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Alison Lawrence

Augustana College, Rock Island Illinois

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Inhabiting “Sore Butt Cracks”: Queering the U.S. Long-Term Care System

Alison Lawrence

WGSS 350: Queer Theories

Dr. Kiki Kosnick

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Imagine you work for a medical transport service. Somebody's grandpa is on your stretcher—his family cheerfully hugs him goodbye, the grandkids blow kisses, and everyone shouts happy promises to visit soon as you wheel Grandpa to the darkened entrance of Aspire Long-Term Care. You walk into Aspire Care and are greeted by a dazzling foyer. The tables are set neatly; blue and green vases line shelves perfectly placed around the room. Twinkling lights line the ceiling, and you hear the faint melody of a Christmas song. You look at Grandpa, look back at the foyer, and imagine it bustling with life, imagine this Grandpa sitting at a table playing cards, sipping soup, laughing with nurses in that belly-laugh way that Grandpas do. But then you realize it's 5:30 in the evening, dinner time, and the foyer is empty. Silent. The elevator dings, and you push Grandpa across the threshold, exiting the lovely foyer and entering the bowels of Aspire Care. As the door opens, you and Grandpa are hit with an odor that is decidedly not a warm, delicious soup—your eyes water from the stench of something foul, a smell all-too-human but barely recognizable as *human* at the same time. The ceiling is stained, the paint is cracked, and every other overhead light flickers as we pass by. You rearrange the tiny room and quietly slide Grandpa into bed, careful not to disturb his new roommate just two feet away. Holding your breath, you move quickly back to the elevator, through the serene foyer, and out into the sun where you can finally breathe easy again.

As it stands, most U.S. nursing homes act as an undervalued, underfunded storage facility for those whom society has deemed no longer productive. Reports of widespread neglect and horrific living conditions in long-term care facilities have gained national attention after the Covid-19 pandemic, revealing the country's appalling disregard for the lives of elderly people

and people with disabilities (Human Rights Watch)¹. Long-term care residents², having reached a point where their futures are limited, are expected to complacently wait for death as the last significant milestone of life. The life lived during this purgatorial period has, apparently, exhausted all potential or value. Our indifferent, damning societal attitude around disability and aging has contributed to a long-term care industry that ignores residents' capacities for joy, autonomy, and community, diminishing their lives by medicalizing the very definition of "comfort" and what it means to be truly *cared-for*. Long-term "care" prioritizes comfort in the medical sense rather than the embodied, as comfort is defined by stable vital signs and reduced pain rather than a rich, holistic sense of fulfillment. That is, the foyers may be pristine, but they are void of laughter and connection. I propose that theories of queerness, such as Jack Halberstam's queer art of failure and concepts of queer temporality, can be employed to examine and subvert our long-term care system due to the parallel position of queer bodies and bodies that are aged or disabled as bodies that fail to adhere to normative standards and narratives of happiness. A new, queer rhetoric would engage with the messy, embodied experiences of long-term care patients to develop a remedy to our failing system, wherein the inevitable period of disability between old age and death is recognized as still valuable. When properly supported, this time may produce exciting, non-normative forms of fulfillment for patients.³

¹ While some long-term care facilities are well-funded and provide exceptional care, these facilities tend to primarily serve affluent populations and do not reflect nationwide trends of neglect and abuse in long-term care facilities. The 2021 Human Rights Watch report "US: Concerns of Neglect in Nursing Homes" details the current conditions in most U.S. nursing homes and calls for action to protect the human rights of patients in these facilities.

² I use the terms "long-term care" and "long-term care residents/patients" to broadly refer to any person requiring prolonged, generally permanent inpatient healthcare services for any reason, including disability, illness, and complications of old age.

³ A note on language: I understand that language surrounding disability is constantly changing according to what best represents and respects the lived experiences of folks with disabilities. In this paper, I use language that follows current guidelines accepted and produced by disability activists, while also recognizing that no single set of guidelines is universally endorsed.

