

Exploring Creativity During Illness

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Abstract

A week before my 50th birthday I was diagnosed with a rare form of mitochondrial disease, so rare in fact that it does not have its own name. While this necessitated negative changes in my life, it also created a window for me to explore my creativity: Something that I had never had time to devote to previously. This started with an introduction to basic acrylic painting. It has now developed into oil and watercolour painting, charcoal drawing, sketching, crochet, and origami. As a social worker I know the importance of sensory therapies such as music, dance, play and art. Sensory therapies are patient-centered treatments that promote self-management and self-care, ameliorating some of the side effects associated with pharmacological treatments. As I was taking over 30 tablets a day, I was interested in exploring alternative options that did not exactly fit into the scope of my medical therapy. In this paper, I have used autoethnography to achieve a meaningful understanding of personal experience from a cultural perspective. Using a psychological constructionist world view allowed for personal iterative inner construction. Exploring creativity happened for me by accident. After I started painting classes, I realised there was a change occurring in my mood. I found that I could live a more positive life with improved well-being, I enjoyed learning more about my creative abilities, including selling items in order to create an income stream. These multiple positive outcomes were unexpected and extremely beneficial, demonstrating the importance of creativity throughout the life course during times of illness.

Implications

- An understanding of this autoethnography study from a psychological constructionist world view will enable other individuals who are facing a similar life-changing circumstance to explore alternative options for maintaining, finding new or discovering lost, creative enjoyments in life
- Developing an awareness of the creative needs of individuals and families during times of illness throughout the life-course, will aid policy makers to develop appropriate supports and programs

Background

Mitochondria in the body have been referred to as the power houses of the cell providing the body with over 90% of the energy it needs to sustain life (Mito Foundation, 2023). Mitochondrial disease occurs when these power houses stop working efficiently and cells begin to die, resulting in multiple systems in the body failing and life being compromised (Mito Foundation, 2023). There is no cure for mitochondrial disease and the prognosis for each individual is extremely varied. A week before my 50th birthday I was diagnosed with mitochondrial disease. There are many types of mitochondrial disease that have already been identified and given names, such as mitochondrial encephalomyopathy, lactic acidosis and stroke-like episodes (commonly known as MELAS) and Leber hereditary optic neuropathy (commonly known as LHON) (United Mitochondrial Disease Foundation, 2023). The type that I have is so rare it does not have its own name yet, meaning, among other things, that research in this area is extremely limited.

Receiving such a diagnosis is life changing. I refer to my behaviour during those early days as having a ‘wobble’. However, the reality is far more sinister. I had trouble functioning and could not quite understand how I was supposed to move on with my life. I was supposed to be strong for my family, and yet I felt that I could not quite manage to do so. People with mitochondrial disease have been shown to develop higher levels of depression and anxiety (Sue et al., 2022). This was certainly true of me. As a social worker I have spent many hours of professional development learning about the importance of self-care. This was something I thought I needed to know for my clients’ benefit. Now I needed to make positive changes to my own life, which meant looking at things differently, thinking outside the box. It became important for me to consider what things in life made me happy. Considering my options from a practical perspective, I knew it was important to ensure my decisions would be something that would make a difference. Putting aside the excuses that excluded me from taking the time to indulge in personal hobbies, I decided to explore my creativity, something I had never made time to devote to previously.

Research Design

This qualitative study explores the meaning of creativity during illness. An autoethnographic approach was used, which uses autobiography and ethnography for both the process and creation of the final product (Ellis et al, 2011). Writing about remembered moments is essential for such a study; incorporating photographs and recording journal entries ensures this is done more accurately (Ellis et al, 2011). The goal is to help both insider researchers and outsiders or cultural strangers better understand the experience or culture of the researcher (Maso, 2001 as cited in Ellis et al, 2011). Psychological constructionism considers the cultural context of experiences, incorporating individualism and externally derived epistemologies as the worldview (Mesquita et al., 2016). All experiences integrate to form these epistemologies (Rashidi et al., 2021). I have therefore used an autoethnographic methodology with a psychological constructionist worldview for this study.

Development of my creativity

I started my creative journey with an introduction to basic acrylic painting course at a local adult education centre. I could not believe the joy I felt in focusing on the painting. It meant that some of the anxiety and depression I had been constantly plagued with was almost ignored for a brief time. Research has identified that creative activities allow the participant to focus on the creativity being undertaken which enables the problem or issue to be forgotten for a period of time (Çetinkaya et al., 2019). In addition to this and completely unexpectedly, I was also pleased by the standard of artwork that I managed to create during the 6-hour class, meaning the positive effects from the class lasted longer. However unsophisticated the painting actually was in reality, I felt it was impressive for my first try at painting since art lessons at school. While not fully appreciating it at the time, it is obvious when reflecting on those early days of artistic endeavours that this was clearly a turning point for me in terms of my mental wellbeing.

