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Art in a Caring Society: An Autoethnographic Narrative

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Abstract

The World Health Organization (WHO) has recently recognized the significance of expressing experiences through artistic expression in promoting health and wellbeing. Artistic expression allows individuals to also articulate their feelings and concerns nonverbally. Creating and experiencing art has been a significant aspect of my life throughout my struggles with multiple chronic illnesses. I create art for selfcare, and to comprehend and capture my emotions nonverbally. Through narrative and reflection on various experiences, I delve into the meaning of art and artistic expression in my personal life and within the context of a caring society. Additionally, my work includes creating drawings and images for others, providing comfort and support, and attending to their needs during difficult times. Creating art with others establishes a meaningful and creatively challenging connection, fostering joy and enabling contact without words about what resonates with us. Creating art with others and sharing this process with distant others in public spaces promotes solidarity and trust, two cornerstones of a caring society, in line with Joan Tronto's definition of care. Actively promoting access to artistic expression and exchange, particularly in a care context, is a valuable strategy for fostering a caring society that acknowledges the realm of the experiential beyond words.

Introduction

The World Health Organization (WHO) has recognized the significant role of art in promoting health and well-being, emphasizing that engagement with art can lead to positive outcomes. The WHO identifies five categories of art having positive health and well-being outcomes: performing, visual, literary, cultural, and online art forms (Fancourt & Finn, 2019).

As an individual living with chronic diseases, I strive to lead a meaningful life (Teunissen et al., 2019) that encompasses essential aspects of well-being (Swenson & Clinch, 2000), such as belonging (Kline-Leidy, 1990), stable relationships (Baumeister & Leary, 1995), and contributing to society. These needs are often challenged by the limitations imposed by chronic illness. As a result, I have often pushed myself beyond my limits, engaging in activities that were detrimental to my health, e.g. attending a meeting while having fever and I really ought to stay in bed (Mead et al., 2011). In response, I have actively engaged in artmaking for several years. Art became a bridge to my body. Through creating, I discovered new strengths and flexibilities, and it also revealed areas where I faced physical and emotional limitations and vulnerabilities. To me, art is a form of self-care, satisfying my need to do something that others can enjoy and I can be proud of. I became particularly interested in nonverbal expression because some of my lived experiences, related to multiple disease-induced bodily and societal disability, cannot be shared with others by means of words only (Teunissen et al., 2015; 2018; Visse et al., 2019). Additionally, I have leveraged my artistic creations – sculptures and narratives – to contribute to social and scientific discourse, featuring them in academic articles, general interest publications, conferences, and educational settings. This engagement reflects my desire to transcend the label of "patient" or "person with chronic illness," aligning with research evidencing the importance of understanding patients' needs and personhood beyond their medical condition and their need to live fulfilling lives (Charmaz, 2020). Instead, I embrace my role as a participant, contributor, and caregiver—in other words take part in a caring society (Bloemen & van Woerden, 2021). Health, I believe, includes more than the absence of disease (IPH.nl). Art has played a significant role in my ongoing pursuit of an active and fulfilling life (Teunissen et al., 2015; 2019).

Method

In this study, I explore how artistic expression can be a medium for care. I will draw on Joan Tronto's definition of care, elaborated below. To highlight the personal nuances and raw emotions of living with chronic illness, I chose to examine my experiences through autoethnographic narratives (Bochner, 2017). As Bochner argued, "By encouraging modes of intimate, personal, caring, and self-reflexive expression, autoethnography raises important questions about the meanings and uses of memory, storytelling, truth, and reality" (p. 67). I

