Creative expression has undeniable sustainable power. It is a renewable energy source that yields valuable insight into what it means to be human. I took up Digital art following early retirement due to a rare illness, that came on during my specialist training in Rheumatology. I am using my story as a starting point to explore ‘using art to transform the illness experience’ into a more meaningful way of living, moving from clinical practice to digital art, after becoming a patient in my own specialty. Taking the opportunity to convey the impact art had on supporting me to take control and manage my long-term condition. How art has helped me to re-define myself after illness dominance distorted my identity and image.

I presently advocate for the use of creativity to cope with long-term illness. Based in Manchester, my work is centred on generating awareness about creative engagement and finding tools such as art to combat the challenges of illness experience, along with other therapies. As well as generating an interest on how expressions of the ‘lived experience’ can help health practitioners and the public gain new perspectives beyond patients’ illnesses.

Being both a doctor and a patient, I had the opportunity to gain a unique perspective of going through the journey of ‘Art n’ the human experience’. Encountering the “face of every day struggles” as patients’ see it seemed very different when seated on the opposite side of the desk for the first time.

Up until then, I had focused on the physical elements of diseases more as a black and white reality, where as the experience of illness is the reality with many shades of grey to the patient.

Articulating the illness experience, especially with long-term conditions, can be rather difficult at times when you are dealing with multiple layers – be it emotional, cultural, spiritual, social, dynamics at work and relationships, all at once. Having no formal art training, my art comes from within. Exploring art and the human factor, my visual expressions aim to highlight why it matters to articulate hidden realities of what the ‘lived experience looks like’ with long-term illness.

Making the “Invisible Visible”, a visual voice trying to give a ‘bigger picture’ of all the understated burdens associated with chronic illness or disability. Giving more visibility to the human factor in the public eye, I am reflecting on the personal narrative of struggle, acceptance and adaptations made over time. This leads to conversations around ‘Narratives in art form’. When circumstances started to define me, my dialogue began. I asked myself, What defines me? Is it what I do? Is it what I stand for? Is it what I believe in? Am I purely defined by the illness? And others, How do you see me? Me the ‘illness’? Me the ‘person’? Do you see the face behind the illness?

Along the way, examining, expanding and looking in to:
- Everyday struggles and challenges
- Understanding invisible illnesses
- Social and cultural isolation associated
- Impact of illness on image, self-identity and self-esteem
- Stereotyping and stigmas encountered

The concept of empowering patients to better engage with self-managing their long-term conditions is changing the world at an ever-increasing pace. The 21st century health care paradigm is shifting away from the medical model focusing on cure to a model focusing on holistic care. Through my artwork, I aim to deliberate on my encounter integrating creativity and healing with life altering situations: ‘Creative empowerment - exploring the healing power of art’.
**My story - Role reversal from doctor to patient**

Creating digital art has had a transformative effect on my ability to manage my condition. I developed Vasculitis, which affects my hand function and mobility amongst other things. I was also diagnosed with postural tachycardia syndrome (PoTs), an abnormality of the functioning of the autonomic nervous system. This was life altering. Simply standing up and walking a few yards became a challenge.

I am currently a patient under the care of Rheumatology services. The start of my illness was during my 2nd year of specialising in Rheumatology as a trainee doctor in Birmingham, UK. It was an illuminating experience both personally and professionally, when I became a patient in my own specialty. Suddenly at cross roads, not knowing the direction my life was heading, facing several changes and dealing with multiple layers of emotions all at once; it was an overwhelming experience. My daily routine took a 180-degree turn and suddenly I lost all that functional independence and freedom I had taken for granted.

Everything revolved around Coping. Adapting. Adjusting. My whole life style changed. A shift in roles and daily dynamics came about. Then came revising priorities. After many failed attempts at returning to work, swapping from full-time to part-time training, and taking countless periods out of training, I finally had to accept ill health retirement.

Chronic diseases/disabilities can turn one’s life upside down gradually changing the landscape of daily living. Feeling powerless most of the time became part and parcel with the variability in symptoms, the unpredictable course of the condition, the disruption of my previous routine and functional independence. Upholding the same level of personal standards and self-worth became a struggle to achieve, let alone maintain. With the balance tipping over gradually, every aspect of my life was suddenly over shadowed by the illness. It didn’t take long to start feeling isolated and lose sight of self-identity.