That first adult foray into my creative self was a surprise for me; I had not anticipated enjoying it so much or gaining such a positive afterglow from the experience. Before leaving the adult education centre at the end of the day, I had already signed up for my next course. As a naturally impatient person, I was frustrated that I had to wait several weeks, which was quite telling in terms of my genuine desire to participate. That next class was a beginners' painting with watercolour course. The outcome from that has developed my desire to continue building my creativity considerably. Having the mindset that positive outcomes can only occur from participation, I entered my watercolour painting into the South Australian Living Artists Festival (SALA Festival, 2023). My mood was quite low and I truly did not expect anything to come from it. However, I received a phone call one day inviting me in for photographs and to hand over my precious original artwork: Figure 1: SALA 2022 Author. After receiving a VIP invitation to the exhibition, I was amazed to find my painting looking beautiful in a wonderful position with a sold sticker attached.

Gaining a place in the South Australian Living Artists Festival and then actually selling my artwork was so amazing for me. I am grateful it came along at the right time and made a change to my psychological health. As a result of this encouragement, I applied for and was accepted to participate in a local arts market. My local council holds this market every year, enabling local artists to have a stall and sell their art works. It is free and usually held in December, when the weather is not too hot and not too cold. At first, I was slightly overwhelmed by the calibre of the other stall holders. However, I need not have worried. My art works were less sophisticated and therefore less expensive (between \$5 and \$250), while some of the other art works were over \$3,000. I felt that the potential customers were not expecting to spend such high amounts, meaning my art works were a good option. Amazingly, I managed to sell two items, a painting and a drawing. Many of the other stall holders did not sell anything, which was another boost to my morale.

This study considers the value of creativity during illness. Psychological constructionism studies the meaning of personal experiences that people make from both internal and external factors, such as sensory, visual and auditory (Faucher, 2013), which fits well with rediscovering my enjoyment in art. Individualism is taken into account when using a psychological constructionist worldview, which supports personal meaning making rather than one truth to fit all (Westfall, 2022). This is particularly appropriate for the individual nature of creativity. The research design

used for this study requires a significant use of reflexivity (Adams & Jones, 2011; Hales & Galbally, 2023). I have actively used reflective and reflexive practice for many years throughout my work, and indeed in my personal home circumstances as well. This has enabled me to be well placed in terms of incorporating reflective and reflexive practice throughout this study. Taking photographs at relevant times throughout my journey has enabled practical and accurate recollection of events and creativity outputs. In addition, I have written in a journal designed especially for this purpose.

Following on from my successful market stall, my joy of this developing creativity continued to ripen. I was feeling brave and reinvigorated. I had been feeling very low and suffering significantly from depression and anxiety. Finding an art form that allowed me to feel relaxed and rewarded caused a shift in my mood. This allowed me to try other types of creativity, including things I always stayed away from as I believed them to be too messy or too difficult. I was only limited by funding; these classes were not cheap and I now had no income due to early retirement because of the illness. I tried to spread out the classes to manage the cost more easily. I am lucky that all these pieces fell into place, allowing me to try out a range of options. I feel it would be remiss of me not to mention that the ability to undertake art classes and buy art materials is a privilege that not everyone can afford.

Starting art classes and growing my range of mediums has enabled me to develop my portfolio. I have enough art works to apply again this year to have a stall at the arts market. Sharing my creative self with others is exciting. For example, one of my favourite creative works is an oil painting I completed during my first introduction to oil painting class, Figure 2: Ball in Oil Author. I am so pleased with it I framed it and have it on display in my study. Perhaps interestingly, it was part of the introduction section of the class, allowing students to get an idea of the texture and feel of the brushes, paint and paper. The final artwork that day did not inspire me as much as this basic practice piece. Just like a favourite wine, we like what we like.

My creativity has now developed further and I have put my hand to charcoal, wax and chalk drawing, sketching, crochet, embroidery, felting (this was a surprise, I had never heard of it before creating a recognisable rabbit!), linocut, needlework, and origami. I have also started attending a craft group at a local church once a week. It is inexpensive, friendly and incredibly relaxed. Taking what I have learned from the more costly classes, I can use and develop my skills during the craft group. Removing some of the stress of feeling that I am required to present a reasonable finished item has, I believe, means that I can play with textures, colours, brushes, tools, and other items, enabling a more natural outcome in my work. I have used clingfilm, aluminium foil, sponges, credit cards, leaves, sticks, toothbrushes, string, and various other everyday household items to create texture and special effects, in my paintings. I still attend the adult education centre occasionally to gain a deeper knowledge of creating artworks. I also enjoy the people and different aspect of attending the adult education centre, which has a positive effect on my mental health. Utilising a reflective mindset means I can continue to link the enjoyment of developing my creativity with an improvement of my mental wellbeing.

