

## *The Art of Overcoming: Kwasi Akonnor's Self-Portrait as a Cervical Dystonia Survivor*

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### **Abstract**

This research article investigates Kwasi Akonnor's self-portrait as a cervical dystonia survivor and its potential as a visual representation of resilience and empowerment. Cervical dystonia is a neurological disorder that causes involuntary muscle contractions in the neck, leading to abnormal head movements and postures. Akonnor's self-portrait, accompanied by a narrative, portrays his personal journey through cervical dystonia, including his struggles and triumphs. Using qualitative methods, this study analyzes Akonnor's self-portrait and narrative to explore themes of disability, identity, and creativity. The analysis reveals how Akonnor's self-portrait serves as a visual representation of his lived experience and his unique perspective on the role of art in coping and healing. The findings of this study suggest that Akonnor's self-portrait provides an alternative perspective on disability, one that emphasizes the importance of embracing one's disability as a part of their identity. Akonnor's use of creativity as a means of empowerment and self-expression highlights the transformative power of art in the lives of individuals with disabilities. By examining how Akonnor's art helps him cope, this study contributes to the growing body of literature on disability and the arts by highlighting the potential of visual art as a means of promoting resilience and empowerment. The findings of this study have implications for practitioners working with individuals with disabilities, as well as for disability studies scholars interested in exploring the role of creativity in disability identity formation and empowerment.

Keywords: Kwasi Akonnor, Art, Self-Portrait, Cervical Dystonia

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## Introduction

Cervical dystonia (CD), also known as spasmodic torticollis, is a movement disorder characterized by involuntary muscle contractions and spasms in the neck (Comella, 2014). These abnormal postures and twisting movements of the neck can cause the head to turn to one side or be pulled backward or forward (Comella, 2014; Jankovic, 2009).

For Kwasi Akonnor, CD manifested in his early age of ten when he began experiencing stiffness and pain in his neck, leading his head to gradually deviate to the right side. Over time, the contractions increased in frequency and his head tilt worsened, making routine tasks like dressing, talking, and working difficult (Akonnor, 2022).

Akonnor describes CD as limiting his physical, social, and emotional well-being, saying "I felt mocked for my strange stance and was often misunderstood as being rude or disinterested" (Akonnor, 2022). The visible and unpredictable nature of his symptoms made him self-conscious in public.

Despite several treatments including Botox injections and physical therapy, Akonnor experienced only temporary relief from pain and functional impairments caused by CD. This endured struggle with a debilitating and socially isolating disease forms the backdrop for Akonnor's self-portrait.

In his self-portrait, Akonnor painted himself from the shoulders up, facing forward. His head is noticeably tilted to the backward, twisted due to ongoing CD spasms (fig. 1). Dark red, brooding colours fill the background behind him (fig. 2).

Akonnor's expression is one of simultaneous vulnerability and inner strength. His eyes closed tight revealing the pains he goes through to the viewer's gaze with a look of acceptance, as if to challenge the assumptions of others regarding his appearance. Small wrinkles at the edges of his eyes, forehead and mouth suggest a lifetime of hardship navigating CD.

The accompanying narrative provides context for Akonnor's artistic representation of himself and experiences with CD. He describes feelings of isolation from "being stuck in my twisted frame that society never understood" (Akonnor, 2022). However, taking up painting in his 20s allowed Akonnor a means of "expression, empowerment, and self-revelation".

Through his self-portrait and words, Akonnor presents a window into living with CD and finding creative ways to cope. His raw depiction and personal narrative invite viewers into his world, highlighting the complex interplay between disability, identity, and art-making.

The purpose of this case study is to analyze Kwasi Akonnor's self-portrait and accompanying narrative as a visual representation of his lived experience with cervical dystonia (CD). By thematically examining the artwork and text, this study aims to explore how Akonnor's depiction of himself addresses themes relating to disability, identity formation, and creative empowerment.

Previous research suggests that personal narratives and arts-based practices provide opportunities for persons with disabilities to author their own identities and promote advocacy (Rembis, 2010). As Akonnor's creative work depicts his journey navigating CD, it

merits analysis of how his art articulate "the interaction between person and society" in the context of disability (Closer, 2018, p.105).