describe my lived experiences with artistic expression, care, and connecting with others through an "in-depth" narrative (Stake, 2000) consisting of several narrative episodes (Heisel et al., 2016) structured around key moments (McAdams, 2001). In this way, I align with Bochner's approach to research that produces "an experience of our experience" (Bochner, 2017, p. 69). The narrative episodes are written from an "insider's" perspective, not only acknowledging my vulnerable position, but also with the purpose of learning from my own vulnerability (Freire, 1985, Holman Jones et al., 2015). In this way I also put myself under a magnifying glass as a researcher, and I am "revealing myself to myself, allowing or facilitating a perspective on my experience that I did not have before I undertook this autoethnographic inquiry" (Bochner, 2017, p. 69). The narrative episodes connect private and societal problems (Ellis, 2004) with social justice, and aim to contribute to sociocultural insights (Denzin, 2014). The narrative episodes are written in Dutch and then translated to English. An episode includes a picture, adding a non-verbal component to the narrative (Teachman & Gibson, 2018). Each episode is followed by a reflection section, on alternative ways to deal with life, so that "you talk back to yourself, commenting directly on what you hear yourself saying; you don't stop there but rather insist on keeping the conversation going, interpreting and reinterpreting, discovering something strange about the self you started with as you try to transform yourself into a new being" (Bochner, 2017, p. 71). I use the concepts of the caring society and artistic expression heuristically to interpret, reinterpret, and discover things about myself and my art practice. The reflections connect the narrative episodes to scholarly insight, both by embedding and deepening, and by challenging the ideas in each episode (Auken et al., 2015). At the end of this paper, I reflect on possible limitations of this study by the seven threats associated with the autoethnographic method, proposed by Woods (2011).

Caring Society

One concept that helped me to, as Art Bochner aptly called it, "talk to and with" others and other insights, is the concept of the "caring society," drawing on care ethics. Care ethicist and political theorist Joan Tronto (1993; 2013) conceptualizes care as a cyclical process encompassing five phases, each associated with core values and ethical principles. These phases are usually entwined and hard to separate:

- *Caring about*, recognizing, and attending to the care needs of others, requiring attentiveness, mindfulness, and openness;
- *Taking care of*, assuming responsibility for identified care needs and ensuring that someone is accountable for fulfilling them. This includes self-care, as well;
- *Care giving*, The actual provision of care, demanding knowledge and competence;

- *Care receiving*, paying careful attention to how care is received, demonstrating responsiveness and adaptability;
- *Caring with*, recognizing care as a shared responsibility, both personal and political, fostering solidarity and promoting social equality.

Translated to society, in a caring society (Visse & Abma, 2018), care is considered a moral-political practice where people learn about the moral good through involvement with all those whose life or work is at stake. In a caring society, people pay attention to the moral good, unfolding in health care practices, to do justice to the human need for reciprocity; to acknowledging differences in gender, race, and sexuality; and to caring, belonging, and community (Bloemen & van Woerden, 2021).

Just like Tronto, others argue citizens have a right to receive care, ideally, through a caring government bearing ultimate responsibility for care (Dronkers & Vosman, 2016). Delving into my own experiences within the context of the concept of a caring society through experiential autoethnography has been a significant challenge, but it helps me to illuminate my place in a society where care is either readily available or sorely lacking, based on the themes that emerge from my experiences.

Artistic Expression

Extensive research (Wang et al., 2017; Lindhout et al., 2020) supports the use of a diverse range of artistic and creative expressions in healthcare, therapy, and well-being practices. Creative expression transcends being just a "nice" activity. In the realm of art therapy (McNiff, 2019), it becomes a "therapeutic aesthetic experience." This means the act of creating art itself has a healing quality, allowing individuals to process emotions, navigate challenges, and even find a sense of peace through artistic exploration. Beyond therapy, creative expression fosters deeper self-awareness (Allen, 1995). By engaging with different mediums like paints, clay, or music, we can access parts of ourselves that might be difficult to articulate with words alone. The creative process becomes a journey of self-discovery, revealing hidden emotions, thoughts, and motivations. Furthermore, creative expression is a source of knowledge production (Eisner, 2007). Through art, we do not just express ourselves; we can also learn about and understand the world around us. Creating art allows us to explore complex ideas, experiment with different perspectives, and gain new insights that might not be readily available through traditional means. This creative process itself is also an "aesthetic experience" (Visse et al., 2019). Engagement with art, whether creating it or observing it, can evoke a sense of beauty, wonder, or even discomfort. These aesthetic experiences can be transformative, prompting reflection and sparking new ways of seeing the world. Finally, creative expression is a powerful non-verbal means of communication (Reynolds, 2003, Visse et al., 2019). This is particularly valuable for individuals with chronic illnesses or disabilities

who might struggle to express themselves verbally. Through art, they can communicate their experiences, emotions, and needs in a way that transcends spoken language. All these insights show that, in essence, creative expression offers a multifaceted toolbox for healing, self-discovery, knowledge creation, aesthetic appreciation, and non-verbal communication.

