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Improvising Care: A Theatrical Exploration of Turner Syndrome Subjectivities

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Abstract This article discusses an ethnographic theater project designed to explore how social performances of gender and disability shape the experiences of those with Turner Syndrome, a genetic condition causing short stature and infertility. Working alongside two interlocutors with the condition, our rehearsals demonstrate subjectivity to be an ethical, relational, and generative practice of striving for good that fosters self-care and empathy for others. Our collaboration exemplifies how anthropological approaches that engage vulnerability and improvisation encourage our interlocutors to investigate their self-understandings with us in real time. Such communal explorations are frequently punctuated by uncertainty, contradiction, and tension, which shape interrelational processes of self-formation and invite the ethnographer to reflect and improve upon shared expectations for the research encounter. This article therefore outlines a care-oriented anthropology that prioritizes accessibility, recognizes the creative in the everyday, and embraces failure as an inextricable part of our research and the lives of our interlocutors.
[subjectivity, ethics and morality, care, performance, Turner Syndrome]

Karen took a deep breath before plunging the pen into her leg. “I did it!” she shouted with childlike exuberance, triumphantly raising her fists into the air. Without missing a beat, she dropped her arms and turned to the camera, her voice returning to its usual register: “Could you guys see that alright? Should I do it in my arm instead?” She rotated her body, making sure she was still in frame and clicked the pink retractable highlighter above her bicep. “How does that look?” she asked. Barb chimed in: “I didn’t use growth hormone, so I’m not sure, but aren’t you supposed to inject the shot in your leg?” Karen thought for a moment. “Now that you mention it,” she shared, “I would alternate my legs every night, but I never injected in my arm.” She pushed her chair back, and propped her leg up, testing her “shot” again. “That looks good,” Barb confirmed. “I think you should do it that way since it’s more accurate.” Karen scribbled a note to herself in her script. With our livestreamed performance quickly approaching, Barb and Karen diligently offered suggestions like these, informed equally by their experiences with Turner Syndrome and the awareness of a future audience who might learn something from our play about the condition. “Great,” I interjected, “let’s take it from, ‘Mom! Can you grab my shot?’”

Through examples from our rehearsals, this article demonstrates how relational practices of vulnerability and improvisation create space for meaning-making in our everyday lives. I began rehearsals with Karen and Barb in 2019 to explore the gender and disability identities of those with Turner Syndrome through the framework of social performance, which I use to refer to both the socially-situated agency of individuals to present their selves and to the structures that shape which kinds of presentations are considered “normal” or “appropriate.” After sharing their experiences with the genetic condition through several theatrical exercises, Barb and Karen assisted me in drafting and editing a short original play. Karen and Barb wanted to honor the ninety-eight percent of Turner Syndrome fetuses who do not make it to term; *More Than Just the Two Percent*, therefore, imagines the life of a girl with Turner Syndrome who was never born.

The two percent of those who are born with the condition make up one in every 2,000 live female births. The result of a partially or entirely missing X chromosome, nearly all individuals with Turner Syndrome experience infertility and short stature, the latter of which can be alleviated with early intervention of human growth hormone, as Karen demonstrated in our scene. Individuals with Turner Syndrome similarly maintain regimens of hormone replacement therapy to begin what is usually otherwise delayed or incomplete pubertal development. Nonverbal learning disability, heart and kidney defects, and early vision and hearing loss are also common. These dimensions of the condition feature in *More Than Just the Two Percent*, which the nonprofit Turner Syndrome Foundation asked us to revisit as part of their virtual Awareness Month events in February 2021. The play and our rehearsal process exemplify the methodologies I practiced with Barb, Karen, and my other interlocutors to explore their experiences with Turner Syndrome while forging new moments of collective meaning.

Informed by the work of Sherry Ortner (2005), Tanya Luhrmann (2006), and João Biehl, Byron Good, and Arthur Kleinman (2007), I recognize subjectivity both as the political and psychological dimensions of internal experience and as a medium through which individuals strive to make meaning in their lives. In my work, I seek to understand the relational processes that shape these inner worlds and that create space for individuals to transform and live through incongruence and uncertainty. Drawing from recent contributions to an anthropology of ethics and morality from Jarrett Zigon (2011) and Cheryl Mattingly (2014), I emphasize how individuals cultivate ethical growth and self-understanding through everyday challenges and moral striving. Expanding Michel Foucault's (1994) contention that working toward an ideal self is a form of care, I suggest that subjectivity formation is on ongoing and relational process of meaning-making that operates as self-care and as an opportunity to practice empathy in the relationships that shape who we are. I therefore argue that subjectivity, ethics, and care are deeply intertwined, not only in anthropological theory, but also in our lives as we transform the uncertain and incongruent into moments for ethical growth. In this article, I call for increased attention to collaborative and creative ethnographic methods, which foster opportunities to care for the self and for others in an environment built on shared vulnerability. Such approaches mirror the processes through which we cultivate ourselves and our relationships; they enable anthropologists to understand meaning-making in real-time alongside our interlocutors.