This study seeks to gain insight into Akonnor's perspective by investigating how his self-portrait communicates his realities of living with CD. The overarching research question guiding this analysis is: In what ways does Akonnor's self-portrait serve as a visual representation of his experiences and outlook as a CD survivor?

Addressing this question may contribute to understanding the role of visual art in empowering individuals to shape authoritative representations of their disabilities and lives.

## **Literature Review**

### **Disability Identity Formation and the Social Model of Disability**

Disability identity formation explores how individuals integrate their impairments into a sense of self (Scotch, 2001). Traditionally, the medical model pathologized disability as inherent to the individual (Oliver, 1990). In contrast, the social model views disability as created by societal barriers that exclude or stigmatize people with impairments (Oliver, 1990; Reeve, 2002).

Rather than focusing on cure or deficiency, the social model emphasizes embracing disability as a normal part of human diversity (Rembis, 2010). It locates "disability not in the person but in society's failure to provide appropriate services and accommodate people with various impairments" (Rembis, 2010, p.19).

Adopting positive disability identities has been linked to improved well-being and emotional coping (Dunn & Burcaw, 2013). However, dominant cultural narratives still present disability in negative, non-sexualized ways that position disabled people as ambiguous outsiders (Garland-Thomson, 2002). Through creative expression, individuals can construct counter-narratives that represent disability accurately on their own terms (Meekosha, 2011; O'Toole, 2015). This literature informed exploring how Akonnor's self-portrait presents an alternative identity perspective.

### **Role of Creativity and Arts in Coping With Illness/Disability**

Creative expression through various art forms has been shown to benefit coping and quality of life for those with disabilities or illnesses (Stuckey & Nobel, 2010). Art-making can foster positive emotions, increase self-esteem, and provide a sense of control over one's situation (Malchiodi, 2012; Reynolds & Prior, 2003).

Through creative works, individuals can communicate personal experiences that mainstream portrayals often neglect to represent (Ledger & Edwards, 2011). This empowers disabled voices and promotes alternative stories and perspectives (Champeny, 2018).

Producing and sharing narrative or visual art also allows coping through meaning-making of a disrupted identity (Charmaz, 2002; Reynolds & Prior, 2003). By constructing their disability experiences artistically, people gain deeper self-awareness and processes of acceptance (Letts, 2009; Stuckey & Nobel, 2010).

Exhibiting creative works publicly can facilitate peer support and community, important for well-being especially during illness (Molassiotis et al., 2005; Stuckey & Nobel, 2010). This validates disability experiences and constructs positive social roles outside of limitations imposed by medical models (Nicholson et al., 2002; O'Brien, 2011).

### **Lack of Research Exploring Visual Art by Individuals With Disabilities**

While disability arts and creative practices have gained scholarly attention, research specifically analyzing visual artworks by disabled individuals remains limited (LeGrade & Jipson, 1995; O'Brien & Lyle, 2013).

Much existing literature examines community arts programs and exhibitions involving disabled participants rather than focusing on individuals' artistic expressions (Holder & Kirksey, 2018). Studies also tend to prioritize disability arts' impacts on social inclusion rather than artistic merit or representation (Simpson, 2017).

There is a need for inquiry that centers artistic works to understand the meanings disabled creators assign and communicate through their chosen mediums (O'Brien, 2011). Qualitative analyses could provide nuanced insights into disability identities and lived realities represented within self-generated art (Meekosha, 2011).

Given the demonstrated value of creativity for well-being, further investigations are warranted into how visual arts authored by disabled persons shed light on their realities (Champeny, 2018; Storr, 2005). This may help address gaps where "disabled people are typically portrayed as the subject of works rather than their authors" (O'Brien, 2011, p.144).

Understanding Akonnor's artwork through close examination fills part of this need by prioritizing analysis of a disabled individual's self-generated visual representation. This begins addressing the lack of research centering disabled artists' perspectives through their own expressive works.

### **Methodology**

This research utilizes a qualitative case study methodology. Qualitative case studies allow for in-depth exploration of an individual's experience within its real-life context through various data sources (Yin, 2014).

