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What I learned by doing craft when I got terminal cancer

On woodcarving and psychophysical wellbeing from an insider perspective

ABSTRACT

In this paper I use theory on craft and psychophysical wellbeing to extract insights on the value and meaning I found in woodcarving after being diagnosed with terminal brain cancer. I continued to carve wood throughout the entire diagnosis and treatment period. I was already an experienced woodcarver and had done extensive research on my own making processes. Both the making and research provided meaning and value for me in my ordeal. I discuss three lessons I learned: 1) Deliberate controlling of attention on the here and now worked as a coping mechanism, giving meaning and value to my situation; 2) Grounding myself in physical touch with a close connection to the material contributed to maintaining my positive identity as both maker and researcher, and acted as another coping resource; and 3) As I made the objects, I re-made myself. My intention to save and finish these artifacts, and the joy I experienced as I finished them, gave meaning and purpose to my situation. These lessons support previous findings on craft and wellbeing, contribute insider insights on the use of wood in art making during cancer treatment, and they could potentially inspire others facing dire straits to use crafting to cope.

Keywords:

woodcarving, psychophysical wellbeing, cancer, tangible connection, craft, research

INTRODUCTION

Craft and art making, hereafter referred to as *making*, is an exploratory, inventive and experimental activity, that is tightly linked to psychophysical wellbeing for the crafter or artist (Huotilainen et al., 2018, p. 1), hereafter called *makers*. Studies from fields like art therapy, and specifically from cancer care, have indicated that making helps patients feel grounded, find beauty, cope (Collier, 2011), direct their attention away from illness or fears of the future (Ennis et al., 2018), feel socially connected, feel

capable, maintain a positive identity and have agency (Reynolds et al., 2008). From a craft science perspective, however, these studies have limitations.

Art therapy is a specialised field of psychotherapy that incorporates art with the explicit goal of being therapeutic (Rubin, 2009, p. 27). Researchers have found it to benefit, for instance, quality of life, and that it reduces anxiety, depression, fatigue and cancer symptoms (Jiang et al., 2020). Variations of art as therapy outside the discipline of psychotherapy also draw upon the knowledge that engagement in making can have therapeutic effects, from the more structured and facilitated to more self-directed artistic pursuits, thereby providing more individual freedom for the maker (Reynolds et al., 2008, p. 212). Ennis et al. (2018) compared the experiences of patients in art programs and self-directed making activities, finding that both types of activities help reduce fatigue, but that persons in self-directed making practices reported a greater sense of control, which is important for wellbeing. This finding ties into research from other fields documenting that the freedom to be creative and express personal ideas is important to the maker's experience (e.g. Sawyer, 2014). With the exception of Reynolds and Lim (2007b) and Reynolds and Prior (2006), however, few studies have examined the entirely self-directed and self-initiated making activities of patients living with cancer.

Most studies on art therapy and art making programs include visual art techniques, like painting, drawing, or sculpting in clay or textile. I have found no art therapeutic studies that include making with wood. The only project I have encountered on woodworking and wellbeing is the UK Mental Health Foundation's "Grouchy Old Men?" project (McMillan, 2011), which studied loneliness in elderly men. This is a limitation because materials used speak to different audiences and have different impacts on the maker's wellbeing.

In art therapy programs, the makers themselves may have little to no prior skills. This makes it harder to distinguish between experiences related to novelty and to changed circumstances in these programs. Further, novice makers have less experience and a smaller vocabulary to describe their making; personal testimonies from patients who were artists before their diagnosis feature more precise concepts to describe their experiences (Reynolds et al., 2008, p. 212). Together, these issues limit our understanding of the contribution of making to wellbeing among people living with cancer.

In this article, I address these limitations by drawing upon my own experience as an experienced woodcarver, researcher of making processes and person living with terminal cancer who independently engaged in a self-directed making process in wood with artistic intent. My aim is to extract core insights on the meaning and value I found in continuing to make during my diagnosis and treatment, and how this influenced my wellbeing. By 'wellbeing' in this article, I mean having a sense of self, identity, self-worth, control or conversely the absence of anxiety, stress and fatigue.

