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Volts of Connection: Visual Case Studies Revisited

Abstract

Suggesting a variety of techniques appropriate for monitoring and exercising our own therapeutic imaginations, in “Volts of Connection: The arts as shock therapy”, the author argued for the use of evocative images other than solely the decorative, innocuous and “pretty” in clinical settings. Using a painting as a visual case study, this article documents the benefits of reflective writing as it acknowledges and reveals the arts’ amazing abilities to pierce the isolating yet protective and appropriate silences with which grief shrouds us. It also helps connect us to others, in their grief and their silence, letting us share others’ feelings without intruding on them.

Introduction

Grief remains one of the few things that has the power to silence us.
Anna Quindlen

Lisa Schnell published an article in *Vermont Quarterly* (2000) about the death of her baby daughter and how she slowly regained her ability to find and express herself in words. When her baby, Claire, suffering from the rare and devastating birth defect lissencephaly, died at 18 months, words were not forthcoming to this connoisseur of words. Schnell talks of “choking on” her grief, her vocal cords becoming, metaphorically, paralysed.

Words had turned on me ... they were language, a reminder of what Claire would never have; or they were just absent – the core of inarticulateness inside me, my helplessness, my inability to turn my grief and fear into a narrative with a happy ending. (Schnell, 2000, p. 26)

Incapacitated by grief, she wished only to be with her baby daughter: “I just wanted to be dead with Claire. I wasn’t suicidal. I didn’t want to make myself dead, just be dead”. Ultimately, this grieving mother found the words for the “lessons” death had taught her.

Only later did I understand that Claire needed me to live; that her dying – and my not – hadn’t been a flagrant violation of some sort of maternal symmetry. I am still Claire’s mom. (Schnell, 2000)

Visual Case Studies

Expanding from the well-known medical mantra, “See one. Do one. Teach one”, I urge a further phrase – “Use one”. The teaching strategy for using visual case studies in group settings, whether with health care professionals or support groups, after the members silently immerse themselves in the image for a minute, is simply to ask three questions: (a) “What is going

on in the image?” (b) “Why do you say that?” and (c) “What else do you see?” The goals are chiefly to elicit concerns, to introduce concepts, to enhance or build skills, to explore attitudes, and, perhaps, even to promote healing.

Moved by Schnell’s writing quoted above, I invited her to take part in a visual case study exercise by asking her to dialogue with a work of art. I sent her a photocopy of Deidre Scherer’s fabric art, “Child” (Figure 1), along with a broad “probe question” to guide her: “Please flesh out your reflections on this image with a story, vignette, title, quotation or any commentary.”



Figure 1.
Child, Fabric and thread.

© 2001 Deidre Scherer, All rights reserved.
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Schnell responded both to the Scherer image and to how it felt to write about it. Here are her words describing how it felt to do the case study:

I was very struck by one particular part of the incredibly moving image you sent me, but in focusing on that I’ve tried to get across some of the complexity of my own experience of mothering a dying child. ... It was good to write it, a more powerful experience than I had anticipated.

And here is Schnell’s response to the visual case study exercise, centring on ordinary plastic tubing but blossoming into something quite extraordinary:

Clear plastic tubing: there was so much of it, and it was stiff and cumbersome in the cold December house at 3 a.m. But the pain of my engorged

breasts was greater even than the discomfort of pumping them out in the cold, quiet house. And so I would struggle with all that tubing, hooking up body to bottle to pump... The anxiety stayed inside, cold as the house, inhabiting the questions that rattled around inside my head: Why couldn't she nurse? Why wouldn't she wake up to eat? Why did she twitch all the time? But for a few moments as I felt the warm swoosh of my own milk, I would relish the dark calm of December and imagine that everything would be all right ...

Clear plastic tubing: months after the breast pump had been put away it reappeared, what seemed like miles of it, stretching from the tiny cannula in her nostrils to the big oxygen machine. It was May now, and the tubing was soft and flexible as we carried her from the living room to the bedroom, and sometimes even outside to the front porch. The gush of milk had long since ceded to the persistent leak of tears; the chill of anxiety was about to be replaced by the everlasting ache of grief. But there was an unmistakable calm in her wide gray eyes as she looked at me, tangled up in all that plastic tubing.

Schnell said she gradually rediscovered the “redemptive power of language”, finding the process of writing profoundly enriching. *“In its simplest formulation I suppose it was a way I could continue to be Claire’s mom.”* (Schnell, 2000, p. 26)

I sent the same visual case study image to Annette O’Brien, a grandmother whose grandson Liam died after a struggle with the same illness, lissencephaly, at age 2 years and 4 months. O’Brien used her visual case study to raise a question that continued to haunt her: Did they serve the Liam’s best interests by prolonging his life – and possibly his suffering – another six months with a feeding tube? Here is her response:

She closes her eyes. She thinks if she holds him a bit longer he may stay to comfort her. She is upright in her chair so sleep cannot creep up on her. How could she live with herself if she were to fall asleep only to awake and find him to be gone? The window is open but she and the child are swaddled together in the all too familiar quilt she had made to celebrate his birth. Now she uses it as a shroud. She is afraid to look into his eyes; she feels his bony prominences; she hears the whir of the feeding pump. Just who is she trying to sustain?”