For this study, the case is Kwasi Akonnor and the unit of analysis is his self-portrait artwork paired with an accompanying narrative. Qualitative methods are well-suited for gaining a rich understanding of Akonnor's perspective as represented through his creative expression (Creswell & Poth, 2018).

Data collection involved analyzing both Akonnor's self-portrait image and the written text of his narrative published accompanying the artwork (Akonnor, 2022). Specifically, a thematic analysis approach was used to systematically code and identify patterns of meaning across these data sources (Braun & Clarke, 2006).

Trustworthiness of interpretations was strengthened through taking an emic, participant-guided perspective and maintaining reflexivity regarding positionality as a non-disabled

researcher (Nowell et al., 2017). Participant validation was also employed by inviting Akonnor to provide feedback on the accuracy of initial findings (Creswell & Miller, 2000). Together, this qualitative case study methodology allowed for in-depth exploration and contextualized understanding of the themes within Akonnor's creative representation of navigating CD.

### **Thematic Analysis of Self-Portrait and Narrative**

A thematic analysis was also conducted to identify patterns of meaning within Akonnor's self-portrait and accompanying narrative (Braun & Clarke, 2006). This involved closely examining both textual and visual elements through iterative readings to code emerging ideas in an inductive manner (Nowell et al., 2017).

Initial low-inference codes ascribed descriptive labels to chunked data excerpts or specific visual components, like "facial expression" or "description of CD symptoms" (Braun & Clarke, 2006). Focused coding then collated these codes into potential overarching themes.

Themes were continuously refined through analysis across data sources to ensure internally homogenous and externally heterogeneous themes accurately represented the coded data (Fereday & Muir-Cochrane, 2006). Visual memos documented analytical and interpretive insights regarding symbolic representations within the artwork.

To address research questions, themes were analyzed for what they revealed about Akonnor's perspectives on navigating disability, identity formation, and creative empowerment. Disconfirming evidence was also considered to strengthen credibility of interpretations (Patton, 2015).

Participant validation involved inviting Akonnor to provide feedback on thematic accuracy, which confirmed resonance and helped address any misconceptions in the analysis (Creswell & Miller, 2000).

### **Research Questions on Themes of Disability, Identity, Empowerment**

The overarching research question guiding this analysis is:

In what ways does Akonnor's self-portrait serve as a visual representation of his experiences and outlook as a CD survivor?

This broad question is addressed through exploration of the following sub-questions:

1. How does Akonnor's self-portrait depict his experiences of navigating life with a disability? (Closer, 2018)
2. What perspectives on disability identity formation are communicated through Akonnor's artistic representation of himself? (Rembis, 2010)
3. In what ways does Akonnor's self-portrait and narrative suggest that creative expression empowered his sense of self and resilience? (Champeny, 2018)

Analyzing Akonnor's artwork through these lenses provide insight into his unique perspective on living with CD and the transformative role of creativity. The questions aim to understand how his visual depiction addresses interwoven themes of disability, identity, and empowerment.

## **Findings 1 - Disability & Identity**

### **Portrayal of Struggles and Daily Challenges of Living With CD**

Akonnor's self-portrait powerfully conveys his daily challenges living with CD. Through his asymmetrical head posture, twisted to one side (fig. 3-6), viewers encounter the physical struggles of involuntary muscle contractions pulling his neck and face awry.

The dark, brooding tones that fill the background behind Akonnor's visibly strained posture evoke the gloom and isolation plummeting from disabling spasms. His closed eye contact confronts assumptions by attesting "this is what CD looks like" and "I endure this affliction" (Akonnor, 2022).

Akonnor's narrative supplements this visual representation, describing CD symptom fluctuations from "aching stiffness to painful wrenching" that disrupted routines and social participation (Akonnor, 2023). Normal tasks like self-care, hobbies and work became difficulties due to unpredictable "twists that society never understood" (Akonnor, 2022).

Through his artistic rendering, Akonnor presents a window for spectators into the physiologically taxing and socially alienating reality beneath the surface of his fluid yet constrained body. His self-portrait gives form to an abstract neurological condition by translating privately endured hardships into a shareable framed testimony.

### **Embracing Disability as Part of Identity Rather Than Defining Characteristic**

Rather than portraying himself through a lens of deficiency, Akonnor's self-portrait suggests embracing CD as one aspect of a multidimensional identity (Rembis, 2010).