In creative practice, professionally trained artists, but also non-professionals, are active and experience the benefits and meanings mentioned above. While some may believe creative expression is reserved for artists with specific skills, research by Groot et al. (2021) demonstrates that even individuals who do not identify as artists can experience significant well-being benefits by engaging in creative activities. I will elaborate on the meanings of this after I present my autoethnographic narrative.

Narrative: Key Moments in Art and Care

Episode 1: Looking for Comfort and Support





Figure 1. Consolation. Teunissen, 2012. Material: serpentine stone.

I am in the waiting room to be picked up for the first X-ray radiation treatment. I am afraid and I want to leave, but my mind is holding me back. Leaving is not going to help me in the long run, I say to myself over and over again. I know . . . I'm just trying to breathe deeply in and slowly out. Just a little longer and then the treatment starts. I have been walking around for days with a sore stomach. I must do the treatment, but I don't want to. Doing something while also wanting to run away feels so conflicting, alienating almost. I look for peace in my head, for comfort but also for relaxation and focus. Concentrating is almost impossible . . . reading a book, pfffff . . ., after three lines I lost the thread of the story. Then I feel in my pocket for my tiny statue of a human shape. Actually, it is a small piece of stone that I have carved, shaping it so that

it fits exactly in the palm of my hand. I wanted to make a tiny shape so that I can take it with me to all these treatments. Deep in my pocket but always accessible to me. I filed, sanded and then it took a long polishing . . . until it was very smooth and shiny.

The shape feels cold. As I think back to how I made it, the stone slowly takes over the temperature of my hand and becomes one with my body. Suddenly I hear: "Mrs. Teunissen! Follow me please" . . . and I realize that it's about to start.

Reflection 1

Cultivating self-awareness and attending to my care needs have been essential in navigating challenging situations. Facing unavoidable tasks that evoke fear often prompts a desire to escape or avoid (Loonen & Ivanova, 2018); however, simultaneously, taking care of oneself – "caring about," in Tronto's (2013) framework – is crucial. I muster my courage and confront my fears, seeking solace in art as a means of comfort and a tangible anchor. The stone nestled perfectly in my hand triggers a sense of protection and security. This tactile encounter exemplifies Puig de la Bellacasa's (2017) notion of a relationship between an individual and an artistic object established through touch. Waiting experiences can be fraught with anxiety and discomfort. These liminal spaces, sometimes characterized by raw or painful emotions, may linger indefinitely (Lapadat, 2017). Art, in its various forms – drawing, imagery, poetry, or music – offers a means to alleviate stress or despair during such periods. Sahabi's (2019) artistic research highlights the challenges faced by individuals in hospitals, despite good care. However, distraction-based approaches may not be effective for individuals with limited creative inclinations. Instead, they may require alternative strategies to manage anxious waiting times, such as reappraising their situation, managing expectations, focusing on potential benefits, or creating distance (Sweeny & Cavanaugh, 2012).

Episode 2: Looking Back



Figure 2. Dandelion. Teunissen, 2021. Material: casting resin.

... "It is still so hard this month . . . it's been four years but I still feel the heaviness and darkness so intensely." I put the phone down after a long conversation with my friend. In this month, four years ago, her two daughters died, and the grief and pain are a wound that does not heal properly. I try to empathize with her by talking, hearing her, listening, but I decide to visit her anyway, since doing all this over the phone feels quite distant. On the table is a dandelion that I have cast in transparent resin, ready to give to her. It looks like glass and it is so clear and light, the dandelion seems to float, it has something dreamy. Searching for the dandelions just before they open and turn into a white fluffy bulb shape and then, very carefully, casting them in resin, is a pleasure in itself. That also carries the actual goal: giving it to the other person as a comfort, as a support or to cheer up. Maybe my friend will experience something of the creative pleasure, the dreaminess and the light; I hope so and wish her that.

Reflection 2

The practice of encasing memories in glass jars as a form of healing dates back to ancient Egypt (Bierbaum, 2023). In this context, it serves as a means of caring for my friend, to really see her (Heijst, 2008). I believe that human existence is fundamentally relational, fostering a caring and inclusive society (Visse & Abma, 2018). My artistic creation embodies this care, serving as embodied listening that provides space and time to express gratitude to my friend for sharing her grief and pain (Komter & Vollebergh, 1997). Feeling the weight of her suffering, I acknowledge my responsibility to respond to her need for care (Tronto, 2013) in a way that words alone cannot fully capture. I am both responsible for the other and I need others in mutual dependence (Nistelrooij et al., 2017). The limitations of verbal communication underscore the importance of non-verbal expressions of care, as highlighted by Teachman & Gibson (2018). These emotional gestures can heighten awareness of what constitutes "good" care and serve as moral markers (Pulcini & Pulcini, 2013). Seeking solace beyond words, I turn to the act of creating with my hands, hoping that my artistic expression will resonate with my friend, offering a touch of beauty and perhaps some comfort.