I used an autoethnographic case exploration that emphasises lived experience (Denzin, 2014; Stake, 2000). I first present my story, then reflect on my personal responses and experiences in light of theory (Alvesson & Sköldberg, 2000). Data include a published research article presenting my case (Gulliksen, 2021), original video, verbal accounts, notes, correspondence with a collaborating neurobiologist and still photos. What is new about the present article compared to my previous one is the dedicated focus on psychophysical wellbeing, and the incorporation of the insights developed in the previous article as data. In the qualitative coding process, I highlighted all instances referring to psychophysical wellbeing to identify emerging themes, then extracted the revised analytical codes in a bottom-up manner. Lastly, based on this qualitative discussions.

Brief presentation of my story

In December 2017 I began carving a new object in my Purkinje series. The series would eventually comprise eight artifacts, made by hand from round trunks of aspen wood (see Figure 1).



Figure 1. *Top*: The Purkinje series. The first and second artifacts from the left were made during treatment. The next six artifacts were made afterwards, positioned in order of making. Note the increasing spatial complexity from left (made in 2018) to right (made in 2021). *Bottom left and right*: Detailed photos of the series items. The series is inspired by Ramón y Cajal's (1899) drawings of Purkinje cells, which are neurons in the cerebellum. Sizes varies from 38 cm to 88 cm long and 11 cm to 19 cm high. They are treated with white pigmented wax and embellished with golden sheet metal.

I had recently started to experience extreme but brief episodes of dizziness, during which I lost track of the position of my right hand and was unable to walk, read or type. Outside of these episodes, I felt tired and unfocused. I "got lost" in the woodshop and did not know where to carve next when turning an item around. I had always found such tasks easy. Now my spatial cognition was severely limited. Carving made me tired and nauseous. I stopped carving the artifact I had begun and began another with a less complicated shape. I could not work without templates or other mental crutches to support my spatial cognition (Figure 2). This realisation led me to initiate research on my making process to document my struggles.



Figure 2. Left: Purkinje #2 underway. Right: Example of a paper template (4 January 2018).

An MRI confirmed a malignant brain tumour in my left parietal lobe, a part of the brain important to visuospatial cognition and especially mental rotation (Zacks, 2008). At the time, the average 5-year survival rate for this type of cancer was less than 2%. I spent the next 6 months undergoing surgery and chemo- and radiation therapy. The treatment caused a reduction in brain oedema, and my spatial cognition, my sense of space (Groh, 2014), returned.

Between treatment sessions, I continued to carve. I carved in the hospital hobby room, in my hospital hotel room, and in the woodshop or at my kitchen table at weekends. I wrote that I was:

Like a heavy oil tanker running full steam ahead. I do not think stopping even occurred to me. [...] It probably also functioned as a way of turning a blind eye, engaging in a familiar activity, a lifeboat to cling to. (Gulliksen, 2021, p. 137)

I applied a researcher's gaze to the carving process, studying what I could and could not do. The day before my surgery, I described one carving session as follows:

I carved as I always had. Yet, I carved as I never had. I was present, and I was not. I did not see, really. Not with my eyes. I saw with the skin on my fingertips, I saw with the sharp end of the gouge. The grain, bumps, wood chips gently poked my skin. Fog clouded my awareness. Was it me carving, or was I watching someone else carve? (Gulliksen, 2021, p. 141)

The first carving session after surgery had descriptions like this:

Next carving session, I went back to the woodshop, upbeat and ready. I targeted a little canyon between three separate forms of different depths, flowing over and under each other. I needed to cut cross-grain downwards, leaving cut, fragile cross-grain fibers on both sides of my cut. Confidently I reveled in the burgeoning feeling of expertise. 'This is what I do. This is how it should feel, as natural as spring follows winter'. (Gulliksen, 2021, p. 145)

I was told I had a few months to live. Yet, 5 years later, I am still here. And I still carve.

DISCUSSION

My combined identity as maker and researcher motivated my carving throughout the process, manifesting in the data as two distinct ambitions. First, I wanted to continue my self-directed making to fulfil my artistic intent. This was an active choice, made mid-crisis, and I did not question whether I could or should continue. In my think-aloud account I stated, "I want to carve now anyway", "this is a part of who I am" and "I need to save these artifacts from being destroyed by black fungus and splintering". Second, as my symptoms included distorted spatial cognition, crucial to subtractive carving processes, I was presented with an opportunity to apply a researcher's gaze on the situation. This reframed my role from patient passively experiencing symptoms, to researcher actively observing and gathering data. In notes and verbal think-aloud accounts, I commented, "I have the idea that not many studies have been published with an insider perspective on three-dimensional visualisation skills", and my documented experiences "could be interesting to go back and look at later. Both ambitions gave me agency and a sense of control, and the data gathering in turn emphasised the making process, my sensory experiences, movements, tool control and cognitive abilities.

