. You have to be there to experience it through a shared embodied experience. And this is one of them.

Being vulnerable with how I was experiencing our conversation and hearing her approach to being vulnerable with me brought a closeness that we both felt. A warmth in the atmosphere of the “virtual room”. It was the smile at each other. The pauses between sentences, that didn't feel uncomfortable and the impromptu disclosure of personal deep-felt information and emotions.
Having said that, embodied reflexivity is challenging. My perceptions were not always easily expressed.

When I set out to write on this topic, I had envisioned speaking with several therapists and getting different gendered perspectives. However, I misjudged the extent of stigma and the fear of being judged. Not many people replied to my call to participate. The people who reached out had to cancel or couldn't schedule a time that worked. This is certainly something to consider next time.

As I conclude this paper, I ask, is it possible to “re-connect” or “re-link” with an oppressive system? Even with a newfound perspective and change in one's axiology or ontology? What impact will being epistemically disobedient have? And will changing the re-lational process make much difference? Will those that oppress ever take notice of their actions? Or will they continue to label victims as “annoying fighters” to maintain the oppressive system?

For therapist warrior and every individual out there fighting different oppressive systems, evident by their daily actions, that shout a resounding “yes”, with a hope that one day things will change for the better – with one “annoying fight” at a time.

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Author

Peace Olufemi Anumah is a Christian, Psychotherapist, Trainer and Coach. The owner of a private practice in the United Kingdom, "Piece Into Peace Limited", that supports individuals, couples, families and groups. She is also the founder of a charity "Ask PIP" that supports and advocates for vulnerable group of children and young people in care. Peace's doctoral research in systemic practice at the University of Bedfordshire focuses on resilience, relational/embodied reflexivity, re-lational inter/intra-rogation, oppressed and marginalised groups and their voices. She has re-ignited her love for poetry.

E-mail: Peace@Pieceintopeace.com

URL: https://www.pieceintopeace.com/

Citation

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