The child is suffering. He no longer wants this artificial feeding that has come to be a painful experience for him. He just wants to lie down beside her and close his eyes. His sunken eyes are wide open. He hopes his eyes will meet hers so that she might see what he is trying to tell her. He looks upwards desperately trying to catch her eyes in a glance. Can't she see what his eyes are saying?

I think about this child. How old is he? How long has he been ill? Was he once a healthy child or, had he been sick since birth? Not that this really matters. The death of a child is always unexpected. It really wouldn't matter if we knew about his

condition for some months or even years, we somehow shelter ourselves from thinking the unthinkable, or thinking that today is the day. We keep busy...that's the American way. We protect ourselves from any unpleasanties such as death. We are the fix-it generation. But not all things can be fixed, and try as we may to sustain life through the symbolic gesture like artificial feeding, we cannot postpone indefinitely the certainty of an impending death.

My eyes become fixated on the subtle image of the white feeding tube that is carefully weaved through his clothing. I find it so difficult to look at this dying child tethered to a feeding pump. Painful memories of our experience flood through my consciousness. This is an image that will haunt me forever. The child here is dying ... food is for life ... what life does he have left. And, what about this sad, grieving mother ... does she really believe that one more ounce, one more feeding and all will be well? Maybe she stays in her chair because she is concerned that his feeding tube will become tangled or dislodged. She is not comfortable and neither is her child. Why do we make dying so difficult, especially for our children?

O’Brien, too, comments on the assignment:

Studying this visual has been a valuable, cathartic experience for me. I hope that sharing my thoughts and innermost feelings about our life with Liam will benefit other families and change the way we look at life of our most precious children. We need to rethink our approach to dying children. We need to look into their eyes and hear what they are saying. There is meaning to their brief lives. We only need to listen. The families are in such pain; guilt can be overwhelming; decision-making insurmountable; and, the ever present force of desperation. They cling to hope, a hope that can never be realized. It is incumbent upon those who are professional caretakers of these families and children to be sensitive, compassionate and most importantly supportive of the decisions these families make. There is no greater love for child than a parent letting their child go...who are we to question their decision.

Curious about their responses to this image 12 years later, I tried to contact both Schnell and O’Brien. At the time of writing, I succeeded only in reaching O’Brien. Her words need no preamble:

More than a decade ago following the death of my two and a half year old first grandson, Liam, Professor Bertman asked if I would look at a picture, “Child” by Deidre Scherer. She asked if I would document any thoughts, feelings and memories that this picture brought to mind. I focused on this picture of a woman and child and within seconds I saw myself as the woman and, the child as my grandson. It had been only 3 months since he passed and my emotions were still raw and far too complex. I felt enormous sadness, anger, frustration and hopelessness. He was gone.

Nothing would change that. This picture brought all those emotions to the surface. Emotions that I had desperately tried to conceal from my daughter, her sisters and my grandchildren for fear that they would absorb my sadness. I put the picture away for a time. It was too close to the holidays and I just could not put my head in that space. I told myself not today, maybe tomorrow, maybe never. The picture was in my office drawer but it became an indelible mark in my brain. I found myself thinking about it over and over again. I knew that I had to deal with this not only for Professor Bertman but for myself as well.

A week went by before I opened the drawer. Now I was ready. The holidays were over; we survived our first Christmas without Liam.

I just sat at my desk and looked at the picture, the here and now. I put my fingers on the keyboard and started to type the story of Liam and me. I identified with this woman in ways that can only be described as intimate, almost indescribable.

I thought to myself that there must be more, but more of what? We have all heard that people handle grief in many ways for different periods of time. What was my time and what was I to do to ensure other families are not subjected to what I can only describe as cruel words, phrases and at times feelings of intimidation. For months I looked into Liam's eyes and I struggled to hear what he was saying. During the last six months of his life we began searching for an in-home hospice program that would support us as we approached his death. We called every hospice within a 25-mile radius of Liam's home and we were shocked to find there were none.

Then it came to me. We should raise awareness of the absence of home-based end-of-life care for children and their families. This was the message and we were the messengers. It was time to use, albeit very painful, our experience with Liam to improve the care for children and families facing many of the same issues.

For the next seven years we worked tirelessly to make a difference. We did make a difference; it is better, not perfect but better. We took our message to conferences, speaking engagements, academic programs and to parents all over the country but most importantly to legislators, regulators and clinicians.

So, as I look at this picture today the painful memories are still there ... I accept that as an important and essential component of our message. Ten years have passed but Liam's lesson continues to resonate. As you have may have heard, "there is no such thing as a bad experience as long as you learn from it." Ours was not a bad experience we had the joy of holding Liam for close to 3 years.

So I say to the woman in the picture today "we saw what you were saying and all is well." I notice now the curtain is gently blowing in the breeze bringing new life, understanding, compassion and acceptance to the end of life for children.

