



PROJECT MUSE®

Choosing Disability, Visualizing Care

Rachel Adams

Kennedy Institute of Ethics Journal, Volume 27, Number 2, June 2017, pp. 301-321 (Article)

Published by Johns Hopkins University Press

DOI: <https://doi.org/10.1353/ken.2017.0019>



➔ *For additional information about this article*

<https://muse.jhu.edu/article/665109>

Choosing Disability, Visualizing Care

ABSTRACT. This article explores how visual images of dependency and care reflect and reinforce perceptions of people who are ill, disabled, or otherwise dependent, those who sustain them, and the meaning of the work they do. Scenes of care are a valuable index for understanding cultural assumptions about who is deserving of care, how and where care should be given, and who is obligated to serve as a giver of care. It positions these images in the context of the emphasis, within the disability rights movement, on independence. I argue that the insistence on independence entails a form of what Lauren Berlant calls “cruel optimism”—desire for the very things that undermine happiness and well-being—because they rely on a willful disregard of the inevitable *interdependency* that is a fact of all human existence, as well as the particular forms of dependency that pertain to many disabled bodies. The end of the article considers works of visual art that challenge dominant modes for representing how care is given and received. If the invisibility of caregiving is one aspect of our willful forgetting that all bodies are dependent, I’ll argue that visual images of care are an essential resource for recognizing and reimagining its status in our society. One desired outcome of such reconsideration would be to complicate the meaning of autonomy—as it relates to choosing disability—as well as how the work of caregiving is acknowledged and valued.

Hanging in the National Portrait Gallery in Washington DC is a painting of Christopher Reeve in a massive power wheelchair. Where we might expect it to prioritize face and torso, instead it brings Reeve’s lower legs and feet to the foreground so that his knees and shins appear monumental. Rosemarie Garland-Thomson has praised artist Sacha Newley for conferring his subject with “dignity and authority” (Garland-Thomson 2010). To her, Reeve is a regal figure, his wheelchair a “throne,” his respirator and shaved head appearing fashionable and restrained. Where portraits have traditionally sought to conceal bodily difference, Garland-Thomson commends this painting for making its subject’s

difference visible without stigma. Its placement in the National Portrait Gallery bespeaks a positive shift in cultural attitudes toward disability.

The Reeve portrait makes a powerful statement about “choosing disability,” the theme of this special issue. Although Reeve himself was more concerned with curing spinal cord injury than disability rights, his public stature after the 1995 accident that left him quadriplegic signaled a new willingness to accept and accommodate people with disabilities. In the decade after Reeve’s injury—five years after the passage of the Americans with Disabilities Act—positive developments in the law, medical care, adaptive technology, and social attitudes made choosing disability a more realistic and livable prospect than perhaps ever before. Within bioethics, “choosing disability” typically refers to prenatal selection. I am going to use this concept more broadly, taking it to mean something akin to Simi Linton’s notion of “claiming disability,” living openly with and accepting disability as a valued form of diversity, and working to make the world better for people with disabilities (Linton 1998). My discussion of choosing disability involves an understanding that many people with disabilities suffer more from limitations in their physical and social environment than the configuration of their bodies and minds and, as a corrective, call for the right to self-determination, to make autonomous choices—whenever possible—about the care they receive, where they will live, work, and socialize.

These commitments are reflected in Newley’s portrait. But I am as interested in those aspects of Reeve’s disability that are hidden by the painting as by those it reveals. Reeve may be regal, but royal bodies, regardless of ability, do not care for themselves. When I look at this picture, I wonder: where are Reeve’s attendants? Where are the assistants who clean, arrange, and dress him every day? Where are the therapists who massage his body, work his muscles, maintain his lung capacity, and posture? The technologists who service his wheelchair? The home health aides who complete his bowel program? If, as Garland-Thomson perceives, this portrait bespeaks Reeve’s elite status, one aspect of that privilege is an erasure of what Eva Feder Kittay calls “dependency work,” the labor of caregiving that goes into ensuring his comfort and well-being (Kittay 1999). In order for Reeve to sit as a well-composed, independent subject, his dependency—and the efforts of those who sustain him—must be invisible.

Sometimes we desire the very things that undermine our happiness and well-being, a phenomenon Lauren Berlant calls “cruel optimism” (2011).

This is an apt term to describe the demand for independence that has been so central to the contemporary movement for disability rights. In a culture that places a premium on individual autonomy, it makes sense that independent living has so often been elevated above other goals. Instead of being warehoused in institutions where their lives were dictated by others, people with disabilities demanded the right to live and work within their own communities. In cases where support was required, they demanded autonomy, the right to make choices about the circumstances of their own care. While many positive changes have come from these demands, they entail a form of cruel optimism because they rely on a willful disregard of the inevitable *interdependency* that is a fact of all human existence, as well as the particular forms of dependency that pertain to many disabled bodies. When independence becomes a prerequisite for “choosing disability” it risks undermining the well-being of many people with disabilities and those who care for them.

As long as freedom of choice remains a paramount goal, the movements for the rights of patients and people with disabilities will rely on a form of cruel optimism that ensures that the most dependent subjects, as well as those who care for them, will remain politically and socially marginalized, while somewhat less dependent subjects will be motivated to deny the fact of their own interdependence and the personhood of those who work to sustain them. Cruel optimism is not about a conscious mentality, but an affective state that includes gestures, expressions, and involuntary responses such as disgust and desire (Berlant 2011; Cartwright 2015). In order to understand how we got into this situation of desiring illusory forms of autonomy it is helpful to turn to visual representations, which offer insight about the imaginative life of a culture. The visual cultures of the United States and Western Europe provide a rich documentary history of how we have envisioned dependency and dependency work.