**What led me to art**

What challenged me the most was feeling that I had lost control - the illness dominating, overtaking and over-powering me? Being confronted with the fear that my illness would distort who I am; my identity and self-image. Creating art has provided me with an escape route. It has helped me to redefine my self-identity, express and symbolise feelings about the illness, and focus on what I can do instead of what I can’t do. I can’t control my symptoms or the course of my condition. I can however, control what I create. I use art as a tool for mindfulness, positive reinforcement and reflective thinking. It gives me the strength to cope. It has helped me to achieve a semblance of normality and enabled me to set more realistic goals around my limitations.

**The role Digital medium can play**

People with certain disorders not only have to deal with the general disability of the chronic illness, but also the physical limitation of expressing what is in our minds. On repeated usage, my hands become numb and painful along with pain radiating to my shoulders. Using a digital application on my mobile has enabled me to create art with minimal physical effort and alternate hands. I experience less pain and fatigue through this medium than when using a paintbrush on canvas or charcoal on paper. For me, this form of artistic expression was a means of self-exploration to convey how I was feeling. This newfound freedom to explore myself through the world of colours, gave rise to my present work.
What I’d like to focus the spot light on

The patient journey can be draining. The roller coaster ride of new symptoms, side effects from drugs, flare-ups and mood swings continue to fluctuate. I found expression through art not only represents symbolic aspects of coping but also demonstrates the many facets of emotions and degrees of pain I feel at various points, as a visual narrative.

Art has helped me immensely to face overwhelmingly traumatic periods during my journey. I use art as a visual language to share my experiences with my family, friends and health team so that they could gain new understandings around the ‘lived experience’. For many, addressing the physical element alone is not enough. Creating art can help people to communicate the emotional, spiritual, and cultural pressures of living with life-limiting conditions or situations. Visual expression can also help others understand emotions and empathise with pain, illness or disabilities.

Art can be more than a form of expression; it is also a way of thinking. It can be an outlet that portrays the subjective somatic or perceptual experience. This can in turn develop self-reliance, coping strategies, social engagement and cultural inclusion. Sharing through creative expression with others’ breaks the isolation and improves social interaction, empowering people to better adapt to challenging situations. Establishing a sense of purpose inspires forward movement, enduring challenges of an illness.

Start more conversations

How the ‘creative force’ empowered me. How it helped me to regain control from over powering emotions and challenges that stemmed from a rare long-term illness. How, regaining a sense of control becomes a significant component in managing the condition and moving forward with life and work. From my experience, adapting to find ways around limitations plays a key role in rebuilding confidence. Having a tool, such as art, on top of other medications/therapies becomes very helpful to cope with the everyday battles. I would like to reach out others in similar situations to share my observations, so they can find similar tools, if they haven’t already done so, to combat the on-going struggles with work, life, confidence and self-esteem. There is mounting evidence to support the use of creativity in reducing anxiety, depression and stress, in turn bringing about improved health outcomes.

Moral imagination

I would like to see more art in dialogue, communicating and disseminating how art can help friends, family, public, health providers to see the multiplicity and the fluid state of the ‘lived experience’. I would draw attention to the potential impact of facilitating ‘Expression of illness experiences’, can have on a person’s identity and self-worth, focusing on the understanding of ‘how people make sense of key life experiences and what it means to them’. When it comes to clinicians, the presentation and representation of illness expressed in various art forms, can provide a voice to reveal the lived experiences of illness in their complexity; a prompt to help bridge the gap between the ‘Biomedical and human focus’. New awareness or understanding about issues faced by their patients opens up communication channels, making room for difficult conversations. ‘Seeing more of the face behind the illness, the person with their strengths, not just the person with the illness.’ It would provide an opportunity to see multiple alternative meanings that may affect health; a wider differential diagnosis; the problems of rushing to a premature conclusion.