Episode 3: Connection





Figure 3. Connection. Teunissen, 2018. Material: paper, coloring pencils, felt tip pens.

I visit my father, living in a nursing home. "Look, dad, what I brought from my garden . . . they're still beautiful, aren't they?" "Yes, yes," my father mumbles, at least that's what I think I understand. I show my father the beautiful blue hydrangea flower that I have now put in a vase on his table. He has hardly talked for a while because of his dementia. Having a conversation with each other is no longer possible. "Shall we draw and color the hydrangea dad?" He nods in agreement. The nurses bring paper and crayons, and we sit at the table together. First, we start with coffee and the soft, sweet chocolates, his favorites. Then I start with the drawing. My father has been drawing and painting for many years, so coloring is not unknown to him. But he doesn't start coloring now. So, I start drawing the contours of the hydrangea and the vase with a pencil. Then, slowly, he takes a crayon and starts coloring. My heart is jumping for joy, and I feel we are connected with each other. Together, side by side, our arms just touching each other, we sit coloring the vase with the blue hydrangea. Just a moment of togetherness, of sharing something, a moment of joy and of being far away from his fog, his confusion and not-knowing-anymore.

Reflection 3

In this instance, multiple aspects of care intersect. It involves 'care giving' (Tronto, 2013) by bringing a moment of joy to my father, while also breaking through the emptiness and silence that engulf his world, allowing for a brief connection with him. As his daughter, I feel a responsibility to address this perceived need for care and actively engage in an activity that resonates with him; drawing together is "taking care of" (Tronto, 2013). My father's illness has isolated him. He used to relish conversations and was always busy in the garden or crafting with wood, iron, or stone; however, his condition has robbed him of his ability to

speak, leaving him physically frail and mentally trapped in the void of dementia. Caring for individuals with dementia is a stressful experience for family caregivers, though.

It is hard for me to witness how he sits with his eyes closed, even when not asleep. Recently, while reading a book to him about Limburg, the Dutch region where he spent most of his life, I thought he had fallen asleep and paused momentarily. But then, ever so gently, he nudged me with his elbow, an encouraging signal to continue reading. This gesture exemplified his need for connection and care. This is "caring about" (Tronto, 2013).

Artistic expression, and doing this together, emerges as a tool for fostering connection and nurturing positive emotions (Groot et al, 2021). Schneider (2018) highlights the therapeutic potential of art in mitigating the effects of dementia and enhancing quality of life, even if momentarily. Creating art together fosters connection and solidarity (Thompson, 2020). Actively facilitating artistic expression, especially in care settings, constitutes a valuable form of "humane" and "aesthetic" care (Niemeijer & Visse, 2016). As Annelies van Heijst (2008) asserts, while technically sound care is essential, it is the care provider's ability to truly "see" the individual that makes a difference.

Episode 4: Dreams About Belonging



Figure 4. Light sculptures. Teunissen, 2017. Materials: clay, cotton, mulberry bark, wood glue.

Preparing for a conference with an art & care group, back in 2017, I make creative expressions around the theme "The Art of Belonging." I want to make a group of sculptures that represents both hard and soft artistic human qualities. Hard and soft as

not opposed to each other, but needing each other to stay afloat, in other words, to be a whole person. Light shining through, dreamy, fragile, and at the same time solid, hard and firm.

Very concentrated, I shape the stiff mulberry bark as a lower body of a human form. It keeps coming loose and, time and time again, I try to shape it. I want to make a kind of counterstatement, showing the other side besides being weak, ill, receiving help, and being cared for. In short: I am more than my illness and I want to show that in these light sculptures. Strong AND weak. Dreamy and solid. Very important since every human being can be or can become dependent on care for a shorter or longer period of time. Accepting adversity must be part of my attitude to life. But to stay afloat, to continue to feel and be a whole person, it takes more than medication and treatments. I depict my dreams about belonging, and about being a vulnerable person among people, with human figures who form a unity in their fragile diversity. Their light may shine, and their expression of feeling and intention may even soften the harsh reality.