Lest neither parent nor grandparent could be found or cared to reply to my query, I sent this image with the same prompt questions to a colleague relatively new to the field of thanatology whose response affirms my beliefs in arts' evocative powers, and reinforces the idea that we cannot look at an image without seeking and making meaning:

*Dr. Bertman has become a dear friend and fellow traveler in the world of thanatology and in life in general. I teach courses on death & dying and ethics of health care but I approached the "assignment" to respond to this image more from a personal perspective. Nearly twenty-six years ago, after a perfect pregnancy, I gave birth to a beautifully formed but irreversibly brain-damaged daughter. Her condition was the result of medical malpractice during labor. Given her prognosis, my late husband and I wanted her to be allowed to die. We found ourselves, as grieving parents, having to argue with the hospital to let her go. I wrote about this in my first book *Lost Lullaby*. Our daughter died after two months of being kept alive. For us, this was a blessing given the projected life she might have had. And, had she survived, I would not have gone on to get pregnant with my son, now twenty-five years old, and doing great. The grand lesson that I learned from my experience with my baby girl is that each of us has his or her own fate. Period.*

And here is her profound and provocative response:

How did it come to this, that motherhood is holding a dying child and childhood is not being allowed to die? But who spoke of dying? No one. What weariness and pain to go on this way. It is assumed and a given: life at all costs. But wait, mustn't love of another include his end? No, no, never. Children shouldn't die. Everyone knows, children must outlive their mothers and fathers, not the other way around. Never. The death of a child is always too soon. It is not their time, if they are a child. But wait, then when is it their time? When they are adolescents? No. When they are young adults? No. When they are eighty years old? No. This is what we tell each other, the time to die is never.

I carried my baby through a perfect pregnancy. Her birth, the greatest joy in our lives. We did it. We created this beautiful baby. She is ours. Our baby. We love her more than we could have ever imagined. Our lives revolve around her. Our greatest achievement. She will grow strong and do many wonderful things. She will make us proud. In her we channel our hopes and dreams.

Oh no - this can't be happening. She is sick. So very sick. She has cancer. Oh my god. What now? What do we do? Who will help us? How will this turn out? She cannot die. She will not die. What must we do to save her? We must save her. We can't live without her. I am her mother and it is my job to save her.

Mamma is so terribly sad and I don't want to make her sadder. But I am suffering and I know this is not how I should be or feel. Poor Mamma. Even though no one told me, I know that I am dying. My world is so small - the halls of a hospital, my bed at home. I've grown thin and have lost my hair. The medicine to make me better instead makes me sicker. I know that things are not right. I silence what I cannot say and grasp my Teddy Bear.

Summary

These three responses are powerful evidence of the ability of art to move us to respond from our depths and to evoke instantaneous empathy. For these women, the very act of putting pen to paper propelled them – as it now propels us – to look again not only at what is in front of us, but what is within us. Even more than catharsis, might we go so far as to claim that this assignment piqued curiosity, defused stress and inspired creativity? Research has shown that the benefits of reflective writing appear to require translating experience into language. The act of shifting emotion and musings into words changes the way that the person organises and thinks about trauma (Pennebaker, 2000, p. 8). Only by making visible that which was invisible do we allow the process to begin.

Healing is neither cure nor closure. In her remarkable book, *A Troubled Guest*, Mairs offers memorable asides about being hastened through the trajectory towards recovery. “Who came up with the idea that words of sympathy ought to instruct or inspire, as though one were addressing not a suffering soul but a football rally or a revival?” (Mairs, 2001, p. 107) Though none of these women would have wished for such an experience, love and gratitude for the time with their dying child is expressed, treasured and voiced in direct proportion to their grief. In one of Proust's condolence letters he speaks to the impossibility of having faith in any reassurance – until a right time – that “an idea that will horrify you now – this intolerable misfortune will become a blessed memory of a being who will never again leave you” (2006). And Lewis, in his brilliant memoir *A Grief Observed*, thinking he could describe the state or chart the course of sorrow, concludes “Sorrow, however turns out not to be a state but a process. It needs not a map but a history, and if I don't stop writing that history at some quite arbitrary point, there's no reason why I should ever stop. There is something new to be chronicled every day” (Lewis, 1976, pp. 68–69). All these commentaries acknowledge intense grief. They also affirm that death ends a life but not a relationship between the person grieving and the person lost.

Grief and empathy are authentic expressions of what makes us human. With any work of art – a poem, a painting, a photograph, a piece of music – there are always a host of participants: the creator, the subject of the work, the reader, the viewer or listener, and perhaps even the teacher, therapist, or “user” of the work for a specific purpose. Grief, either written or read about, reaches to us in our isolation and helps us to step out of our personal despair.

Aesthetic distance is not detached concern; art – using visual case studies – is a therapeutic technique that enables us to reflect upon scenarios vicariously, before, during or after we face them in our lives. The case studies help us and to prepare for forthcoming situations. Grief does remain one of the few things that has the power to silence us, but it is through the arts that we can once again find our voice and connect to the silence of others.

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