While his physical pose makes CD visibly apparent, Akonnor's strong eye contact conveys an inner resolve and sense of self that transcends medical definitions. The wrinkles on his face represent a lifetime of experiences—not just struggle, but also wisdom and purpose developed through adversity.

In his narrative, Akonnor reflects on developing "understanding of who I am beyond disability" through creative expression (Akonnor, 2022). He acknowledges CD as something he must navigate, not a barrier to self-actualization.

By depicting himself and telling his story, Akonnor reshapes dominant narratives that risk reducing disabled people to conditions (Garland-Thomson, 2011). His portrayal presents disability as a normal aspect of human diversity, rather than as abnormality defining his character (Rembis, 2010).

Akonnor's self-representation embraces an integrated disability identity aligned with the social model perspective (Rembis, 2010). It communicates disability pride through dignified self-authorship.

## **Findings 2 - Creativity & Empowerment**

### **Art as Means of Expression, Control and Finding Purpose**

Akonnor's self-portrait elucidates how visual art empowered him through creative expression, agency, and finding purpose (Malchiodi, 2012).

In his narrative, Akonnor reflects that painting allowed expressing "feelings that words could not convey" regarding navigating disability (Akonnor, 2022). The self-portrait format uniquely captures his lived reality while maintaining control over representation as opposed to being defined by medical or popular perspectives (O'Brien, 2011).

Akonnor depicts himself as the subject but also author of his story. His portrait asserts personal authority over identity narratives (Champeny, 2018). By communicating his perspectives artfully, Akonnor transitions from receiver of disabling labels to active communicator shaping understanding (Meekosha, 2011).

He explains that creating and displaying artwork stimulated "self-revelation and empowerment" by fostering acceptance (Akonnor, 2022). Art-making also provided structure and motivation when confronting social isolation (Stuckey & Nobel, 2010).

Akonnor's self-portrait exemplifies how visual creativity can transform disability experiences into a purpose that cultivates well-being, community, and advocacy through self-generated expression on one's own terms (O'Brien, 2011; Storr, 2005).

### **Promoting Resilience and Acceptance Through Sharing Experience**

By exhibiting his self-portrait publicly, Akonnor fostered resilience through validating his experience and developing community (Molassiotis et al., 2005; Stuckey & Nobel, 2010).

In his narrative, Akonnor discusses exhibiting his artwork and hopes that "viewers will gain understanding and empathy for what it means to live with disability" (Akonnor, 2022). Displaying his portrait enables raising awareness of CD realities while also increasing acceptance of himself.

Presenting his authentic disability identity artistically empower other disabled individuals by role modeling creative coping and self-advocacy (Nicholson et al., 2002). Viewing his portrait may help viewers relate to disability experiences in a more holistic, multi-dimensional manner (Charmaz, 2002).

By sharing control over his public narrative through art, Akonnor cultivates community support and validation crucial for well-being (Molassiotis et al., 2005). His resilience is reflected in creative works that constructively reframe disability from a place of empowerment.