Through looking at art, we can enhance the capacity to recognise the moral dimensions of clinical experiences. Explore the question of empathy and ethics in healthcare provision, increase awareness of emotional reactions to ethical issues, and develop what’s known as “moral imagination”. It would foster and harness abstract thought and inner reflection to expand and deepen perspectives in such a way as to facilitate detailed clinical observation and ‘thinking out of the box’ approaches to everyday clinical practice. Art can also bring about discussions around cultural understanding and cultural determinants of health. The supportive evidence looking into art in health promotion, prevention and illness management is continuing to grow worldwide and rapidly gathering momentum.
Place more emphasis on the power illness has on image, identity and self-esteem
Seeing beyond the illness - creative expression can help to redefine self-identity. Creativity can be used to explore and represent one’s individual journey - The way chronic pain, illnesses and health challenges are constantly changing shape, defining and re-defining itself.

Better understand invisible illnesses and stigma
Given the opportunity, people facing pain, chronic illness, disability and other challenges can freely express themselves without physical, social or attitudinal barriers. Therefore by engaging in the arts, they can connect and contribute to their communities; challenge existing stereotypes and stigmas. Help build a culture truly representative of all people.

Promote the role of digital apps/medium
Present day represents the Digital Age where Digital Technology in healthcare is rapidly evolving worldwide. The use of digital medium for creativity, especially for people with limited hand function or dexterity issues can be a constructive as well as an enjoyable pursuit to cope with struggles of day-to-day life.

Connect and Collaborate with others in the field of arts and health
Using my personal insights, I am focusing on triggering a wider interest in the role of art as a tool, potential therapeutic benefits of creative engagement as a non-medical approach to self-management in people with long-term conditions/disabilities; involving patients, carers, health professionals and the public. Over the last two years I got the opportunity to do a few workshops with patient support groups, students and carers both in the UK and Sri Lanka exploring the idea of ‘Art, a catalyst for healing?’. Conversations with others in similar situations, as well as with health and allied health professionals, have brought out and pointed to the positive influence, creativity imparts.

“What is creativity? It's taking two or more ideas that have never been put together before and dipping them in the magic池塘. You get a new thought. Albert Einstein”

What does the evidence say?
The practice of arts and healing dates back 40,000 years. For centuries, across civilizations creative expression has been used as part of healing rituals. The idea that creative expression can make a powerful contribution to the healing process was embraced by many different cultures. Throughout recorded history, people have used pictures, stories, dances, and chants as healing rituals. It was believed that art healed the world, not just the individual. That art and music changed the hunt, fertility, the crops, the weather, the life of the tribe, and the earth. Over time, a sense of mystery and magic was attributed to some of these practices, which unfortunately made them questionable. However, over the past few decades they have started to come back and there’s increasing evidence supporting their usage.

Research supports the notion of Arts having the potential to assist in promoting health and healing to help the increasing demands on health resources. Supportive evidence demonstrates that the bio-psycho-social processes facilitating creative activities can reduce anxiety, depression and stress in turn improving health outcomes. These benefits can be a catalyst for healing. The role of the arts in healing complements the biomedical view by focusing not only on sickness and symptoms but the holistic nature of the person bringing emotional, somatic, artistic, and spiritual dimensions to healing.

Guillemin, one of the first to use drawings in an effort to understand experiences of health and illness, examined how 32 women with heart disease understood their condition. Each participant was asked to “draw” her heart disease. Patents found visualizing their condition to explore understandings of illness insightful. Another study looking at the role of art in chronic illness patients demonstrated that art filled occupational voids, distracted thoughts of illness and maintained a positive identity. Its value was conceptualised by one participant as a ‘lifestyle coat-hanger’ organising numerous roles and activities that gave purpose to life. It also offered a versatile means of overcoming the restrictions imposed by illness on self and lifestyle, in many cases creating a more enriched lifestyle than before.