Critics such as Tobin Siebers and Michael Davidson have argued that aesthetics has a close connection to our perceptions of and feelings about disability (Siebers 2010; Davidson 2015). In Siebers’s words, aesthetics tracks “the sensations that some bodies feel in the presence of other bodies” (2010, 1). From this vantage, art offers a rich repository of evidence about which bodies have been considered beautiful, and which have been sources of loathing and repulsion. Because aesthetics traffics in the realm of feelings, it offers a purchase on the submerged fantasies, desires, and anxieties that underlie our perceptions of bodies in states of dependency and those who care for them.

In what follows, I survey some of the aesthetic traditions that inform the Newley portrait, to consider how a long history of visual images of dependency and care reflects and reinforces perceptions of people who are ill, disabled, or otherwise dependent, those who sustain them, and the meaning of the work they do. Scenes of care are a valuable index for understanding cultural assumptions about who is deserving of care, how and where care should be given, and who is obligated to serve as a giver of care. Space does not allow for a comprehensive historical survey; rather I will offer a sampling of images from across the centuries, selected because they represent influential and enduring tendencies. My mashup focuses on three social roles that make the gendered, racialized, and class-based aspects of caregiving relations particularly visible: mothers, nurses, and paid caregivers. I will discuss the traditional visual rhetorics that have been used to represent these figures, as well as how representations of children, the elderly, ill, and disabled showcase the disparities between what Jackie Leach Scully calls “permitted dependencies” and those that are pathological (2008, 164). From there, I will consider some work that challenges and seeks to reconfigure dominant modes for representing how care is given and received. If the invisibility of caregiving is one aspect of our willful forgetting that all bodies are dependent, I’ll argue that visual images of care are an essential resource for recognizing and reimagining its status in our society. One desired outcome of such reconsideration would be to complicate the meaning of autonomy—as it relates to choosing disability—as well as how the work of caregiving is acknowledged and valued.

MOTHERS AND OTHERS

In Edvard Munch’s 1897–99 painting, *Dead Mother and Child*, a female corpse lies in bed, its wasted body the same sickly, translucent yellow as the bedclothes that cover it. Indistinct figures clad in somber colors hover in the background, their shoulders hunched in grief. The viewer’s attention is directed to the foreground, where a girl in a red dress stares out at the viewer, her pose—hands clasping her cheeks, eyes and mouth wide with shock—evoking Munch’s more well-known painting, *The Scream*. Munch’s image attests to the horrifying vacancy left by the mother’s passing. The child’s expression communicates a tragic reversal in which the vulnerability of the person designated to care for her has been exposed. The emotional tenor of this painting is all the weightier given the long history of images

in which mothers are visually defined by their capacity to nurture others and children by their need for care.

The equation of mothers with nurturance has been enshrined in western art for many centuries. Paintings of mothers naturalize the association of femininity with care, and position maternity as definitive of a woman's identity. Unless they are elderly, mothers in visual art are almost synonymous with images of caregiving. Feminist philosophers have attempted to reclaim this tradition by holding up the mother-child bond as a model for caregiving relations (Gilligan 1982; Noddings 1982, 2002; Ruddick 1989; Tronto 1994). For example, Sara Ruddick asks whether "some practices of mothering" might be the basis for a politics of nonviolence and proposes the notion of "maternal thinking" as a way to recognize and revalue the intellectual and physical work of caregiving (1989). Eva Feder Kittay offers the concept that we are all "some mother's child" as a more just alternative to the social contract (1999). Where the social contract equates personhood with reason and autonomy, thereby excluding those who lack the capacity for independent agency, Kittay's model points to our universal origins and the fundamental caring relations required to sustain human life. Instead of valuing relations based on mutual self-interest, it looks to relationships "forged through the care of a vulnerable dependent, and to the value that this relation imparts both to the one cared for and to the caregiver" (Kittay 1999, 25). There is much to be said in favor of these models, which seek to make visible the worth and meaning of women's work and to elevate the value of caregiving. However, such thinking may also reinforce the status obligation of motherhood, the assumption that mothers are naturally and universally inclined to care simply by virtue of being mothers, thereby constraining the autonomy of women to make choices about how and if they will engage in the work of caregiving (Glenn 2012; Gouldner 1960).

From Christian portraits of Madonna and child to the impressionist scenes of Renoir, Morisot, and Cassat, in visual art caregiving is what defines a woman as a mother and motherhood, or its potential, is what gives a female an attractive womanliness. These virtues stand in opposition to virginal girlishness or agedness, the only two stages of life where women are not expected to mother. (Think, for example, of the elderly subject of James McNeil Whistler's famous 1871 portrait of his mother, who poses alone because she has already finished raising her son to become a successful artist. Her solitude, combined with the painting's somber tones, conveys a sense of exhausted purpose.)

Even as styles shift across the centuries, paintings of mothers are immediately recognizable through a consistent visual rhetoric. In Christian art, the Madonna is typically seated, gently holding the baby Jesus on her lap. Sometimes she clasps him to her breast and nestles her head gently on his. In others he perches on her lap, gazing up at her. Later artists echo the conventions of Christian aesthetic tradition, granting a sacred quality to secular depictions of mothering. Here, interdependence is sanctioned and even idealized. In the warm pastels of Mary Cassat's *Mother and Child* (1890), a woman dressed in a flowing print dress cradles a child on her lap. She looks adoringly downward, while the child leans back against the mother's shoulder and gently touches her face. Pierre-August Renoir's *Mother and Child* (1910) employs a similar palette to show the interconnection of its subjects. The mother rests one hand on the child's knee, the other curled around his back. Her ample, rounded figure suggests lush fertility, one breast exposed almost to the nipple evoking its role in nourishing the child. Images of children receiving maternal care are comfortable and pleasing since they depict a stage of life characterized by permitted dependencies. Children delight in being cared for and mothers, bound by their status as wives, women, and parents, take joy in the obligation to care. There is no corresponding visual tradition to suggest that mothers too need and desire to be cared for. Indeed, the Munch painting suggests the horrifying absence left when this expected social order is violated by a mother's illness, disability, or death.

Another horrific paradox is presented by mothers who neglect or harm their children. Perhaps the most well-known of such figures in western art is Medea, the mythic sorceress who murdered her children after her husband, Jason, left her for another woman. Paintings by Eugene Delacroix (1838), Frederick Sandys (1868), Aimé Nicolas Morot (1876), Henri Klagmann (1868), Victor Mottez (1809–1897), Corrado Giaquinto (1750–52), and Paul Cézanne (1879–1882) depict Medea with breasts bared, either just before or immediately after the murder. In some, she brandishes a sword or dagger, the phallic blade and slain children contrasting with the womanly body supposed to provide comfort and nurture.

A deviation from the rule that mothers must be the givers, rather than the receivers, of care comes in cases of exceptional wealth and privilege. Mothers of the milieu depicted by Renoir and Cassat often had servants to help with the work of caring for children. Motherhood oppresses Emma Ponteliev, protagonist of Kate Chopin's novel about the stultifying constraints of bourgeois white womanhood, *The Awakening* (Chopin

1899). But readers will notice that most of the labor of raising her children is done by a nanny simply referred to as “the Octoroon.” In the popular TV show *Downton Abbey*, children of lords and ladies are brought out to be admired and petted by their mothers, leaving the work of cleaning, nourishing, or disciplining to servants. The painting *Le baiser enfantin* (1865), by the French artist Jacques Eugène-Fayen, idealizes the servant as caregiver. It depicts a child sitting on the lap of a white woman being kissed by a second child in the arms of a smiling black nanny. The pale color of the white woman’s shirt ties her visually to the two white children, who wear white dresses, while the black woman is set apart by her dark skin and more colorful clothes. The expression of her face and body suggests that she is at ease and takes pleasure in the activities of caregiving. A similar figure appears in two paintings by the American Lee Green Richards, *Nanny Holding a Baby* (1911) and *Nanny with Child in a Garden* (1912). In the first, the black nanny peers down at an infant cradled gently on her lap. In the second, she helps a slightly older child toddle around a lawn. No mother is visible; she has been freed, we might imagine, to realize herself in some way other than tending to this child’s needs.

While women do the lion’s share of dependency work, only the most affluent are recognized as needing care. Take for example Edouard Manet’s 1893 *Olympia*, depicting a white woman—believed to be a high-class sex worker—lying nude on an unmade bed, while a black servant stands at her side proffering a bouquet of flowers. Olympia profits by servicing men, but she also receives the services of a lower-status caregiver. A higher status elite did no work at all. Before the twentieth century, the dependency of queens, nobles, and wealthy women was affirmed and even required. Status was defined by being cared for by others. Paintings depict such women at their toilette assisted by at least one servant. William Faulkner’s fiction depicts how antebellum southern culture put white women into a situation of forced dependency. Upon her death, Ellen Sutpen in *Absalom, Absalom* is described as having “now served her purpose, completed the bright pointless noon and afternoon of the butterfly’s summer and vanished” (Faulkner 1966, 94). Valued for being attractive and delicate as a butterfly, Ellen and others of her ilk are reliant on slaves to maintain their bodies and households.

Another less welcome, but recognized, category of dependency is illness, often associated with an effeminate weakness and vulnerability. Throughout much of human history, sick and disabled people were cared for in the home by family, friends, neighbors, and servants. Hospitals run

by religious orders also served the sick and poor. The work of nursing was frequently performed by nuns. Beginning in the nineteenth century, hospital care became more common and more professionalized. In the United States, professional training programs began to appear around the time of the Civil War, when large numbers of wounded soldiers created a demand for skilled nurses. As nursing was transformed into a profession, early schools exclusively admitted women, thus reinforcing the gendered labor of caring for the sick. “The study of the history of nursing serves as one vehicle with which to study the history of women,” write Chad E. O’Lynn and Russell E. Tranbarger, calling attention to the equation of nursing with femininity in their book, *Men in Nursing*. “Nursing serves as a visible example of the valuable contributions women have made, as well as revealing a vestige of the discriminatory gendered roles forced onto women” (O’Lynn and Tranbarger 2006, 4). Because of its association with femininity, nursing is also one of the primary ways women’s professional lives have been tied to dependency work. Even today, men dominate healthcare as doctors and researchers, while women track into less prestigious careers as nurses and home health aids.

The gendered history of caring for the sick is visible in western art. By linking caregiving to illness, and associating illness with the sickroom or the hospital, paintings of nurses confine dependency to particular times, places, and subjects. In visual art, the nurse is defined by her femininity and her participation in caregiving activities. She is also assumed to be healthy and able-bodied, qualities that designate her a giver, rather than receiver, of care. For example, the nurse in Victor Tardieu’s impressionist painting of a World War I field hospital, *The Duchess and the Soldier* (1905) stands erect, wearing a flowing white uniform that connotes her professional status as male patients lie passively in bed waiting for her care.

The association of nurses with wartime is similarly evident in paintings by the Harlem Renaissance artist, William Johnson, such as *Red Cross Nurses Handing Out Wool* (1942). There, nurses administer care more indirectly by dispensing wool to be knit into garments for soldiers on the front. Alice Neel’s drawing, *City Hospital* (1954), shows a more intimate scene of care in which a nurse gazes compassionately at her patient, resting one hand on her brow, the other on her chest. Nurses in the work of Neel and Johnson are black, drawing attention to the racialization, as well as the gendering, of caregiving. Since the era of slavery, black women have been channeled into dependency work, although professional nursing remained segregated until the late twentieth century. Today, the deinstitutionalization

of people with disabilities and changes in the healthcare system have moved more nursing work back to the home. As Welfare Reform of the 1990s drove many women of color into the workplace, they came to dominate the home health aid profession (Hiltonsmith 2014). Increasingly, African-Americans refused to do this work and it was passed along to lower-status immigrants and other women of color (Glenn 2012). These women, whose work is poorly compensated and physically and emotionally demanding are, to this point, largely absent from the visual arts.

To be sure, in western art nurses are not alone in caring for the sick. There are also noteworthy paintings of doctors (almost always male) directly engaged in acts of care. In a fifteenth-century fresco by Domenico di Bartolo the doctor kneels on the ground as he washes the feet of his seated patient, reenacting Jesus' humility before his disciples on the eve of the Crucifixion. In Francisco de Goya's *Self-Portrait with Doctor Arrieta* (1820), the artist reclines weakly against his physician, who gently encourages him to drink. Louis Hersent's late eighteenth-century painting, *Marie Francois Xavier Bichat Dying Surrounded by the Doctors Esparon and Philibert Joseph Roux*, shows a doctor stroking his patient's forehead, while another sits at his bedside. The doctor in Sir Luke Fildes's well-known 1891 painting sits attentively at the bedside of a sick child, the mother comforted by her husband in the background. Both men in this image are nurturing and compassionate toward the woman and child in need.

But it is more common in western art to see doctors contemplate, research, examine, opine, or operate. Where the nurse's identity is defined by caregiving, paintings of doctors remind us that care is only one aspect of the medical profession, one that, today, is rarely seen as a doctor's work. In *The Anatomy Lesson of Dr. Nicolaes Tulp* by Rembrandt (1632), the doctor lectures at the side of a partially dissected cadaver as a group of students listen eagerly. A seventeenth-century painting by Johann Cordua depicts a doctor surrounded by the accouterments of his profession: an open book, a skull, instruments, and a beaker filled with fluid. The subject of Thomas Eakins's 1895 *Portrait of Doctor Samuel E. Gross* stands confidently amidst a team of colleagues operating on a patient's thigh, using a new procedure he has developed to treat bone infections. While the doctors appear absorbed in their work, a woman sits in the background shielding her eyes from the grisly procedure. Men attend to the immediate business of healing, while their more empathic female counterpart registers the suffering and horror of the operating theater.

While the participants in and practices of caregiving vary across cultures and historical periods, together these images of mothers, servants, nurses, and doctors reinforce a number of widely shared assumptions about giving and receiving care. The first is remarkable in its absence. Returning to the painting of Reeve, we can see that even as it makes disability visible, it also belongs to a long history of erasing the assistance that allows its subject to thrive. In portraiture, the signs of disability are rare; the signs of dependency and dependency workers are virtually invisible, except in scenes of nursing and mothering. Second, caregiving is almost always women's work, and, in the case of mothers and nurses, womanliness is defined by the provision of gentle, compassionate care. Third, we see that caregiving is racialized. During some historical periods, women of color were assumed to have a natural aptitude for nurture, although in others their perceived inadequacy made them the targets of social reform designed to improve their caregiving skills (Glenn 2012). Fourth, these images confine dependency to particular places, status positions, and stages of life. When children are the recipients of care, dependency is depicted as natural and right. The same is true for wealthy elites who relied on servants for their bodily care. Other forms of adult dependency are pathological, and therefore confined to hospitals and sickrooms. Finally, these images create an opposition between givers and receivers of care, suggesting that a person may occupy only one side of this divide. There is little intimation of the physical and emotional tolls of dependency work that might diminish the well-being of caregivers, nor of the contexts in which dependents might also serve as givers of care.

This brief survey is meant to establish some of the more traditional ways visual artists have pictured embodiment, dependency, and care. Visual culture may reinforce received ways of seeing, making familiar identities and actions seem timeless and natural. It may solidify our comfort at seeing dependency confined to particular subjects and spaces, and dependency work performed by particular kinds of caregivers. But it also has the potential to challenge familiar truths by helping viewers to see the world differently. Since the era of modernism, Michael Davidson observes, artists have used disability to “make strange” assumptions so engrained into the everyday world that they become invisible. “Aesthetic defamiliarization and disability deconstruction are joined by their critique of mimesis—the idea that there is a putatively ‘real,’ ‘given’ world that must be represented and cited,” he writes. “When art foregrounds its own operations, when disability unsettles the normative body, mimetic criteria are shattered

and the means of aesthetic and social reproduction exposed” (Davidson 2015, 28). Art can aspire to reflect the world around it, but it can also make the world look different in order to illuminate its otherwise unseen operations. Throughout the history of western art there are doubtless images that challenge the visual iconography of giving and receiving care that I have identified here; however, in what follows I focus on a series of contemporary artists who use modernist techniques of defamiliarization to expose the cruel optimism of the demand for independence that often goes hand in hand with the more affirming aspects of choosing disability. They do so by exposing forms of vulnerability and dependency that portraiture and related visual genres often conceal, by challenging core assumptions about how care should be administered and by whom, and by seeking to dignify social roles that have long been viewed as abject and unsightly.

In a culture that values individual freedom of choice, the agency of women and people of color is evacuated by an aesthetic tradition that suggests their identities are defined by either a natural predisposition or a structural obligation to care and nurture. How can one choose to be a caregiver if it is always already assumed that is what you are? How can one make a claim to deserve care if one’s status as caregiver seems to preclude also being a recipient of care? And what happens when women and other expected caregivers refuse to buy in? One answer is offered by images of what I call the “bad caregivers,” which defamiliarize the social roles and practices associated with dependency work.

In her 1992 project, *Immediate Family*, photographer Sally Mann violates the powerful association of mothers with caregiving by abandoning her post as protector and helper to get behind the camera. Some images in Mann’s series deliberately call attention to her absence, such as a photograph of her sons lying on the ground, shot from above, one with a nosebleed that runs down his chin and stains his shirt. Seeing this photo of Mann’s bloody child, viewers expressed shock that her first reaction would be to take a picture rather than tend to his needs. Other images raise similar questions: Mann’s children nude, their poses suggesting a combination of eroticism and vulnerability; her tween daughter staring confrontationally at the camera, a cigarette dangling from her fingers; children playing naked at a picnic, surrounded by blankets, coolers, and cast-off clothes. In some photographs, children are gazed at or caressed by adults in poses that seem to invite a pedophilic gaze. Where is their mother? These images provoke us to ask. A savvy commentator on her

own work, Mann responds by asking why we assume these children to be vulnerable, and their mother to blame.

Mann insists on the status of her project as *art*, accusing her critics of confusing it with reality (Mann 2015). When they described her work as “manipulative,” “sick,” “twisted,” and “vulgar,” Mann responded by defending its power to make strange scenes of dependency and care. She explained that many seemingly spontaneous snapshots were posed with the knowing participation of her children, who also consented to have their portraits exhibited to the public. Only a naïve viewer would believe these scenes just happened, Mann writes. Her accomplishment lies in making portraits that *look* unposed and immediate. Her art is anything but naïve, restaging the conventions of documentary to draw attention to the fact that photography—even the most spontaneous snapshot—never simply captures reality but instead is shaped by choices of timing, composition, and editing. Rather than reflecting bad caregiving, these photographs defamiliarize it, inviting viewers to confront their expectations about the proper roles for adults and children, creators and subjects of art.

Mann also insists that her status as an artist is distinct from her social identity as a parent and caregiver. To be a mother need not be an exclusive and all-encompassing occupation, and to be an artist need not mean compromising her children’s care. “For all the righteous concern people expressed about the welfare of my children,” Mann writes, “what most of them failed to understand was that taking those pictures was an act separate from mothering” (Mann 2015). *Immediate Family* thus forces viewers to reconsider their assumptions about motherhood, the female artist, and the gendering of care.

Mann is also concerned with the agency of her subjects. Attributing to her children a clear understanding of the difference between art and reality, she establishes their capacity to consent to pose and to have their images displayed to the public. Her project raises questions about whether she is empowering her children to make their own choices, or simply exploiting them. Similar questions about consent have been debated by bioethicists, who observe the cognitive maturity of children with chronic or life-threatening illnesses. Although they are not legally entitled to consent, their greater understanding is used to justify the argument that their wishes should be taken into account in decisions about treatment and care. Similarly, Mann suggests that children who willingly participate in the creative process have a mature understanding of representation. In this, she asks viewers to rethink what it means to be dependent. Should

consent be determined on the basis of age alone, or should other factors such as experience and understanding be taken into account? She insists that her children are not passive and naïve, but knowing collaborators. Seen in this new light, she is not a bad caregiver at all but rather one who expands her children's horizons by recognizing unacknowledged depths of comprehension and granting them the right to make choices, even risky ones.

There is no such redemption for bad caregivers in the work of artist Kara Walker, whose trademark silhouettes draw attention to the racialization, as well as gendering, of caregiving. Where Mann challenges the association of mothers with a selfless and nurturing care, Walker's work is a rejoinder to an aesthetic tradition that has naturalized black women's labor or rendered it invisible. Walker asks what would happen if the gentle, smiling black women like those pictured by Eugene-Feyen or Richards were to erupt into violent rage at the subordination of their needs. Instead of offering affection and nurture, Walker's caregiving figures are neglectful, abusive, and visibly oppressed. In her series "Emancipation Approximation" (2000), a black female silhouette bends under the weight of a white figure wearing an enormous gown. This image literalizes the burden of a system that makes some women responsible for cleaning, grooming, and maintaining the health of others. Walker suggests that neither party is well served by this arrangement: the white woman is rendered immobile by her massive dress, while the black woman bends under the weight of her load. In another untitled silhouette, a black mammy holds one of her charges upside-down, his legs kicking in the air while vomit spews from his mouth into the outstretched hand of a girl standing below. Instead of cleaning and nurturing, the mammy rebels by dirtying and sickening the children under her care.

Another kind of untoward caregiver is the subject of Richard Prince's nurse paintings. Inspired by the covers of pulp novels from the 1950s and 60s, Prince's series draws attention to the erotics of dependency work. As we have seen, more traditional paintings of nurses work strenuously to banish the suggestion that desire might play a part in caregiving scenarios. But when bodies are vulnerable, exposed, and in need of attentions that may be tender, intimate, soothing, or painful, how can desire *not* sometimes be present? Indeed, the nurse has long been a figure of sexual fantasy (Melosh 1982; Fiedler 1988). Think of the many stories of men who love and desire their caregivers, from *Jane Eyre* to *Coming Home* to *Me Before You*. The cover photo of the November 1983 *Playboy*, which features

Christie Brinkley posing in a white uniform, immediately reads as sexy because it evokes a tradition of seeing nurses as figures of erotic desire.

Prince's nurses are beautiful yet removed, their faces alluring and mysterious because they are partly hidden behind masks. Sometimes their bodies are clothed in familiar—if exceptionally form-fitting—white uniforms and aprons; in others the clothes are ripped open to disclose sexy, lingerie-clad figures beneath. Color runs down the surface of the paintings, suggesting the nurse's proximity to various kinds of bodily fluids. Although these nurses wear the uniform of their profession, it is notable that Prince never shows them in the act of caretaking. He focuses on how the nurse's body becomes available as a subject of campy erotic fantasy, not the work it does to care for others. Like Mann, Prince uses techniques of defamiliarization that invite us to consider how caregiving is gendered, but also how it may be eroticized. Is the sexy nurse a bad caregiver because she exploits the vulnerability of her patients, or is she providing precisely the forms of care that are needed but obscured by the mistaken belief that those who are ill and disabled lack sexual desire? These women's expressions of agency and self-possession are both disturbing and titillating, since they make viewers aware of how the nurse's body and desires are implicated in scenarios where caregivers are assumed to be selfless and diffident.

Images of bad mothers, nurses, and nannies make strange a visual tradition that naturalizes the physical and emotional work of caregiving. A second category of revisionist images attempts to defamiliarize by restoring personhood that may be lost or diminished in the process of giving and receiving care, particularly in medical settings. In her 2016 memoir about becoming quadriplegic, *Body Undone*, Christina Crosby describes the imbalance of power and knowledge between caregiver and dependent. Of her Home Health Aide, she writes, "I know a lot about Donna, yet her life remains, in many regards, unknown to me and unknowable. She works *for* me, in *my* home, and has to learn *my* ways and the ways of *my* household" (Crosby 2016, 141). Although Crosby acknowledges that she and Donna share a certain degree of interdependence, "there's plenty I don't know about her life, despite our personal closeness." Crosby chooses to draw readers' attention to how the caregiving scenario necessarily flattens the personality, history, and desires of the caregiver, as well as how her own personhood is diminished by her disability. As a wheelchair user who wears a brace and loosely-fitting clothes, she is often mistaken for a man. Where once being a woman and a lesbian were important aspects of her identity,

as a person with a disability, she is shorn of her gender and all traces of desirability. Crosby's account points to the difficulty of maintaining the full personhood of caregiver and receiver simultaneously. As we have seen, too often the dignity of the dependent subject is established by marginalizing or erasing caregivers and the work they do, while the selfhood of those who are ill and disabled is diminished by the fact of their dependency.

Two artists offer a rejoinder by using visual imagery to defamiliarize care work, suggesting that the personhood of the caregiver may be enhanced rather than evacuated by attending to others. Raymond Holman is a photographer who began to depict the caregivers of people with Alzheimer's when his father was diagnosed with the disease. Like Walker, Holman, who is black, draws attention to the racialization of caregiving, as well as a disease that disproportionately affects African-Americans. A self-portrait depicts Holman holding up a black-and-white photograph of his father in the act of shaving (1997). The older man's brows are furrowed in apparent confusion and we can surmise that he will soon need assistance even with such basic activities of daily care. Holman, pictured in color, stands by a window that illuminates one side of his body, leaving the other in deep shadow. His sober expression suggests the loss evoked by the photograph of his father. Juxtaposing the heads of father and son, the portrait suggests an intimate relationship. But it is also about the generational and cognitive limits of that intimacy, connoted formally by the use of color to depict Holman as belonging to the present moment captured by the photograph, and black-and-white to picture his father as belonging to the past. The two images bespeak a poignant reversal as a younger generation is tasked with caring for elders in decline.

Other portraits in Holman's series picture professional caregivers, people like Crosby's aide Donna, whose work is often invisible and unappreciated. Holman's subjects are well-groomed, relaxed, and neatly dressed as they pose against neutral studio backgrounds. Picturing the caregivers alone, the images challenge the notion that dependency work entails a complete relinquishing of self. Their expressions, postures, and choice of garments attest to a personhood that exceeds their professional duties. At the same time, some of the portraits are accompanied by quotes that remind viewers of the important and often invisible work they do. A portrait of a smartly dressed black woman is accompanied by the caption:

Meet Joan, she was one of my father's caregivers. Her shift was from 1:00PM-7:00PM. I found out later Joan would sometimes come back later in the evening to see if he was OK. One night he wasn't, she found

him covered with his own bowel movement. She lovingly cleaned him up.
(Holman 2013)

Nothing about Joan's portrait suggests the intimate labor described in the caption. While the words associate her with the soiling, the visual image shows her dressed in a spotless white shirt and pants. The injunction to "meet Joan" interpolates the viewer, inviting us to acknowledge the personhood of its subject. Meeting Joan means acknowledging the respectful and compassionate care she gave to Holman's father, which extended beyond her paid hours and assigned duties. At the same time, we should note how Holman's caption focuses exclusively on Joan's work as a caregiver. Meeting her in this way tells us nothing more about her desires or life circumstances. The portrait thus reinforces the imbalance noted by Crosby, in which the recipient of care will always be more fully known than the provider.¹

Another project that complicates the visual rhetoric of dependency is Mark Gilbert's "Here I Am and Nowhere Else: Portraits of Care," produced while he was artist-in-residence at the University of Nebraska Medical Center. Gilbert unsettles the divide between patients and caregivers by depicting subjects across the spectrum of health and ability, some of whom belong to both categories. Recall how Victor Tardieu's painting of the World War I field hospital established a contrast between the health and agency of the female nurse and the wounded passivity of her male patients. In life, the positions of health and illness are not diametrically opposed and can easily be reversed. Our choices are diminished by failure to recognize our shared interdependence. This is not to deny that some people need more care than others, but rather to acknowledge that we are all both givers and receivers on a spectrum of care. In order to signal "the mutuality and reciprocity between giving and receiving care" (Gilbert 2009, 22), Gilbert notes that he "tried to avoid obvious signals or symbols that explain whether one is a patient or a caregiver" (2009, 40). Gilbert recognizes that the static nature of visual images might further reify the roles of caregiver and recipient. He works against that fixity by integrating accounts of the process of sitting for and responses to the finished artwork into his project. He also paints multiple portraits in different styles that show both artist and subjects evolving over time and in response to changing circumstances. These changes do not suggest a uniform path of development for either artist or subject, as the health of some sitters deteriorates while others move from illness to recovery.

“Here I Am” works on multiple levels. The most immediate is that it had a restorative effect on the participants. If portraits have traditionally aspired to condense the subject’s memorable qualities into a single pose, who would choose to be captured at a moment of weakness and physical decline? Subjects who were ill admitted to deep ambivalence about, if not outright antipathy toward, their appearance. But to their surprise, they claimed to feel affirmed by the process of sitting, even though Gilbert’s art did not idealize or attempt to erase the signs of illness and treatment. Some sitters said they discovered otherwise buried depths of feeling in looking at their portraits. For example, Gilbert’s portrait captured the averted eyes of John Smith before undergoing surgery to have a portion of his tongue removed because of cancer. When asked about his expression, Smith admitted that he was afraid his wife would be ashamed of his impairment. Once he acknowledged his feelings, Smith could discuss them with his wife, preparing her to better attend to his emotional, as well as physical, needs after the surgery (Greiner 2008, 71). The mother of five-year-old Daisy wrote about the happy contrast between portraits that captured her daughter’s vitality and joy, and the brutal treatments she had endured for cancer over her short lifetime. If portraits have historically presented a self that is composed for the public, a composite of personality and history, Gilbert captures his subjects at a particular moment, sometimes revealing worry or vulnerability, at other times finding unexpected strength and confidence.

Beyond its impact on the individuals directly involved, however, Gilbert’s project—with its emphasis on process, interconnection, and shared vulnerability—functions as a rejoinder to a cultural logic that assumes health and ability are chosen, that patients are consumers, and that healthcare should focus exclusively on outcomes and results. By this logic, there would be no point in painting Roger, in the last stages of ALS, or Jarad, whose terminal cancer left him 2–3 months to live. These subjects point to the failures and limitations of a treatment that has recovery as its only goal. Gilbert strives to galvanize viewers to seek a more human and empathic healthcare system that does a better job of recognizing the personhood of patients and caregivers at all stages of wellness. Where portraiture has traditionally erased the dependencies that come with illness and disability, Gilbert’s work makes them visible. In doing so, it is a reminder that choices, particularly those involving disability, are never the exclusive activity of individuals, but rather belong to a network of interconnected persons and social locations.

CONCLUSION

There is another image of Christopher Reeve that sends a very different message about dependency and choice than the National Portrait Gallery painting with which I began. In this 1999 photographic portrait by Mary Ellen Mark, Reeve and his wife Dana pose wrapped in a blanket that covers everything but their heads and one of Dana's arms, which embraces his neck. She rests her head lovingly on his shoulder. The folds of blanket make it impossible to tell where one body ends and the other begins, or where the boundaries between bodies and chairs might be. Where Sasha Newley's portrait of Reeve spoke of independence *in spite of* disability, this is an image of *interdependence* regardless of ability.

With its image of bodies entwined, the Mark portrait also speaks powerfully to the notion of choosing disability. Reeve certainly did not choose to become disabled, and the choices he made about how to live with his disability were controversial to many advocates for disability rights. He was widely condemned for wanting to find a cure for paralysis rather than to make the world a better place for people with disabilities. His attitude was typified by a controversial 2000 Superbowl ad that used special effects to depict Reeve standing up out of a chair and walking across a stage. But despite Reeve's avowed desire to overcome, the public visibility of his wife and caregiver, Dana, sent a different message about disability.

Where the Superbowl ad and the Newley portrait erase relations of care, Dana spoke out about her role as a caregiver. When she did so, she reinforced her husband's status as dependent. Just as Reeve's disability was unchosen, Dana was honest about not choosing to become her husband's caregiver, as well as the emotional and physical strains of dependency work. Tending to her husband's needs was physically and emotionally stressful, and forced her to sacrifice many opportunities for personal and professional advancement. Dana also recognized the extent to which she was insulated by privilege and used her celebrity to advocate on behalf of ordinary caregivers. Aware that injustice is exacerbated by invisibility, she worked to get caregivers listed on the 2000 census as a first step toward enhancing their rights as workers.

Tragically, Dana Reeve's own life became an example of how easily one can move from giver to receiver of care when she was diagnosed with breast cancer that would lead to her death. In this sense the Mark portrait is prescient. Its images of bodies and devices entangled attests to the inevitable entanglement of social roles. Dana's presence in the portrait is a reminder that choosing disability is never just about individuals but

about the structural factors that determine who will occupy the positions of givers and receivers of care. We all deserve to inhabit both at different stages of life and according to our needs.

Choosing disability may mean actively selecting for or opting not to alter traits considered to be disabling. But as I have used it here, choosing disability also means choosing *how to live with* disabilities that are more often than not the product of happenstance. Too often such choices rely on the cruel optimism of independence which, as I have argued, excludes a great many people with disabilities and those who care for them. We must find ways to enable people with disabilities to live full and dignified lives without making independence a prerequisite to their thriving.

In this essay I have proposed that the visual arts are a rich resource for understanding our deep antipathy toward certain forms of dependency, as well as those times and places where dependency is permitted, who we imagine as acceptable dependents and who the proper givers of care. Because these assumptions reside at the level of feeling, as much as reasoned principle, aesthetics offers a powerful means of accessing our fantasies, fears, and desires about dependency, care, and those who administer it. While these feelings often remain unacknowledged, art also provides opportunities to reveal the unseen, insights that should inform a robust debate about the meaning and consequences of choosing disability.

ACKNOWLEDGMENTS

I am grateful to Steve Campbell and Lance Wahlert for inviting me to be part of the “Choosing Disability” workshop at the University of Pennsylvania, and to the participants in that workshop and the anonymous readers at the *Kennedy Institute of Ethics Journal* for helpful comments and suggestions.

NOTE

1. In fact, Crosby details Donna’s physical impairments, which are exacerbated by the difficult work of caregiving and her lack of access to medical treatment.

REFERENCES

- Berlant, Lauren. 2011. *Cruel Optimism*. Durham: Duke University Press.
- Cartwright, Lisa. 2015. “Affect.” In *Keywords for Disability Studies*, edited by Rachel Adams, Benjamin Reiss, and David Serlin, 30–32. New York: New York University Press.

- Chopin, Kate. 1899; 2016. *The Awakening*. New York: Oxford World Classics.
- Crosby, Christina. 2016. *A Body, Undone: Living on After Great Pain*. New York: New York University Press.
- Davidson, Michael. 2015. "Aesthetics." In *Keywords for Disability Studies*, edited by Rachel Adams, Benjamin Reiss, and David Serlin, 26–29. New York: New York University Press.
- Faulkner, William. 1966. *Absalom, Absalom*. New York: Random House.
- Fiedler, Leslie. 1988. "Images of the Nurse in Literature and Popular Culture." In *Images of Nurses: Perspectives from History, Art, and Literature*, edited by Ann Hudson Jones, 100–12. Philadelphia: University of Pennsylvania Press.
- Gabbard, Christopher J. 2015. "Human." In *Keywords for Disability Studies*, edited by Rachel Adams, Benjamin Reiss, and David Serlin, 98–102. New York: New York University Press.
- Garland-Thomson, Rosemarie. 2010. *Re-Presenting Disability: Activism and Agency in the Museum*. New York: Routledge.
- Gilbert, Mark. 2009. *Here I Am and Nowhere Else: Portraits of Care*. Exhibition Catalogue. Omaha, NB: Bemis Center for Contemporary Art.
- Gilligan, Carol. 1982. *In A Different Voice*. Cambridge: Harvard University Press.
- Glenn, Ellen Nakano. 2012. *Forced to Care: Coercion and Caregiving in America*. Cambridge: Harvard University Press.
- Gouldner, Alvin. 1960. "The Norm of Reciprocity: A Preliminary Statement." *American Sociological Review* 25: 161–78.
- Greiner, Carl. 2008. *Here I Am and Nowhere Else*. Exhibition Catalogue, pp. 67–76. Omaha, NB: Bemis Center for Contemporary Art.
- Hiltonsmith, Robert. 2014. "How Home Healthcare Aides Are a Microcosm of the Job Crisis." *Demos*, July 22. <http://www.demos.org/blog/7/22/14/how-home-health-care-aides-are-microcosm-jobs-crisis>
- Homan, Raymond Jr. 2013. "Alzheimer's Disease and Dementia." Raymond Holman Jr. Photography blog. <https://raymondwholmanjrphoto.wordpress.com/>. Accessed May 4, 2017.
- Kittay, Eva Feder. 1999. *Love's Labor: Essays on Women, Equality, and Dependency*. New York: Routledge.
- Linton, Simi. 1998. *Claiming Disability: Knowledge and Identity*. New York: New York University Press.
- Mann, Sally. 1992. *Immediate Family*. New York: Aperture.
- . 2015. "Sally Mann's Exposure." *The New York Times*, April 17.
- Melosh, Barbara. 1988. "'A Special Relationship': Nurses and Patients in Twentieth-Century Short Stories." *Images of Nurses* 128–49.

- Noddings, Nel. 1982. *Caring: A Feminine Approach to Ethics and Moral Education*. Berkeley: University of California Press.
- . 2002. *Starting at Home: Caring and Social Policy*. Berkeley, CA: University of California Press.
- O'Lynn, Chad E., and Russell E. Tranbarger, editors. 2006. *Men in Nursing: History, Challenges and Opportunities*. New York: Springer.
- Rosenfeld, Sophia. "Free to Choose? How Americans Have Become Tyrannized by the Culture's Overinvestment in Choice." *The Atlantic*, June 3.
- Ruddick, Sara. 1989. *Maternal Thinking: Toward a Politics of Peace*. New York: Ballantine Books.
- Scully, Jackie Leach. 2008. *Disability Bioethics: Moral Bodies, Moral Difference*. New York: Rowman and Littlefield.
- Siebers, Tobin. 2010. *Disability Aesthetics*. Ann Arbor: University of Michigan Press.
- Tronto, Joan. 1994. *Moral Boundaries: A Political Argument for an Ethic of Care*. New York: Routledge.