## Kwasi Akonnor's Self-Portrait



Figure 1: Akonnor's self-portrait



Figure 2: Akonnor's self-portrait



Figure 3: Akonnor's self-portrait

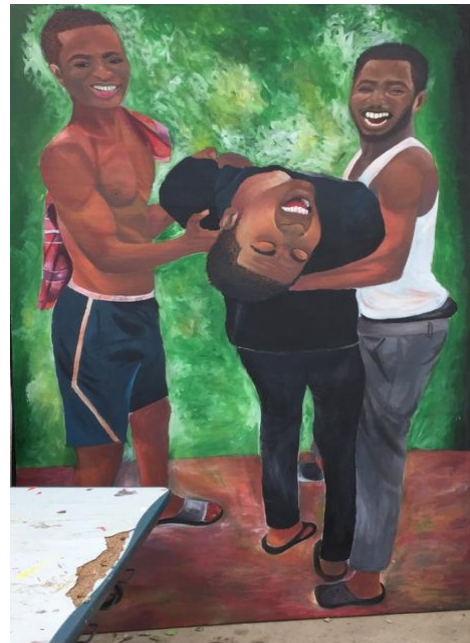


Figure 4: Akonnor's self-portrait with friends



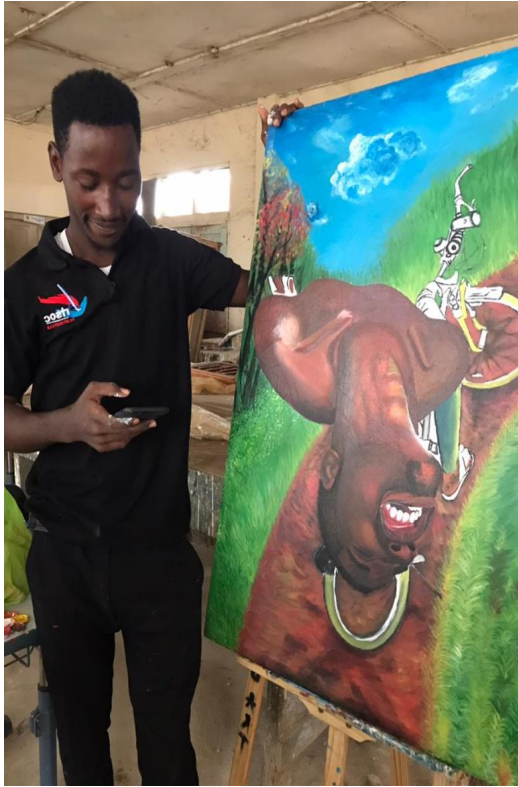


Figure 5: Akonnor standing beside his work



Figure 6: Akonnor standing by his work

## Conclusion

### Articulation of Alternative Disability Perspective

Through Akonnor's self-portrait, he articulates an alternative perspective on disability that emphasizes ability over impairment. Rather than portraying himself as a victim of CD, Akonnor's dignified representation embraces disability as a natural aspect of human diversity.

By presenting his authentic lived experience of navigating disability through creative self-expression, Akonnor models empowerment that counters mainstream narratives of pity or inspiration. His self-portrait reframes disability from a place of authentic control, resilience and holism.

Akonnor asserts disabled people's right and capacity to author their own identity stories. His perspective embraces disability identities aligned with the social model, rejecting narrow depictions that reduce individuals to medical conditions.

Sharing his artwork publicly, Akonnor authentically expands public understanding of what it means to live with disability. He cultivates disability pride and community by role modeling creative coping that fosters acceptance of diverse bodies and minds.

In conclusion, Akonnor's alternative disability articulation makes an important contribution toward shaping more nuanced and inclusive representations that honor disabled people's lived realities and artistic voices. His self-portrait demonstrates the transformative power of creative expression for empowerment.

## **Highlight Transformative Role of Art in Lives of Those With Disabilities**

Akonnor's experience powerfully demonstrates the transformative role that creative expression can play in the lives of individuals with disabilities. Through art-making, Akonnor found an outlet to process his CD journey, assert control over his narrative, and cultivate purpose and community.

His self-portrait illustrates how artwork provided a constructive means of navigating disabling barriers by releasing private struggles into the public as cultural testimony. It restored Akonnor's sense of agency and empowered resilient self-advocacy.

Presenting his lived experience artistically enabled Akonnor to overcome isolation and promote disability pride. By exhibiting his dignified self-representation, his role modeled creative coping that fosters acceptance and well-being.

Akonnor's story suggests the value of creativity for allowing non-conforming expressions of impairment, identity and purpose that cannot be reduced to medical models. His alternative articulation expands public understanding of disability intersections with identity and empowerment.

In conclusion, Akonnor demonstrates the transformative power of art to reshape experiences with disability from places of empowerment, resilience and advocacy. Creative works merit closer analysis to better support disabled individuals' holistic flourishing through self-generated expression.

## **Practical Applications for Disability Support and Future Research**

### **Practical Applications:**

- Incorporate arts/creative therapies into clinical disability support to foster holistic well-being through emotive and agentic expression.
- Develop disability arts programs and advocacy through exhibitions/resources that center self-authored works and alternative narratives.
- Train support staff on asset-based models of disability that reject narrow conceptions and affirm creative identities.

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