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The Communicative Body's Call for Prospective Organ Donors: Montefiore Health System's *Live and Let Live* Digital Platform

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Nini Skye is an eight-year-old child in Far Rockaway, and she needs a kidney transplant. Her best chance of survival is to find a living donor who would be willing to donate a kidney. In the two-minute film released through *Live and Let Live*, a digital platform by Montefiore Health System (2021), viewers are introduced to Nini's family and friends, invited to witness some of her deepest passions, such as drumming, and told of her aspirations of becoming a chef when she grows up. Against the backdrop of archival footage of Nini's childhood and candid video recordings of her daily life, periodic interruptions of a black background with typed text intrudes the narrative of Nini's dreams and desires. Through this effect, the film advertises an untraditional "product" to viewers—a chance to save a life, by donating an organ to someone who they have never met.

Like Nini, more than 100,000 people are on the national transplant waiting list for a liver or kidney, and about 20 percent of those are in need to find a living donor (U.S. Department of Health & Human Services, 2021). Often times, patients waiting for an organ transplant take grassroots means to expand their chances of finding a living donor by renting billboard spaces or crowdfund-

ing within their networks. This requires a lot of time and effort. To allay the challenges of finding a donor, Montefiore Health System launched *Live and Let Live* to provide a digital presence for patients to build out intensely personal ad campaigns to reach a wider network of potential donors beyond their personal circles of connection. Other patients' stories listed on the platform follow a similar narrative format to Nini's story. Viewers are taken through the story of patients' lives by introducing their families, homes, hobbies, and dreams—connecting patients to viewers who may have experienced similar circumstances. By taking a closer look at Nini's narrative, I will demonstrate how *Live and Let Live* idealizes what sociologist Arthur Frank calls “the communicative body” (Frank, 1995), transforming personal stories of patients in need of an organ transplant into persuasive marketing campaigns that “sell” prospective donors the idea that they can potentially save the life of a stranger.

According to Frank, the communicative body is not only an ideal body type, but an *idealized* one (p. 48). The communicative body provides the ethical ideal as it accepts contingency and is fully associated with the self. At its core, the communicative body is dyadic and produces the desire to receive assurance through storytelling with others, which “crystallize the body's ethical dimension” (Frank p. 49) as it recognizes that other bodies can relate to the suffering as being shared. Throughout Nini's story, viewers witness her deep desire to continue to live. She elaborates on the many goals she dreams of accomplishing

and the people she hopes to be there for, saying things such as, “I want to be here for my mom, Alba,” and “I want to get really good at music.” The video ends with her simple request, “Can you help me?” and later, her ultimate desire, “I want to live.” Viewers witness Nini playing the drums, kissing a picture of a tiger, playing with her best friend, and spending time with her mother and father on the beach. Viewers also hear her voice, and the voices of other important people in her life, stitching a narrative that inherently involves the viewer into Nini’s life through her testimony. Now that viewers are invested in Nini’s future, they face with the great responsibility her request for a kidney donation. It is through Nini’s communicative body that the viewer’s body becomes aligned to hers and is led into a communion of her dyadic desire. This presents a reminder to the viewer that Nini’s body does not belong to herself alone, but is constructed in relation to the viewer’s body. Nini’s communicative body sets a dyadic relationship with a body outside of hers and by offering it in a highly personal and visible medium, she creates the space for “reciprocity that is storytelling ... offer[ing] herself as a guide to the other’s self-formation” (Frank, p.17). Although she is still a child, Nini’s dyadic body represents “an ethical *choice* to place [her]self in a different relationship to others” (Frank, p. 37) because her communicative body calls viewers to sacrifice for another. By virtue of the video format, there are multiple times Nini looks straight into the camera, directing her gaze to the positionality of the viewer, which deepens her story as coming to be hu-

man in relation to the viewer. Who wouldn't want to donate a kidney so that Nini can live? Nini's story reclaims and redefines the need for "living for the Other" (p. 15) that Frank argues has been sufficiently lost in modernist culture. Thus, Nini as teller, and the viewer (and, hopefully, a potential donor) as listener, enter the space of the story for one another and redefine what the responsibility of living for others means.

Nini's communicative body recursively creates itself as one that chooses which actions it desires to bring into being. She lists the reasons for why she wants to live in the video, and it is this reclaiming of interruption brought on by her illness, and acceptance of her body's contingency, that allows for her desires to reach others. Frank describes that "only the communicative body can reclaim interruption because only it associates with its own contingent vulnerability. The communicative body makes this contingency the condition of its desire, reaching toward others who share this vulnerability" (p. 165). The dual senses of Nini's body gaining self-reflection and making itself real in action can only be achieved through the communicative body—because it makes her story a compelling one for potential donors. In fact, her story has more than 11 million views already, and is Montefiore Health System's most watched video on YouTube.

However, a perfect story does not exist. Even the idea of placing more weight on an ideal body type, such as a communicative body, marginalizes other types of bodies and narratives that may not fully possess the privileged medium of storytelling.

Upon further research, I found out that Nini's story is fictitious. Although the details have not been specified other than that her story "is based on an amalgamation of real Montefiore patients' stories" (Gianatasio, 2021) and that Nini is not sick, her film was a pilot ad to launch the *Live and Let Live* platform. With no disclosure that Nini's story was invented by the advertising agency that created the platform, the stories of real people who need organ transplants are undermined. Under Nini's video, there are many comments by people who wish they could donate their kidney so that Nini could live. What would happen if they found out that her story was not real?

In addition, the video prioritizes patients who are willing and able to advertise themselves in this highly public way. Guided by prompts, patients can include as many details about their personal lives and relationships as they are willing to share, along with images and audio, which the platform will transform into a heartfelt film (Beer, 2021). I find this very dangerous. The repetitive narrative arc that the *Live and Let Live* platform crafts and replicates through each video is not only disrespectfully simplistic, it also reduces an illness story into a linear narrative form. Patients' stories should not conform to a template structure that is filled out in a Mad Libs-esque way. Otherwise, it creates a "social rhetoric of illness" (Frank, p. 21) that affects how others tell their stories and also shapes the mediation that happens when editorial forces come into play. The formulaic nature of a cut and paste template may help to circulate the stories of patients who seek organ transplants

quickly and persuasively, but they uphold and embed the common metaphors of renewal and “gift-of-life” language that dominates the transplant industry. *Live and Let Live* should trust that their patients are educated and capable of making meaning of their own stories.

While the story advertised through Nini’s video is fabricated, it still offers a testimony that entangles others in what they witness when they receive her account. This forms a “reciprocity of witnessing [that] requires not one communicative body but a relationship of communicative bodies” (Frank. p. 282) between the teller and listener, as well as teller and story. Nini, as the main protagonist of the narrative constructed in the video, adds other individuals—the viewers—to her understanding of her illness and expands the nature of her testimony by placing her story on the greater continuum of other patients’ stories through the community that now exists on the *Live and Let Live* platform. Although finding out that Nini’s story is fictitious undermines the dyadic relationship set up between the teller and viewer, perhaps there is still potential for an ethical demand of real people who are sick and in need of an organ transplant on the *Live and Let Live* platform. Other bodies may commune with their pain if they explore the expansive nature of their testimonies by not limiting what they share to respond to the platform’s cookie-cutter prompts, designed to generate a good story. That way, patients are seen for what their bodies testify to and are a witness to their story as well as the stories of others. In contrast to how the platform’s name—*Live and*

Let Live—places more power in the hands of the organ donor to decide whose life is worth saving, let us instead ask ourselves: “What is my relationship, as a body, to other persons who are also bodies? How does our shared corporeality affect who we are, not only to each other, but more specifically *for* each other?” (Frank, p. 35). Only then can the bodies of the teller and listener be joined in their shared vulnerability and orchestrate a communication of recognition that opens the space of the story for the other.

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