Reflection 4

Imagining both strength and vulnerability (Teunissen et al., 2015) requires attention to the quality of a caring society with solidarity and trust (Visse, 2017), and in particular to whether no one is excluded and everyone can have the feeling of belonging (Hall, 2014). A central aspect here is relationality—the notion that everyone is depending on others, and everyone is both capable and incapable at the same time (Nistelrooij et al., 2017). This is a personal and political concern: "caring with" (Tronto, 2013). Being able to make art and share it with others in curated, public spaces, here at a conference, also offered me an opportunity to discuss topics such as justice, equality, freedom and the need to belong. Through sharing my practice with others, I foster solidarity and trust, the two pillars of a caring society (Visse & Abma, 2018).

Episode 5: Hold My Hand

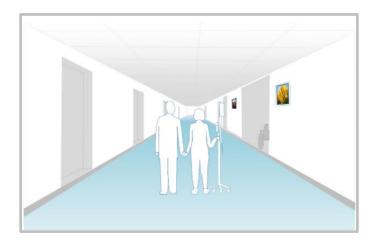


Figure 5. Hold me. Teunissen, 2015. Materials: paper, pencil, paint, photo.

I put on my clothes, as good or bad as it goes, and carefully arrange the IV-tubes. Paul and I take a walk away from the hospital ward together. Just trying to get out of the hospital atmosphere: no alarm bells, noise of rattling food carts and not seeing a bed for a while. Let's see if there is some distraction so I can try to focus on something else than my own body. Paul is also happy that I want to walk around again. Walking next to each other in normal clothes gives a reassuring feeling, a bit like everything is back to normal. It also makes him visibly feel good to notice that I am enjoying doing something again. He is very worried about me, I notice that. A little distraction will also do him good, and me, definitely, as well. The hospital has a map indicating a walking route along the works of art currently on display. We are looking for the start. The hospital looks deserted in the afternoon just after 5 o'clock; the outpatient clinics are closed, a last visitor is on the way to the exit. We start with art object number 1 . . . I surrender to what I see and try to imagine what the colors and shapes can mean. Au! ... don't walk too fast, my head hurts! ... Really nice to walk together hand in hand through the corridors and standing in front of a painting . . . Paul enjoys it. We are here together, suddenly with a feeling of "we will get through it." While talking about what we see, we walk through the huge quiet building with white corridors in search of the next work of art. I feel a bit like a whole person again, having desires and dreams, enjoying bright colors, finding things funny, beautiful or ugly, trying to understand its meaning or criticizing its quality. It feels good to be together again as partners and loved ones. For a little while we just pretend to be not in a hospital but in a museum. Looking at art, colors, shapes, materials, has a comforting or healing effect

on me. I like the connection with the artwork and its stone or wood. At the same time I feel the connection with others enjoying the art. I become aware of the cocoon I had ended up in: hospital, infusions, bed, pajamas, and the repetitive conversations about treatment, medication, how long this has to be done, and what I should do when I get home. I feel the need to get away from this for a while, from being alone. I want to be distracted by having conversations with each other, other than about my illnesses. I am especially feeling the need to be together again.

Reflection 5

Becoming aware of my own care needs and deciding what to do about them, and also being aware of the care needs of others, are difficult while being ill. I take care of myself and my partner at the same time when we look at art together in the hospital: "care receiving" (Tronto 2013). Art can reflect, represent and carry an experience and its associated emotions, allowing the maker to separate from it. Both self-care and catharsis can be accomplished by artistic expressions (Milne, 2016). Receiving and giving affection is necessary for self-worth and resilience (Baart, 2005) and for being able to function independently (Honneth, 1995). People want to matter to others (Schwartz, 1992) and to belong (Baumeister & Leary, 1995). My partner and I both need this walk to relax and to find comfort during my hospital stay but also to keep hope for the future. However, this joint walk amidst artistic expressions might not be the preferred way to escape the hospital atmosphere for everybody. A trusted friend or a family member could also join in a walk, medically facilitated if needed, e.g. going to a silence room, restaurant, recreation area, or outdoors for fresh air, a view, or a park (Douglas & Douglas, 2004).