To do this, we must step back over the threshold together once more. By immersing ourselves in the often pungent, shadowy reality of long-term care, we can foster new modes of thinking about our bodies, aging, and joy. As we embark on this journey, I will ground our analysis in the lived experience of one such long-term care patient as an example of resistance against normative conceptions of end-of-life *life*. Youtuber Clay-The-Comedian is a long-term care patient who creates parodies of popular songs and performs comedy shows about his life inside of a nursing facility. While his jokes make light of his situation, they also serve as a resistance to the long-term care industry itself, as he details experiences of grief and discomfort brought upon him by a system that habitually fails to meet his needs or recognize his personhood. I will specifically highlight his video “Old Town Road wheelchair parody Crow Creek Road ft. Theo the dog” as a starting point for our analysis. True to the legacy of subversion initiated by Lil Nas X's original song, “Old Town Road,” which subverts normative narratives about the "wild west" and country music by centering queer, Black identities, Clay's version similarly calls for a radical reimagining of dominant narratives surrounding individuals who need long-term care.⁴ Throughout the song, Clay emphasizes joy and hope while also forcing listeners to confront his embodied reality as a white, male, long-term care patient through descriptive lyrics about bed sores, pee, and sore butt cracks. His song serves as a dual critique of the long-term care industry, as he not only demonstrates his autonomy and desire for fun in opposition to normative narratives surrounding long-term care patients, but also sheds light on the many ways that nursing facilities violate residents' dignity by ignoring their right to personal fulfillment. In calling his audience to dwell in his experiences with him, Clay points to empathy

⁴ While a lyrical comparison is not the focus of this paper, the significance of Clay's use of “Old Town Road” is worthy of analysis due to the original song's context of Black, queer advocacy. I recommend Julianne Stella Swope's analysis of Lil Nas X's advocacy efforts, “Black Gay, and Unapologetic: How Lil Nas X Is Bringing the Out Group In” as a resource for further understanding the significance of this song and the important legacy of activism that Clay is participating in.

and creativity as critical tools for building a long-term care system that prioritizes holistic care for all patients.⁵

Clay's first radical act is inviting us to engage with the intimate realities of his space and physical body, urging us not to shy away from the discomfort that this engagement brings. The camera itself acts as a direct window into the nursing facility where he lives, showing us a cramped bedroom with shelves and bedsheets in various forms of disarray ("Old Town Road" 0:09). He introduces us to the space, unashamedly naming it as it is: "Welcome to my living room, office, bedroom, bathroom, kitchen" ("Old Town Road" 0:05). In doing so, he bashes his audience with the sobering realization that the room we are seeing is the room to which all of his life functions are confined; in a singular space, he eats, sleeps, shits, performs, and lives. Society might regard his static and limited lifestyle as a failure to live up to the standards of successful adulthood, where one cares for oneself and moves freely throughout the world. However, we may question these normative definitions of success versus failure through the lens of Halberstam's "queer art of failure." Similar to Clay's supposed failure to live up to adulthood, the queer body is associated with a failure to live up to hegemonic standards in its embodiment of "nonconformity, anticapitalist practices, nonreproductive lifestyles, [and] negativity"—all failures when juxtaposed with the heterosexual ideals of "advancement, capital accumulation, [and] family" (Halberstam 89). That is, the alternative lifestyle and family structure exhibited by queer individuals is regarded as a failure in comparison to the idealized heterosexual nuclear family. Rather than condemn this failure to conform, however, for queer theorists "failure presents an opportunity rather than a dead end...the queer artist works with rather than against

⁵ It is important to note that I approach my analysis from the perspective of a non-disabled person and a healthcare provider who has had extensive contact with the long-term care industry. While my critique is intended as a call-to-action for non-disabled folks and caregivers, I recognize that folks with disabilities may find Clay's song meaningful in different, equally significant ways that are worthy of exploration by folks who identify with his experiences.

failure and inhabits the darkness” (Halberstam 96). Essentially, engaging with failure allows us to imagine solutions that push back against our very definitions of success. By rejecting societal norms, failure functions as a disruptive position from which we might recognize and dismantle flaws in our society. Therefore, when Clay invites us to look into his room, he prompts us to “inhabit the darkness” with him and revisit our definition of a successful life. Like queerness, requiring long-term care services is viewed as a type of failure, as it indicates a loss of independence, future-orientation, and control over one’s body. Clay’s room represents this loss. When we inhabit this space with him, we become immersed in its subversive potential and begin to dream of something better.