Working as a qualified and registered social worker has given me a sound awareness of the importance and value of sensory therapies such as music, dance, play and art. Sensory therapies are collaborative, patient-centered treatments that promote self-management and self-care, removing some of the side effects associated with pharmacological treatments (Crawford et al.,

2014). At the time of starting my creative journey, I was taking over 30 tablets a day. I did not like taking so many tablets for several reasons, such as the potential side effects of some of the medicines; possible harm that can occur from the range and mix of tablets; and the physical difficulties of swallowing so many tablets every day (mitochondrial disease affects the muscles of the body and given the oesophagus is a muscle I have trouble swallowing now my health has deteriorated further). However, I knew that some of the tablets were lifesaving and absolutely necessary for my continued survival. Taking this into account and recognising that I would need to continue to take some tablets, reducing some of these medicines would be psychologically helpful for me in the long run. I was definitely keen to try something that I felt I would enjoy and would result in an improvement to my health as well. My new-found creativity had already demonstrated that there was real possibility for improved mental health and wellbeing. I could see no reason for not continuing along this path, while ensuring, of course, that I understood the importance of maintaining my ‘traditional’ medical supports and including any benefits from my creative self as a collaborative addition.

Methodology

This study has used autoethnography to achieve a meaningful understanding of my personal experience from a cultural perspective. Autoethnography has been developed from ethnography, sitting within the field of anthropology; it refers to research conducted by a researcher who is an insider (Danahay, 2019). This type of approach seeks to describe and analyse personal experiences in order to better understand cultural experiences (Ellis et al., 2011).

Autoethnography sees “analysis as something that happens within the story itself” (Shepherd et al., 2020, p. 3), which means it combines both the act of undertaking the research and the results from the research (Ellis et al., 2011). Autoethnography has been criticised as being self-indulgent, lazy and privileging the researcher’s own perspective (Chang, 2013; Delamont, 2007; Sparkes, 2002). However, it has also been identified as a valid approach to research providing (among other things) the ability for “deep reflective, emergent and generative insights into artistic experiences” (Harwood & Eaves, 2017). This research approach uses a human account to explore human experiences (Badley, 2022).

Reflexivity is a significant aspect of autoethnographic research (Adams & Jones, 2011; Hales & Galbally, 2023). Indeed, all research requires a substantive aspect of reflexivity in order to reach the meanings of the topic to be understood (Riach, 2009 as cited in Hales & Galbally, 2023). Coffey (1999 as cited in Delamont, 2009) argues that “reflexive writing and the judicious use of the autobiographical in such writing about research” is a completely different thing to autoethnography (p. 58). Perhaps interestingly, there has been discussion regarding the “overabundance” of interest in reflexivity in research to establish ethical rigor (Koopman et al., 2020; Pensoneau-Conway et al., 2017; Berger, 2013 as cited in Rowlands, 2022, p. 7). However, there is valid argument that reflexivity is still and will always be a necessary aspect of autoethnographic research in order to maintain sound ethical practice and for practitioners to be considered leaders in their fields (Greschke, 2023). Consequently, I have undertaken meaningful self-reflection by keeping a journal recording my thoughts and feelings, in addition to taking regular and relevant photographs throughout the process of this study to ensure a sound ethical process.

Significant research in the fields of anthropology and psychology exploring emotions has argued from a psychological constructionist viewpoint that “emotional experience is culturally constructed” (Mesquita et al., 2016, p. 31). Meaning making from the knowledge we have gained through sensations is known as situated conceptualization (Lindquist et al., 2015). The knowledge is derived from concepts around us, such as situations (for instance a creative art class) and the emotions that are stimulated as a result of that concept (Lindquist et al., 2015). What I find interesting about using a psychological constructionist world view is that it is equally valid when exploring a positive situation (such as a creative art class), as well as a negative life experience (such as a breast cancer diagnosis) (Rashidi et al., 2021). This is of particular interest to me, given my personal journey of illness through the life course.

One of the main aspects of psychological constructionism is to make meaning of personal experiences from internal and external factors, including sensory, visual, auditory, tactile and so forth (Faucher, 2013). Psychological constructionism also utilises the concept of individuality, meaning that each person undertaking the research (or being a participant of that research) has their own version of fact rather than a collective construct of reality (Westfall, 2022). Using a psychological constructionist world view has enabled me to develop a personal iterative inner construction. This topic is a particularly personal one for me and consequently using this world view fits well with the various parameters of the study. For me, making meaning from the development of my creativity during a time of illness has allowed for greater understanding of the connection between the external stimuli and my resulting mental wellbeing.

Conclusion

Exploring and developing my creativity happened for me mostly by accident. I did not expect to develop such a love for painting or charcoal or origami or especially embroidery. However, it was immediately after I started painting classes that I realised there was a change occurring in my mood, in addition to recognising that I was enjoying the act of the painting process. Growing my creativity further, I found that I could live a more positive life with improved well-being, enabling me to be a better role model for my family, among other things. I enjoyed learning more about my creative abilities, including having a painting in an exhibition and selling several items in order to create an income stream (albeit minimal). These multiple positive outcomes were unexpected and extremely beneficial. Many people would not be able to consider developing their creativity in such a way and alternative options must therefore be considered. For me, utilising an autoethnographic approach with a psychological constructionist world view has enabled me to demonstrate the importance of creativity throughout the life course during times of illness.

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