Attention control

My dual ambition is interlinked and inseparable in the material, and resulted in a control of attention, turning my focus deliberately towards the making activity and its documenting.

Both pre- and post-surgery, I deliberately initiated carving sessions. I reserved time to carve, made sure that I had time to rest before and after each session, and facilitated places to carve in the hospital, at home or in the woodshop. During making sessions, I gave full attention to the material, the tools, and how I felt and experienced the situation. When my thoughts wandered off, I gently reined them in. Word frequency analysis of transcribed audio and video reveals that I focused on the slow and steady cutting of small chips, the rhythm, the sounds of dry wood being cut and the various ways I interacted with the piece of wood, as with words like 'cutting sounds', 'quiet', 'piece', 'becomes', 'iron', 'cut', 'feel', 'angle', 'sense', 'thickness', 'shapes' and 'pain'.

The researcher gaze also focused my attention and framed my experience of symptoms as "interesting" or "pretty fun to observe to be honest". I did not express fear verbally or in my body language. Rather, I delved into my symptoms, asking follow-up questions and comparing what I sensed in the here and now to how it felt earlier: "Why, I haven't felt this in a couple of days", I once remarked. In the first session post-surgery, this attention helped me register small improvements I probably would not have noticed without this deliberate focus: "It feels good, I don't get particularly tired in the head. I can find the growth direction much better" (audio, 11 February 2018).

Initially, I did not deliberately use the researcher focus to avoid negative thoughts, yet it had this effect. Twelve days post-surgery, I wrote, "As you might have guessed, I'm now using mental strength to focus on what I can do and can change and not on what I cannot do/change" (e-mail, 12 February 2018). As such, I used my dual ambition to maintain my identity like Reynolds and Lim's (2007a) respondents. What separates my case from theirs, however, is how explicitly I used making as a deliberate attention control, and how the researcher gaze added distance by which to cope.

Previous studies on arts and wellbeing often emphasise making as granting positive attention to something (Collier, 2011). However, making is not always pleasant, though makers continue to make anyway (Huotilainen et al., 2018). To me, before surgery, I faced so many problems when making that I was almost unable to continue. My focus on making gave value anyway, though not as "an energy-restoring activity that has the potential to enhance the lives of people with a diagnosis of cancer" (Ennis et al., 2018).

Lesson learned

The deliberate control of attention on the here and now worked as a coping mechanism, giving meaning and value to my situation.

Tangible interactions

My aim as a maker is most often to experience and sense the world, and to slowly change my surroundings, one artifact at a time. Physical touch and a close connection to the material is important to me (Gulliksen, 2001), and I brought this perspective into my research, training myself for more than three decades to recognise and verbalise my embodied making experiences.

At the time of my diagnosis, I therefore had skills to dive into making and experience my body and the material. This gave me something tangible to hold on to. The data are strewn with references to this tangible interaction: how the material feels, how the tools feel, how my hands and fingers move, how my body moves in different positions. Videos reveal how much I relied on sensory input and motor output. My fingers and hands move nonstop over the artifacts with or without tools, sometimes guided by vision, sometimes with my eyes closed. Previous research on craft science and phenomenology (Gulliksen, 2001; Merleau-Ponty, 1962) has described this focus on sensorimotor interaction with material, the experience in the here and now, as "flow" (Csikszentmihalyi, 1996, pp. 110–113), with an emphasis on bodily involvement, sensory input and motor output (Gulliksen, 2020; Huotilainen et al., 2018, p. 4).

Before surgery, my body language radiated stress: uneven breathing, shaking muscles, white finger joints. Through analysis I found indications that these symptoms increased when I became tired, and my mind moved to worry. I stopped carving and lost my grip on grounding in the material. Post-surgery, I fastened the pieces to a workbench, used more power and allowed myself more focus on the artistic ambition (video 6). My negotiating interaction with the material increased, and even though I carved difficult parts of the piece and once commented "this is difficult", I more confidently chose the right tools. I finally experienced instances of flow, when tools and woodgrain fit perfectly for a short while, "like rivers melt[ing], flow[ing] into shallow valleys" (video, February 24, 2018).