Beyond inviting us to inhabit his space through his song, Clay also beckons us to inhabit his physical body with him, invoking physical disability as a lens of supposed “failure” from which we might learn. Clay spares no details when describing his situation, using language such as “sore butt crack” and “bandages and poopy” that might make the typical viewer queasy, or at the very least uncomfortable (“Old Town Road” 2:45, 1:55). He describes, without shame, his embodied reality as somebody increasingly reliant on others for the maintenance of his body when he sings, “Started getting fatter, infections in my bladder, I peed on nurse Betty, you can go and ask her!” (“Old Town Road” 1:45). To an audience of people without disabilities, the idea of losing control of one’s body in such a way is not only terrifying, but also humiliating. However, Crip theorist Robert McRuer points out that “able bodied status is always temporary, disability being the one identity category that all people will embody if they live long enough”; therefore, he argues that a lifetime avoidance of disability is actually impossible to achieve due to the constantly changing and aging nature of everybody’s bodies (494). When we try to ignore difficult realities like Clay’s, we buy into the illusion that we can maintain our non-disabled

status indefinitely. By forcing us to confront his humiliating, even disgusting reality in the eyes of ableist society, Clay calls us to not only engage with his experience of his body, but also our own ever-changing bodies. Crip and queer theorists alike argue that we must be willing to dwell in the failures of our bodies—or as Crip theorist Heather Love names it, feelings of bodily “backwardness”—to “recognize something in these darker depictions of [life] without needing to redeem them” (Halberstam 99). That is, instead of trying to protect ourselves from our collective fear of disability by believing we can avoid it, or “redeem” ourselves, we must get comfortable with the uncomfortable realities that come with having a body and use this perspective to produce new modes of thinking. Clay’s song about his “sore butt crack” proudly reclaims his embodied experience, never denying his discomfort, but also refusing to let anyone overlook it. His honest declaration of embodiment points to Crip theorist Ellen Samuels’ question of what it might look like to celebrate our bodies, “yet also allow ourselves to feel the pain...its melancholy, its brokenness” (3). Rather than simply clinging to happier normative illusions, the choice to inhabit failure, backwardness, and brokenness is an act of celebration and empathy that creates space for honest, realistic problem-solving.

Apart from pushing us to acknowledge his, and therefore our own, embodied realities, Clay also challenges us to reexamine our understanding of normative life timelines. Part of the Crip theory of “backwardness” involves a sense of literally moving backward through time—or, at the very least, no longer progressing forward (Samuels 3). Clay’s situation may feel “backward” because he is forced to rely on others for his care, as if he has returned to childhood. Backwardness thus constitutes another failure shared by both queer bodies and bodies with disabilities: a failure to adhere to normative standards of the progression of time. For instance, heteronormative time emphasizes a linear series of milestones through which a successful person

progresses throughout their lifetime, such as puberty, marriage, and reproduction (McCann and Monaghan 215). Queer individuals, for whom puberty, marriage, and reproduction may be undesirable or unattainable, are considered failures for not adhering to such norms. Clay exhibits a similar inability to adhere to normative time due to his position in long-term care; for folks with disabilities, “disability and illness have the power to extract [people] from linear, progressive time with its normative life stages and cast [them] into a wormhole of backward and forward acceleration, jerky stops and starts, tedious intervals and abrupt endings” (Samuels 2). In other words, disability can make it impossible to follow the standard timeline for starting a career, getting a degree, marriage, retirement, or other linear markers of time due to the disruptive nature of illness, pain, and bodily limitations. Long-term care as Clay’s specific experience of disability characterizes a period entirely lacking normative milestones; it is a period associated with no future in a future-oriented society, which implies that there is no longer potential for linear growth. Clay, however, adamantly informs us that he has “places to go, people to see, and things to do,” reminding viewers that his life still has value despite lacking a normative “future” to look forward to (“Old Town Road” 0:56). As Halberstam notes, “the constantly diminishing future creates a new emphasis on the here, the present...[expanding] the potential of the moment...[squeezing] new possibilities out of the time at hand” (McCann and Monaghan 223). Rather than simply sitting and waiting to die, Clay shows us that long-term care patients are still entitled to personal growth and fulfillment, though these experiences may fail to conform to the ideals of the normative timeline. The limited nature of the future is exactly what drives creative solutions.