General Insights and Discussion

Engaging in artistic practices can only occur when one risks being vulnerable. The vignettes demonstrate the oscillation between my fear and my self-awareness (episode 1), my darkness and my giving (episode 2), the loss of my father as I knew him and renewed connection (episode 3), and being alone in bed and walking together with my loved one (episodes 4, 5). Working with the arts in these experiential spaces, fully engaging with them, brings a wealth of benefits to people who live with chronic illness. These practices can evoke a spectrum of emotions and (renewed) connections due to their aesthetic and materialized appeal. My practice filled forced breaks from work and breaks from being away from loved ones, offering a sense of purpose and fulfillment. Notably, artistic expression has the power to distract individuals from illness-related thoughts, further enhancing their overall well-being. This is because art stimulates the imagination, resonates with viewers' emotions, and ultimately provides comfort and reduces stress.

Teunissen: Art in a Caring Society

Above, I mentioned creative expression is not just reserved for artists with specific skills, and is accessible to all. I referred to research by Groot et al. (2021) demonstrating that engaging in creative pursuits can be a universal human experience, accessible to anyone regardless of skill level or artistic background. My narrative shows how creative expression encompasses a wide spectrum of activities and that the choice of materials matters and aligns with moments, feelings, and key events. I experienced finding an outlet that resonates with me made the experience more enjoyable and sustainable. Many of these creative activities require minimal resources, making them accessible to a wide range of individuals. Even though this article showed images of various artistic expressions, I want to emphasize the meaning of the journey, not just the outcome. In non-professional contexts, the focus should also be on the process of creating and self-expression, rather than achieving a perfect final product.

I shared these insights autoethnographically, presenting evocative vignettes that hopefully created a relational space for the reader to engage and decide the meaning of my work for them. I am aware of various limitations of this paper and I do not generalize in any way. My purpose was to develop a caring relationship with readers instead of standing apart from them in the name of rigor and objectivity. I leave that up to others. I hope to have increased the trustworthiness of my insights by being specific and reflecting through seeking relationships with scholarly works like Tronto's (1993; 2013) five phases of care as a framework for structuring the narrative episodes, which helped me to maintain clarity and coherence. Also, my narrative monologue is strengthened by incorporating contrasting perspectives (Auken et al., 2015) in the reflection sections, preventing the study from becoming a mere self-serving narrative. Finally, the narrative reflects a Western, Dutch, white, female perspective, potentially limiting its applicability to individuals and organizations from other cultural backgrounds. Ultimately, I hope to inspire others to explore their own experiences and engage with diverse narratives through various methods. This will lead to a more nuanced understanding of the meaning of the arts across different cultural backgrounds and identities.

Conclusion

In conclusion, my insights suggest that individuals can, to a significant extent, cultivate self-care and care for others, and contribute to a more caring society through art's transformative power. The narrative accounts in this chapter illustrate the possibilities I encountered to connect art, creative expression, and care. A noteworthy observation from this narrative study is that the five phases of care described by Joan Tronto (1993; 2013) appear to be intertwined, suggesting the absence of a rigid hierarchy or sequence in their practical application.

To further bridge the gap between care, art, and creative expression, I encourage exploration in several key areas. Firstly, delving into the potential of art as a tool to enhance the meaningfulness of care experiences is crucial. This involves understanding how artistic

expression can enrich caregiving and support the well-being of both caregivers and recipients. Secondly, examining the impact of art experiences on individuals unfamiliar with the art world is vital. This exploration can shed light on how art can be made accessible and impactful to a wider range of people. Thirdly, it is important to identify and understand the diverse forms of creative expression that hold value and meaning for individuals. This can involve acknowledging the various ways people connect with and find meaning through creative outlets. Finally, I feel that addressing ethical considerations in arts-based care practices is essential. This includes exploring concepts like co-ownership, cooperation, and shared decision-making to ensure that art is incorporated into care in a way that respects the autonomy and agency of all involved. By investigating these areas, we can foster a deeper understanding of the multifaceted connection between care, art, and creative expression, ultimately leading to more meaningful and impactful experiences.

My research, encompassing both literature as referenced in this study and my personal narrative, supports my suggestion that art and creative expression can indeed serve as a powerful medium for care. It allows individuals to care for themselves, for others, and even for society as a whole. This compelling evidence underscores the value of embracing "art for the sake of care."

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