These descriptions show that even though I first entered a flow state after surgery, it was grounding in physical touch, being in the here and now, that reduced my anxiety symptoms, as Jiang et al. (2020) described in their systematic review and meta-analysis. My tactile interaction impacted my attention, like Stanko-Kaczmarek and Kaczmarek (2016) have outlined. This is also in line with Huotilainen et al.'s (2018) finding that craft can act as a means of shifting from a fight-or-flight to a flow state (pp. 10–12). My example further illustrates how liminal the balance is between grounding and worry. Together, these data show how I immersed myself in the making process, how this grounding helped me cope and express my identity as a maker and researcher and supported an enhanced "tolerance for the discomforting experience of inhabiting a liminal or threshold space between life and death" (Reynolds et al., 2008, p. 212).

Lesson learned

Grounding myself in physical touch with a close connection to the material contributed to my positive identity as both maker and researcher and acted as a resource for coping.

Contributing something new

The artistic intent behind my carving consistently fuelled my making. First, I began making one artifact but then started a second one with simpler shapes, since my spatial cognition was compromised. Then, both artifacts were invaded by black fungus after being stored wet in plastic bags for 3 days while I was in hospital. My desire to save the objects took on a metaphorical function. While carving, I said, "Can *it* survive... I know I will survive. It can end well." And I whispered, "If not [surviving the operation], this is what I want to do. Spend time on [carving]" (26 January 2018). These data indicate that the act of making these objects was important to me, and that they contributed new meaning to me.

Post-surgery, I re-adjusted my ideas when the rapidly dried wood splintered. I also chose not to carve much material away, leaving the artifacts thicker than I had originally planned. I focused on devel-

oping lines with clear directions and curves. This slow process of developing shapes and lines continued throughout the process, limited only by my working conditions. I wanted to finish these artifacts, carve each surface and make them as beautiful as possible.

As I worked on the artifacts, I also worked on my view of myself. As I cut off small woodchips and revealed new shapes, I took pieces of myself – thoroughly scrambled by the diagnosis – and remade myself in a new status quo. I also redirected my fears into tangible products which could live on after my death, as Abra (1995) and Reynolds et al. (2008) formulated. And in July 2018, both artifacts were finished (Figure 3).

Lesson learned

As I made the objects, I re-made myself. My intention to save and finish these artifacts, and the joy I experienced as I did so, gave meaning and purpose to my situation.





Figure 3. Top: Purkinje #3 and Purkinje #2 (left and right, respectively), the artifacts discussed in this article. Bottom left: Purkinje #2. Bottom right: Purkinje #3. Photographer: Marek Podowski.

CONCLUSION

The discussion above has shown how crucial continuing to make artifacts was for me, when diagnosed and treated for terminal cancer. From the viewpoint of a long-term survivor, I discerned three lessons on how making influenced my psychophysical wellbeing.

My case supports previous research on art therapy, craft science and other fields, linking creative making to subjective wellbeing, and to maintaining and even reforming a positive identity (Reynolds & Prior, 2006). It challenges art therapy notions of making as a pleasant pastime (Collier, 2011, p. 110) or energy-restoring activity (Ennis et al., 2018), as I continued to make even when it was not. My case also expands Huotilainen et al.'s (2018) conclusion that making is a useful pursuit to support resilience, engagement, involvement and meaningfulness. The redirection of my focus towards the tangible object led to grounding in the here and now and heightened my tolerance for fear and discomfort. My desire to save and finish the artifacts took on a metaphorical meaning: as I made the objects, I re-made myself.

I made objects in wood, unlike in previous studies. My prior experience and ambition in woodworking were key: I knew the techniques, had the material, could organise suitable workspaces and continued carving even when it was hard. I could support my identity as a woodcarver and researcher, like textile makers in previous studies (Collier, 2011; Reynolds et al., 2008). My case might provide useful insights into therapeutic situations regarding the differences between novice and professional makers, and on the value of a reflective approach in art as therapy.

This study's limitations include the narrow perspective on one case, which limits any new or substantial theoretical contributions. The autoethnographic approach is also limiting, as it is not possible to generalise my situation to others. However, this approach is what provides the study its substance, and it might be useful in future studies.

Continuing to make when I became ill gave me value and meaning. The three lessons in this article could thus potentially inspire others who are facing similar dire straits to use crafting to cope.

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