Furthermore, a study examining pain in 50 adult cancer in-patients following a one-hour art therapy session showed statistically significant reductions in the measured symptoms thus demonstrating the efficacy of art therapy in reducing a broad spectrum of symptoms in these patients. There is sufficient scientific evidence that indicates art enhances brain function. Recent studies looking at physiological recordings using electroencephalography and brain imaging techniques such
as PET scans and functional MRI scans have allowed us to gain a better understanding of the brain mechanisms important in visual creativity.\textsuperscript{7,8}

Quantitative studies looking at patients with cancer, chronic illness, dementia and stroke reveal significant improvements in mood, physiology and symptoms like pain, fatigue. A review of current research to determine what is known about art and healing, covering the period from 1995 to 2007 peer-reviewed research on arts and healing states: “Art helps people to express experiences that are too difficult to put into words, such as a diagnosis of cancer. Some people with cancer explore the meanings of past, present, and future during art therapy, thereby integrating cancer into their life story and giving it meaning. This shows how artistic self-expression might contribute to maintenance or reconstruction of a positive identity”.\textsuperscript{1}

A growing body of research looking into the cognitive effects of making art reveals how drawing and painting stimulated memories in people with dementia and enabled them to reconnect with the world. Doing so has been linked to improved memory, reasoning, and resilience in healthy older people. Decades of research have demonstrated that in people with dementia and other progressive neurological diseases, the ability to create art remains long after speech and language have diminished.\textsuperscript{9} Evidence is also emerging that art participation can augment rehabilitation, helping to address the psychosocial effects of stroke and prepare survivors for fulfilling lives after rehabilitation. Assuming that art participation in art is a valuable adjunct to rehabilitation, it is vital that we seek to understand how it works and the outcomes that it influences. In line with other rehabilitation interventions, such understanding will enable us to refine the intervention to target it at those most likely to derive its known benefits.\textsuperscript{10}

Finally, a recent investigation looking at the relationship between discrete positive emotions and immune mediators (Interleukin 6) found activities that inspire awe were the strongest predictor of lowering levels of inflammation. This work suggests a potential biological pathway between positive emotions and health.\textsuperscript{11} This begs the question ‘Does making art influence illness progression?’ Further understanding of the biological responses to drawing is needed to examine potential pathways reducing inflammation when engaging in artistic activities.

“Where there is love for humanity there is also love for art” ~ Hippocrates

**What roles can artists play?**

Given the momentum research and practice of ‘Arts in health’ is gathering, artists may be able to play a role in healthcare. During a time of uncertainty, economic constraint and turmoil within healthcare, can “arts” have a meaningful impact on the ‘Future of healthcare provision’?

Governments across Europe and the world are realizing that there is an untapped, low risk, highly cost effective health benefit to participation in arts. Evidence supports referring people to creative activities can reduce demand on the healthcare system and empower people to feel in control of their own health. Taking this into account, possible considerations for tapping into the arts, more than currently practised is something to explore further along with the question of ‘could an artist have an intermediary role in healthcare?’

**What next?**

I would like to conclude by inviting reflections on the clinical implications of the arts for healthcare professionals, educators and general public while bringing your attention to ‘how art has the capacity to capture a sense of what the patient reality resembles’ and play a contributory role in clinical care. A great deal of diagnostic power can be drawn from the visual world, opening tangential pathways of learning. Visual arts can help explore the understanding of the human aspect of medical practice. There is room to think about adding art as a supplement to medical training. Most of the time we are taught what to look for in medical curricula but not necessarily, how to look for it.

Engaging in visual-art based exercises can complement medical students learning of empathy, observation and interpretation. The exercise of viewing and interpreting art, picking up subtleties in the detail is something that is not unfamiliar in clinical medicine as observation is a core component in medical decision-making. When it comes to evaluating the impact of using the arts, investigations reveal that many health-care practitioners reported new awareness or understanding about issues faced by their patients\textsuperscript{12} and planned to alter their clinical practices to better meet patient needs.\textsuperscript{13}
I hope that creative engagement can be considered as a complementary part of the multimodal approach to care, given the innate benefits of artistic expression and output can have on self-management, supporting wellbeing. Art is richly complex and possibilities of learning from it are endless. Given the opportunity, art can influence, inspire and enable change – individually and collectively.

“I see the person beyond the illness
Where the illness ends, I begin…
Do you see me?”

References and External links: