Love in the Time of Ableism

If we were constantly remembering that love is as love does, we would not use the word in a manner that devalues and degrades its meaning.

- bell hooks, "Clarity: Give Love Words"

On December 29th, 2019, a woman by the name of Corina Knoll published a story in the New York Times. This is not, in and of itself, remarkable; Ms. Knoll has at the time of this paper published 20 such stories in the NYT alone since she came from the Los Angeles Times, where she worked for over a decade. A quick glance at her previous stories reveals headlines like "Nanny Asked Ex-Boyfriend to Return Key. He Arrived With a Knife," and "From 'Smallville' to a Sex Cult: The Fall of the Actress Allison Mack." Clearly, Ms. Knoll is no stranger to sensationalizing news events. In fact, her short bio for the NYT bills her as someone "focused on narrative storytelling." So when her latest piece, "Sweethearts Forever. Then Came Alzheimer's, Murder and Suicide," debuted, this was nothing out of the ordinary. The article outlined the all-too-common decline of Alma Shaver into late-stage Alzheimer's disease, from forgetting if she had changed the sheets to being unable to dress herself to her eventual murder at the hands of her husband. A tragic and salacious tale, the sort Ms. Knoll is all too familiar with. None of this was groundbreaking on its own. Alzheimer's is one of the leading age-related disabilities, and its frightening, debilitating nature makes it a darling of the press; in fact, media coverage of Alzheimer's has been increasing at a near-exponential rate in recent years¹. No, the kicker came

¹ For more on the coverage of Alzheimer's in the press, see (PDF) Coverage of Alzheimer's Disease From 1984 to 2008 in Television News and Information Talk Shows in the United States: An Analysis of News Framing

in the subhed, "'They were absolutely soul mates." and the accompanying (now deleted) tweet, saying the story was "one of love."

What is love? bell hooks, poet, activist, and author (though these terms do little to explain the breadth of her influence), defines love as "the will to extend one's self for the purpose of nurturing one's own or another's spiritual growth" (4). To love is akin to planting a garden; it takes care and effort and nourishment. One must tend a garden, trim and water and fertilize the living things one wishes to grow. When weeds begin to sprout, one does not set the garden ablaze. Love, then, exists in antithesis to murder: one cannot love what one wishes to kill.

If love is not murder then how can a murder story be framed as a love story?

According to the Ruderman White Paper "Media Coverage of the Murder of People with Disabilities by their Caregivers," at least one disabled person² is murdered by a parent/caretaker every week (Perry, 1)³. Those caretakers are lauded as loving heroes even as they poison (Courtney Liltz, 28), stab (Alex Spourdalakis, 16, Hakan Erdem, 12), and shoot (Dustin Hicks, 14, Evelyn Harvey, 93, Joann Canfield, 72, Jean Carol Adams, 77) the very people who are supposedly under their care. Disabled people are constantly erased from their own stories, overshadowed by those who loom as their supposed caretakers in the spotlight. Courtney Liltz's murderer, according to a friend of the family, "deserve[d] an award for the years of sacrifice she

² As a disabled person myself, I choose to use identity-first language instead of person-first, as I personally believe that disability is an integral part of my interaction with the world and that to distance myself from it implies that it is an undesirable thing. However, I also recognize that many in the disability community prefer the person-first term "people with disabilities," and I do not intend any disrespect to those individuals.

³ It is important to note that despite the majority of caretakers being women, the vast majority of caretaker murders are committed by men.

⁴ These names represent a miniscule portion of disabled murder victims

gave her daughter" (McCoppin). The overwhelming media narrative around these murders is that these are killings of mercy, not malice.

What's wrong with so-called "mercy" killings? Let's take a look at the underlying assumptions that support the concept. Surely a life lived in pain and frustration is not worth living, and who would want to be a burden on their family, causing other people's misery along with their own? Well, every life is lived in pain and frustration, from hangnails to broken bones to heartbreak. Framing the negatives as the sole experience of disability neglects the positives, all the skippable lines and rock star parking, all the innovation and tenacity and community that it takes to exist as a disabled person in a world that devalues you. Assuming disabled people are burdens displays a belief that disabled people simply take and take and never give, once again ignoring all the contributions the disability community has made, all for the sake of a more binary worldview⁵. That curb cut that makes using a shopping cart or stroller so easy? That elevator on the days when it's just too hot to take the stairs? Those only exist because of the persistence of disabled activists. But caretakers devote huge portions of their lives to their wards, surely they must love them; the strain of caring for someone for so long and so intensely finally got to be too much, that they simply couldn't take it anymore. Yes, often caretakers do love the person in their care. But as hooks herself said, "care is a dimension of love, but simply giving care does not mean we are loving."(8) The framing of disabled murders as acts of love belies a gross misunderstanding of what love is, what mercy is. Where is the mercy in looking another human being in the eye and deciding for them that they are better off dead?

⁵ Side note: abled people are never asked to justify their right to life on the basis of their ability.

Ableism, or the set of beliefs or practices that value the normative abled body and devalue the outlier (Garland-Thomson), is baked into our society thanks to fear: the visible existence of disabled people reminds abled people just how fragile their abled-ness is. Robert Dawidoff, in his foreword to Paul Longmore's Why I Burned My Book, explains that seeing a disabled person "challenges our uncomfortable, if usually repressed awareness that anyone can become disabled... We regard disability as a kind of *memento mori*, except that we take it as reminding us of a difficult and torturous life rather than the inevitability of death." This is frightening, this memento debili, and that fear is mirrored in the systemic treatment of disabled people. Ugly Laws, for instance, made it illegal for "any person, who is diseased, maimed, mutilated or deformed in any way, so as to be an unsightly or disgusting object, to expose himself or herself to public view" (Schweik, 85), quite literally criminalizing the existence of disabled people in public. The last Ugly Law saw its demise in 1974, and systemic ableism still threatens immigration status, voting, reproductive rights, employment, education, and marriage equality. Ableism is present in our news, our entertainment, our advertising, present in our legislature, present in the very architecture we live in. It's the supervillain in a wheelchair beaten to a pulp by the brawny hero, the sexless autistic best friend who serves more as a plot device than a person. It's the "wrongful life" claims (Brown), involuntary sterilization (Buck v. Bell, 1927)⁶, the Ugly Laws. It's the man who brutally ripped his wife's autonomy from her with the business end of a firearm being framed as a Byronic hero.

In deconstructing this narrative of caretaker-as-hero even in the face of murder, a pattern of dehumanization appears. The comfort of the abled caretaker is routinely given greater merit

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⁶ Buck v. Bell was a landmark ruling by the Supreme Court of the United States wherein the involuntary sterilization of a disabled woman, Carrie Buck, was sanctioned. It is widely considered the peak of eugenics theory in the United States. It has never been overturned.

than the life of the disabled victim. The life of the disabled victim is seen as lesser, not worth living, because of their disability. The issue with these assumptions is that they neglect to account for one very important point: the intrinsically valuable human life and autonomy of the disabled individual.

Corina Knoll is not at fault for any of this. She is, at worst, an unwitting proponent of a largely-unquestioned belief system that teaches us from the day we are born that we are better off dead than disabled. And there is little doubt that caretaker murders make for good stories—there's a reason they rise again and again to national prominence, and it's not because of compassion for our fellow human beings. At the same time, Ms. Knoll's story shines a stark spotlight on the blithe and callous assumption that the life of a disabled person isn't worth living. But every garden has green things in it, and no garden thrives on fire.

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