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An Art-based Case Study: Reflections on End of Life from a Husband, Artist and Caregiver

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Dr. Robbins declares that she is a close friend of Pat and Norman Gilbert who are the focus of the narrative in this manuscript; in support of Norman's work and for curatorial purposes, Dr. Robbins conducted the original interview referenced in this article in a non-research capacity.

Abstract

This study explores the reflective processes of Scottish artist, Norman Gilbert, as he created twenty-five drawings depicting his wife, Pat Gilbert, as she lay dying following an Alzheimer's-related stroke. Norman, ninety-one, had drawn Pat regularly over their sixty-five-year marriage. One week after Pat died, Norman was interviewed by a family friend to chronicle his reflections on the drawings. The drawings along with the interview transcript are analyzed qualitatively as a case study. Norman's *Hospital Drawings of Pat* transform what was initially a private experience into a shared comprehension of end of life and bereavement.

Keywords

End of life, Visual art, Reflection, Bereavement, Drawing, Resilience

Introduction

Scottish artist, Norman Gilbert, has created drawings and paintings of his wife, Pat, for over sixty-five years. A walk through Norman's home and studio in Glasgow, Scotland, will introduce you to Pat Gilbert and draw you into a rich visual portrait of her life. Hanging on the walls throughout their Victorian terrace house on Glasgow's south side are paintings of Pat as a wife, a mother and a grandmother (Fig. 1). Norman's pictures of Pat form a vast portfolio of images that serve as an intimate and complex visual record of their life together in relationship with the world around them as husband and wife, as parents to their four sons, and as artist and model. In 2010, Pat was diagnosed with Alzheimer's disease and, although, with time she grew frail and relied on Norman's care more and more, she never stopped sitting for Norman and he continued

to draw and paint pictures of Pat (Fig. 2). From July 2 through July 23, 2016, Norman exhibited a selection of his life's work, *Norman Gilbert Retrospective Exhibition*, which included a sequence of drawings and paintings of Pat (from 1954 to 2016) at The Sutton Gallery in Edinburgh, Scotland, Pat and their sons attended the opening; this was the last exhibition of Norman's that Pat was able to attend.



Fig. 1 Woman with Scarf (Pat), Charcoal on Paper 1992

Pat died at the age of eighty-six, on August 3, 2016, six days after suffering a devastating stroke. Norman's final drawings of Pat were carried out as he kept vigil by her bedside during her last days. The resultant series of twenty-five drawings, *Hospital Drawings of Pat*, depict Pat as she lay dying in the hospital. The series of drawings culminates with one final drawing created in the moments immediately after Pat's death. To complement his final drawings of Pat and chronicle their creation, Norman recorded an interview conducted by a close family friend on August 21, 2016, just weeks after Pat died. The interview, which was intended to add context to the drawings for curatorial purposes only, provides us with a rich and complex record of Norman's experience that can be analyzed qualitatively to explore an Alzheimer's caregiver's experience through the lens of an artist. This case study is aimed at examining Norman Gilbert's final drawings of Pat Gilbert along with an associated transcript from this interview to explore Norman's reflective processes related to his experience as a partner in care with his loving wife who lived with and ultimately died from an Alzheimer's related illness.



Fig. 2 Pat II, Indian Ink on Board 2014

In the interview, Norman described *Hospital Drawings of Pat*, plainly calling the drawings “a record of a week that [he] spent in the hospital.” Analysis of his account of the week that he and Pat spent in the hospital reveals that Norman engaged in two distinct forms of reflection—reflection-in-action and reflection-on-action (Schön 1983). Reflection-in-action refers to the more intuitive responses to any current experience.

This form of reflection is fundamental to artistic practice as the artist relies on the more tacit processes of being present with and thinking in the moment to determine each next move to sustain a continuous responsiveness to the experience (Jarvis 2007).

Reflection-on-action refers to more critical retrospective reflection, which occurs after any action of focus and involves assessment of what has happened to determine how to move on from that point (Schön 1983). This case study recognizes reflection-in-action and reflection-on-action specific to the practice of drawing.

When Norman was engaged in drawing Pat in the hospital, he vacillated between simply being present with her and mindfully narrowing his focus in on the grounding details of what was before him and widening his lens to the aesthetic whole to consider how to respond continuously to not only the drawings but also the bigger picture in the process. When Norman was engaged in the interview process, he described the experience of creating the drawings and shifting between merely telling the story of his life with Pat and reminiscing about their final week together in the hospital and examining, through critical reflection, the stories he told to assess the final outcome.

Reflection-in-action

The work of the artist requires attention to physical, mental, spiritual and emotional details to build a picture that resonates and seeks not just to inform but also to evoke and inspire. Although Norman was acutely aware of the gravity of the situation that he and Pat were in, the act of drawing, at times, moved his attention away from the past and the prognosis to attend to other specific details within the present. By focusing his attention on the particulars to build the picture, Norman was able to observe stimuli and respond, in a non-judgmental way, by mindfully noticing and engaging with both Pat and the drawing. In this way, making marks on the sheet of paper allowed him to focus in on parts of the picture and experience what he was sharing with Pat without judging the whole picture (Fig. 3).

Early in the interview, Norman spoke about his initial focus on the formal elements of what he was seeing and his search for the stability of a pattern in the linens and the clothes surrounding Pat, stating, "They put one [mat] beside Pat's face...that had a pattern on it. And, they also put her into a night dress, one of the ones...that laces up the back, and it had checks on it, which was a lot better than the one that they had previously, that said something like *The [National] Health Service*, a thousand times in tiny wee lettering" (Fig. 4). Norman's depiction of the patterns parallel a lifetime of his preoccupation with such visual elements, as his compositions heavily relied on the patterns of the clothing his figures wore as well as the surrounding décor to describe form and space. In *Hospital Drawings of Pat*, the patterns provided Norman with familiar visual elements that allowed him a place to focus attention on details that helped ground him and construct some semblance of order and harmony within a very difficult and unfamiliar situation.



Fig. 3 Pat(I) Pencil on Paper 2016



Fig. 4 Pat (II), Pencil on Paper 2016

Hospital Drawings of Pat are composed with the same economical, deliberate, linear mark making that characterizes so much of Norman's prior artistic output.

Nevertheless, the raw, unflinching depiction of Pat's open but unresponsive eyes and filled-in blackness of her open mouth engenders great expressiveness and a heightened sense of realism and emotion that amplifies the viewer's perception of being a witness to the final stages of life (Fig. 5). As Norman became a witness to his final days with Pat in the hospital, he focused in on Pat, deliberately choosing to disregard certain external stimuli. As he explained, "I could have put on the radio, or a television. I didn't put that on for the whole time." By avoiding distractions, he was able to construct and sustain a space to draw and purely attend to the reality of the situation. The reassuring and familiar practice of drawing served as a means of both engagement and reflection.

Interestingly, the act of drawing offered Norman a paradoxical diversion. Norman explained, "When I was doing the drawings, I forgot! I was just drawing Pat again. And, I had drawn her thousands of times before." Norman concentrated on what he knew he could do, draw pictures of his wife. At times, he was so focused in drawing the details that the big picture began to fade away. As Norman explained it, "I forgot about ...why I was there. All I was doing was concentrating in the drawings and hoping I could do them sufficiently well...And that gave me something to concentrate on that really made me forget...what I was actually doing." He balanced the action of consciously gathering fragments of information (patterns, proportions, shapes, form) with a more passive stance of beholding to create a unified, credible and believable aesthetic whole. Norman's time in the hospital was divided between being and doing, providing care and drawing, seeking a balance between effort and surrender.



Fig. 5 Pat (III), Pencil on Paper 2016

The balance between empirical description and artistic expression helped Norman respond from his mind and his heart. Each mark that Norman made required attention with care. In the pictures, Norman had the freedom to express himself and to decide what, how and when to draw. During the making of *Hospital Drawings of Pat*, Norman considered not only his perspective but also what he imagined would be Pat's. In the interview, at times, Norman paused to take time to laugh and cry and share some of the many thoughts, feelings, observations and memories of his lived experiences of his final days with Pat. Although Norman's emotions did not obstruct the acuity of his observations and the process of establishing clarity of vision, they did, at times, influence the choices he made in how he presented Pat.

Drawn through Norman's lens, *Hospital Drawings of Pat* articulate a deep level of concern and respect for Pat's perspective, demonstrated in not only what he chose to draw but also what he chose not to draw. As he described, "Pat actually had a [breathing] tube up her nose, with a safety pin stuck in it, to stop it going down her nose. And I missed out the safety pin, and... the tube." Norman considered what he imagined would be Pat's viewpoint and explained, "I said to the nurse you will need to find something more aesthetic than the safety pin...I really don't think that Pat would have liked a drawing of her with a tube down her nose with a safety pin to stop it." These details that Norman consciously selected to leave out demonstrate how deeply he recognized her in the process. When Pat couldn't speak for herself, Norman reflected on his historical knowledge of his wife and internally heard her voice. He responded accordingly, and, as is evidenced in the drawings, Norman exhibited high regard for Pat's perspective by honoring how she would like to be seen.

Norman conveyed, again, his awareness of Pat when he poignantly lamented being unable to show the drawings to her, saying "I have always shown everything that I have done to Pat." He stated that he thought to himself, "I can't show [the drawings] to her...[I] can't ask her what she thought of them." He even confessed, "At one point I did say, there's no point in doing them because I can't show her them." That said, Norman also considered what Pat would think about him drawing her, and concluded, "I think that she would have been surprised if I had not done the drawings." Although he recognized that Pat may never see the drawings, he knew her well enough to know how she would think or what she would say in response.

Looking back on the initial sketches, Norman chronicled, "I just wanted to make sure I could do it. And then, that gave me confidence." Norman was able to assuage his own feelings and fears by attending to the familiar and reassuring act of drawing. With each drawing, he said he "grew in confidence." Throughout the interview, Norman repeatedly referenced his desire to "do justice" to Pat and the time constraints of the situation they found themselves in. He questioned his abilities to accomplish what he had set out to do and disclosed his uncertainty about his ability to draw Pat, admitting, "I was absolutely terrified that I would not be able to do it. I was completely relieved when I found that I could do it. I thought, all I need to do is to try and do it better. But, I

wondered, under these circumstances...would I be able to do it? I was relieved to find that I could.”

Ultimately, doing the drawings created a safe and familiar place for Norman to hold Pat’s hand, communicate with her, become a witness to the end of her life and to share lived experiences with her through his art. When asked about the future role he would like to see these pictures play, Norman asserted, “I didn’t do them thinking maybe I will be able to make use of [the drawings] in any particular way.” Although he had no agenda in mind for the pictures, he did explain that while making the pictures he thought about sharing them with his son, Mark. Norman acknowledged, “While I was doing it, I thought Mark would be interested. I could visualize myself showing them to Mark” because “he wasn’t there himself so I thought well the next best thing is draw it.” Here, Norman considered the perspective of the viewer and explicitly recognized the capacity of the drawings to tell a story.

Reflection-on-action

While discussing the creative process involved in making *Hospital Drawings of Pat*, Norman expressed deep appreciation for the fact that he and Pat were given a room to themselves. Norman had a reclining chair in which he could fitfully sleep. In reference to the drawings, he stated, “I was fortunate that not only had I the ability to do them, but I also had ...a place where I could have done it. There was nobody else there.” To engage in the drawings, Norman relied on his ability and confidence as well as the time and the space with Pat and the privacy that the room presented. He noted that “The whole thing was made possible partly by the hospital, by [Pat] having a room to herself the whole week” and the fact that “the hospital didn’t bat an eyelid” and “didn’t think that this [drawing Pat] was peculiar or anything.”

Being interviewed about *Hospital Drawings of Pat* allowed Norman to reflect on the drawings and his relationship with Pat, the inspiration of so much of his work. Pat and Norman met when they were students at Glasgow School of Art, and both became art teachers. During the interview, Norman remembered an old photograph taken of Pat when she was a student, “sitting on the windowsill of a bank, drawing in a corduroy suit,” and he commented, “I can visualize her like that far easier than I can last month.” Conducting the interview created space for Norman to revisit not only pictures and memories but also the drawings and emotions related to his last days with Pat. In this way, Norman was able to create a new understanding of the experience. He described his role as an artist creating the drawings of Pat, as a husband over the course of their sixty-five years together and as a caregiver by his wife’s side in her final days.

Although it was unusual and, at times, painful to reflect on the state that Pat was in, the act of doing so gave Norman the chance to consider his experience of her last days and find appreciation for the good that they shared over their lifetime together. In the interview, Norman remembered Pat’s funeral and recounted, “It was nice that so many of her former pupils, got in touch and said what a great teacher she was. I always

knew that she thoroughly enjoyed teaching.” He stated, “We were fortunate that we were both teachers, which meant that it was easier...our holidays coincided with the children... this is how we managed to have four sons, and at the same time I could go on painting, and she could go on with her job. The whole thing worked out very well in the end.” Norman even managed to laugh a little when drawing on memories from the past and stated, “I think that the people at art school thought that they would give the marriage a week!” He said, “I hope she had a good life... There were bits of it that could have been better, I am sure.” He later added, “I realize that we had a totally loving relationship. We both appreciated each other.”

Norman reflected back on the night that Pat was admitted to the hospital and said, “[When] she went into hospital, I was told that she would only last for hours, or days. Not weeks. But she actually lasted for over a week. And the first night –I didn’t think that she would last through the night. And I sat up with her all night.” Norman described his sleepless nights in the hospital, saying, “Every time I woke up I looked to see how Pat was. After I had done that the second night, I was spending so much time during the day with her, I did have the idea of taking my sketchbook and doing some drawings of her.”

In the interview, Norman recounted how he began by tentatively drawing Pat’s hands only. He said, “I did the usual absolute line drawings that I always do. Her hands...and her head were out of the sheets...But the one [hand] that the stroke had affected pretty well remained in the same position all the time for the whole week. Even when the nurses turned her round the other way, her hand more or less remained the same.” Norman described the drawing of Pat’s hands as “terribly evocative.” Pat’s stroke affected her right side, and this can be seen in the sensitive rendering of limpness of her right hand (Fig. 6). As Norman narrated the process of creating the drawings, he detailed how he interacted with Pat and recalled that “the hand that... wasn’t paralyzed was the one that [she] could move.” He fondly recounted this, saying, “For the first two days that she was in the hospital, if I squeezed her hand she squeezed mine back.” He reminisced, “I used to talk to Pat all the time. Even when I wasn’t beside her I used to talk to her.” He said, “She never moved her head. And, her mouth was invariably open ...and sometimes her breathing got faster and faster and faster. And I thought ‘This is what’s going to happen.’ She’s going to just get faster and faster and faster –and that’s how she’s going to end.” He shared, “I thought that she can’t keep that up for long...there were a whole lot of false alarms, where we thought that she was dying, and she didn’t.”

In the interview, Norman was able to describe vividly his memory of Pat’s last moments and how he was compelled to draw Pat one last time, immediately after she died. Norman explained “At the end, I was sitting in the chair beside her, and I was covered up with the hospital blanket. And, I woke up at about two o’clock in the morning, and felt her arm. And it was colder than usual. And I looked at her chest, and it was going up and down slowly. So I knew she wasn’t dead or anything. But then I

looked at her mouth. Her mouth was really closed compared with what it usually was. But she was still breathing, but very slowly. And, then I started counting between each breath. And she would breathe, and then I could count, one, two, three, up to ten before she would take another breath. So that there were long gaps between each breath...I sat doing that for about fifteen or twenty minutes. Just counting between each breath. And then the last breath...she just took a breath and then there was a wee gurgle...and then there were no more breaths after that. And, I thought I've drawn her in every position up until now, so I will need to draw her this way too. And, I did. So the first thing I did after she died...was draw her again."

Reflecting on his own drawing of his dead father, the writer and artist John Berger stated, "people talk of freshness of vision, of the intensity of seeing for the first time, but the intensity of seeing for the last time is, I believe, greater" (1976, 81). Looking at this final drawing of Pat, the viewer can witness a haunting otherness and awkwardness in what Norman saw; this image attests to the 'intensity' and urgency of Norman's own struggle to give form to what he saw and felt (Fig. 7). This final drawing is less detailed and perhaps less assured than the others. Pat's eyes remain slightly open and are rendered with the tiniest of dots. Her ambiguous expression is notably different from the prior drawings. She seems almost content, at peace. It is unlikely that those who knew Pat would recognize her in this final drawing. This drawing is different than the others in *Hospital Drawings of Pat*. There is a notable shift; she is no longer alive. The drawing is a testament to Norman's attempt to express and record what happened, what he witnessed, what he felt and how he struggled to weave these together into his own aesthetic whole.

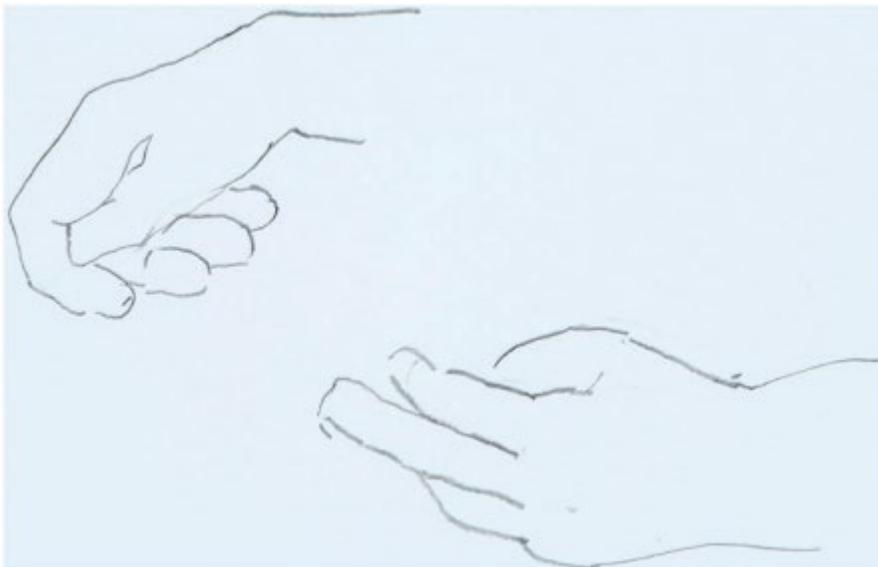


Fig. 6 Hands (Pat), Pencil on Paper 2016

Norman's experience of Pat's death is intimately connected to all that he witnessed not only as a husband and caregiver but also as an artist. When asked to

speak to the final drawing of Pat, Norman acknowledged, “It’s not the best drawing...but perhaps it’s got a significance that the others haven’t.” Here, Norman explains that he sees the drawing as not only a work of art but also a reflection of the loss of his wife and the end of their battle with Alzheimer’s disease. Reflecting on the final picture, Norman said, “I didn’t say to myself ‘it’s not a very good drawing. I’ll try again.’ I could have done that. But, I didn’t. I thought...I am not trying to do a sort of academic drawing.” Norman was simply being present with what was, non-judgmentally witnessing the end of Pat’s life and mindfully respecting what he saw before him and what came from within him. The process of reflecting on the pictures stimulated analysis of the life he shared with Pat, calling him to consider further the role that he played as her caregiver and the many roles that she played over the course of their life together. Norman said, “The Alzheimer’s didn’t have the effect that I think that it could have had because she felt secure. I actually think that anybody in her position needs to feel secure.”

In analyzing both the drawings and the interview, it is evident that Norman learned from the process of drawing. He, himself, explained, “I draw...and learn from what I have just drawn. So that the next time I have come to do it, it should be a bit better as I have learned from what I did last.” Looking back, Norman recognized how the context surrounding Hospital Drawings of Pat informed his perceptions, stating, “They are probably not the best drawings that I have ever done...I don’t know. But, probably, they are the most significant, in a way, drawings I have ever done, just because of the subject matter.”



Fig. 7 Final Drawing of Pat, Pencil on Paper 2016

Conclusion

Norman's personal process of reflection is dynamic and truly unique to the story that he and Pat share. Nonetheless, a closer look at his account of the week he spent in the hospital with Pat can highlight the potential impacts of creating space for the visual arts in end of life and bereavement experiences. Reviewing good memories and finding some satisfaction in the story he shared with Pat may have allowed Norman more space to accept Pat's death. In the interview, Norman said, "I suppose, I'd known that she wasn't going to recover. I didn't want ... her to go on in the state that she was in." As he explained, "there was a certain amount of relief that it could not go on...it had to end. And I was glad it had ended...for her sake, as well as for the rest of us. I wouldn't have liked her to stay on like that."

When asked about the resultant collection of drawings, Norman said, "I'll always keep them...I don't know how often I will look at them...It just reminds me. But, I will never forget. I don't need to be reminded." As he revealed in the interview, "I am glad I did them. Absolutely." In the initial days after returning home from the hospital, referencing *Hospital Drawings of Pat*, Norman said, "I look at them most days...I wish that I could go back and do more of them." Although he cannot return to that week in the hospital, he has returned to the studio and art practice that carried him through that week. In reflecting on the drawings, Norman said, "I am just trying to get on with my work now. And I think that is the best thing that I can do." Ultimately, Norman created the pictures more for the process than the product. When describing the drawings he did in the hospital with Pat, Norman said, "It actually took my mind off completely what I was doing. I mean...one of the doctors did come in...and saw that I was drawing, and I said, 'It is alright. It just keeps me sane.'" In trying to explain why he did the pictures, Norman said, "It was partly to give myself something to do. And partly because I knew I could do it. And partly because...it kept me sane. And I did forget...the circumstances I was in while I was doing them. And that was a sort of... relief." His reflections surrounding *Hospital Drawings of Pat* and his engagement in their creation, inspired growth, transformation and healing. Ultimately, as is demonstrated in Norman's story, engaging in reflective practices, making *and* viewing drawings like these, can bring some relief during difficult times.

End of life drawings have the capacity to transform what is initially a private experience of the patient and artist or caregiver into a shared, more public experience. In the case of *Hospital Drawings of Pat*, Norman has invited others into his story and offered up a deeper level of comprehension of dementia, end of life and bereavement. Death and loss are significant themes in all the arts and when we engage with images depicting illness and the end of life, we are invited to consider what we may fear most (O'Connor, Schatzberger & Payne 2003; Lange 2014; Townsend 2008; Bolton 2008). The arts, in all their forms, have the capacity to inspire reflection and engage not only artists but also viewers and listeners in transformative experiences that can be positive, instructive, constructive and even beautiful or sublime. Works such as *Hospital*

Drawings of Pat encourage us to reflect on our own stories and experiences of loss and bereavement. Like Norman, we can engage with these drawings and turn what many find most challenging and harrowing into an opportunity for reflection, growth and transformation.

Reflecting on the pictures brought up many different memories for Norman. Norman recollected, “We had been married for sixty-five years, and she died the day after our anniversary. We were married on the second of August and she died on the third.” *Hospital Drawings of Pat* are a visual elegy that express feelings and tell pieces of their story that honor Pat and the resilient and loving relationship she shared with Norman. Far from ending her story and their life with each other, the drawings sustain the life they have together. Through the drawing, Norman expresses himself as one part of a loving partnership that took a number of forms. Just as their interdependence is evident in their roles as artist and sitter, offering care and support from both sides of the easel, a great level of compassion and mutuality is apparent in their relationship as husband and wife and latterly as partners in care as Pat’s dementia progressed. As such, the drawings are a testament to the fluid roles that we are all asked to play at some point in our lives when we care for those we love and fall ill ourselves.

The diagnosis and treatment of Alzheimer’s disease is associated with physical and psychological distress for both patients’ and their caregivers. At a time when the ability to tell one’s story may be compromised, it can be healing to create a form for one’s experience that can engage and invite us all to deeply inquire into our own thoughts and feelings and allow us to validate aspects of our own experience and the stories they engender. Norman’s drawings of Pat can form the basis for a powerful contribution to the public and professional understanding of the relationships needed for caring for someone with dementia and specifically to understanding how people with dementia die and how that impacts those people who love and care for them. We may perceive that someone living with dementia or in their final days as having lost so much that they have nothing left to give; something as powerful as Norman Gilbert’s *Hospital Drawings of Pat*, can prove that notion wrong.

If thoughtfully presented, Norman’s drawings can inform care provider education. The drawings enable all viewers to build their own picture, and they can help health professionals engage in their own reflections and re-assess the care they provide for people experiencing illness, their carers and those who are facing the end of their life or that of a loved one and those recently bereaved. As Rita Charon described, “reflective practitioners can identify and interpret their own emotional responses to patients, can make sense of their own life journeys, and so can grant what is called for – and called forth- in facing sick and dying patients” (2001, 1899). This practice, according to Charon, “can help physicians offer accurate, engaged, authentic and effective care” to the sick and dying (1901). The loving and caring regard that created *Hospital Drawings of Pat* can engender a greater comfort in students and physicians, by opening them up

to the rewards and challenges of being with someone at the end of their life when all other medical options have been rendered redundant.

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Compliance With Ethical Standards

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

This article does not contain any studies with animals performed by any of the authors.

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Mr. Norman Gilbert submitted a letter of consent for the Journal to publish his images/artwork.

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