In asking us to engage with embodiment and non-linear timelines, Clay calls us to inhabit the position of failure as a point of departure for subversion of our current approach to long-term

care. When we spend time in these spaces of failure, from Clay's room to his body to feelings of backwardness, we realize that the true failure is not long-term care patients' failure to adhere to societal standards. Rather, *society* has failed to accommodate the needs of all different types of bodies. When Clay laments, "Can't somebody help me with somethin', can't help me with nothin'," he draws our attention to the nursing facility's failure to not only appropriately care for his physical needs, but also support his right to continued personal growth and fulfillment ("Old Town Road" 1:34). Recognition of this failure opens our eyes to the futility of using normative thought processes to solve non-normative injustices, subverting our typical approach to the body, time, and everything. A queer theory of "lateral growth" may serve as a means of achieving fulfillment that departs from normative milestone-driven, future-oriented time (McCann and Monaghan 227). For Bond Stockton, lateral growth "locates energy, pleasure, vitality, and (e)motion in...back-and-forth connections (2009, 13)," which can be achieved by "shifting focus from linear development to lateral connection" (McCann and Monaghan 227). By emphasizing the value of connection as opposed to forward-mobility, Stockton's lateral growth accommodates disability's "jerky" timeline, making growth accessible regardless of what time looks like for different individuals. Clay's song exemplifies lateral growth because he does not resist the limitations of his body, but rather engages with them as a source of comedy that promotes laughter, camaraderie, and empathy among his peers and online. While his work does not push him toward any normative future, the songs allow him to foster present connections. Clay models a new approach to long-term care that celebrates the personhood of all types of bodies while simultaneously never diminishing the often difficult reality that bodies requiring long-term care face.

Our subversion of long-term care must make room for both “sore butt cracks” and “having places to go, people to see, and things to do” (“Old Town Road” 2:45, 0:56). In order for inevitable pain and radical joy to coexist in long-term care, we need to redefine our concept of “happiness” itself. According to queer theorist Sara Ahmed, “the cultural imperative to be happy...is always linked to normativity”—meaning the very idea of happiness is rooted in normative timelines and normative ways of being, which makes normative forms of happiness inaccessible to non-normative bodies (McCann and Monaghan 231). Clay’s situation can hardly be described as “happy” as defined by ableist society, but it is evident from his demeanor that he lives his life *happily*. Ahmed uses the metaphor of the “happy queer” versus the “happily queer” to juxtapose normative happiness with subversive, universally accessible happiness. For Ahmed, the “happy queer” is a queer person who, by definition, occupies a non-normative body, while still attempting to align themselves as closely with heteronormative standards to fit in with dominant society (McCann and Monaghan 232). The “happy queer” does not question the status-quo, and therefore participates in furthering normative systems that disadvantage other marginalized bodies. On the other hand, the “happily queer” rejects societal norms and instead creates their own definition of happiness that acknowledges their non-normative position and differing needs; essentially, “the happily queer...refuses to give up their desires, even if these desires take them outside the parameters of happiness” (McCann and Monaghan 232). The adverb “happily” thus denotes a necessary subversion of norms that creates space for difference. Applied to long-term care, the “happy patient” might be described as quiet and sedated, one who waits by the window for death because normative definitions of happiness are inaccessible to them. Clay, on the other hand, represents the “happily patient,” or the patient who redefines

happiness as it suits him. Clay has a “sore butt crack” *and* is “livin’ life without a frown” (“Old Town Road” 2:45, 2:30).

Clay’s version of embodied happiness resists the unjust long-term care system, urging us to expand our understanding of what constitutes a fulfilling life in long-term care. It is important to note, however, that the responsibility for supporting this happiness is not the responsibility of the patients themselves—providing the support necessary to achieve new forms of happiness is the responsibility of our long-term care system, to which these patients have entrusted the last years of their lives. Care that ends at physical comfort is not enough; our society is obligated to support holistic comfort, which includes creatively making the “happily” possible for everyone. We can find inspiration for this reimagining of long-term care by inhabiting spaces of failure, failed bodies and failed time.

Let us bring ourselves back to Clay’s room, or to our imagined Aspire Care facility. Sit in it, smell it, breathe it all in. Look back to the pristine foyer, to the neatly set tables and beautifully positioned vases. As Halberstam notes, a swimming pool “becomes a trap for the human body when the water has been emptied out” (113). So too does the foyer, a beautiful space that is useless in a long-term care facility because it is designed for normative bodies only. What might a new foyer, or a new long-term care system, look like if we paid more attention to the reality of patients’ bodies and personhood rather than getting caught up in normative illusions of ability and happiness? As we reimagine long-term care, we must emphasize connection, embodiment, and the present. We must make room for shit and bed sores, while also supporting happiness in all its forms.

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