During our original in-person exploration in 2019 and our virtual revisitation in 2021, our literal and metaphorical rehearsal space created unique opportunities for Karen, Barb, and I to explore these processes. We relied on the possibilities of improvisation, some of which I incorporated in our rehearsal materials, but much of which Barb and Karen forged as they tailored our time together to meet their needs and aspirations. Our improvisation, I argue, magnifies the ways in which working through the unexpected shapes our everyday interactions. Through additional theatrical approaches including role-playing, Karen and Barb dramatized real-life scenarios that demonstrated the contradictions inherent to the simultaneously internal and external dimensions of experience. Together, Barb, Karen, and I established a dialogic spirit of openness, not only with one another, but with our future audience members.

It is in these moments of improvisation, tension, and vulnerability, I contend, that meaning-making is laid bare. As they reenacted defining moments, Karen and Barb reexamined ethical transformations in their lives while simultaneously creating new opportunities for us to practice care with ourselves and one another. In turn, I include reflexive passages where I grapple with what Nancy Scheper-Hughes (1989) describes as doing “good enough.” By embracing discomfort with the inevitable shortcomings of ethnographic research, I make room to critically examine the indelible ways Barb and Karen have contributed to my own self-understanding and to a reimagining of my approach to accessibility in our rehearsals. This article, therefore, calls for movement toward a care-oriented anthropology that prioritizes accessibility, recognizes the creative in the everyday, and embraces failure as an inextricable part of our research and the lives of our interlocutors.

“She let me be me”: Role-Playing Subjectivity

Karen and Barb sat on the floor of the large dance studio as I handed them each a pen and clipboard filled with lined paper and a copy of “Scripted.” Our first rehearsal together in 2019 was a new venture for all of us, and I wanted to start with something that felt performative but not overly intimidating. I decided on “Scripted,” a role-playing exercise I devised that asked one person to cycle through the roles of Doctor, Mother, Date, and Researcher while another responded as herself to prompts like, “The one thing you should know is,” and, “I am most proud of.” My hope was that “Scripted” would reveal the ways in which Barb and Karen imagined their interactions with others, including how Turner Syndrome impacted these relationships. I explained the exercise, leaving time to answer questions. There were none. Karen volunteered to play herself first, while Barb took on the role of Doctor. But rather than offer Karen the first open-ended prompt, “I go to the doctor because,” Barb immediately went off script: “Why have you come to my office today?” I felt a wave of confusion wash over me, but Karen was unfazed, picking up Barb’s cue: “I’m here for my annual checkup.” In this moment, Karen and Barb implicitly communicated the terms of our rehearsals: they were to be filled with improvisation.

Improvisation is to be expected, if not necessitated, in theatrical explorations. However, in the context of rehearsals I designed to explore the experiences of its interlocutor-actors, Barb and Karen's extemporizations reveal the prominence of improvisation beyond the stage. As Elizabeth Hallam and Tim Ingold emphasize, "There is no script for social and cultural life. People have to work it out as they go along. In a word, they have to *improvise*" (2007, 1). While there are no scripts that predict the course of our lives, I clarify that there are ideological frameworks that provide suggested stage directions for our actions. Like Pierre Bourdieu's (1977) concept of the *habitus*, individual agency operates within and through internalized social and cultural dispositions. As we improvise in our daily lives, then, we create opportunities to perform against these assumptions and expectations, particularly when faced with unexpected moments of tension and conflict that destabilize our sociocultural contexts and rupture our understandings of the world. Improvisation, as a necessary tool for meaning-making in the everyday and in moments of uncertainty, is therefore fundamental to the ongoing formation of our subjectivities. Throughout "Scripted," Karen and Barb demonstrated improvisation, and the subsequent opportunities for meaning it fosters, as a cultural, relational, and emotional process.

"What medications are you currently taking?" inquired Barb, looking intently at Karen. Barb had been playing Doctor for less than a minute, and I already noticed a change in her behavior. She sat upright, clipboard held securely at her chest, scrawling notes even as her full attention remained on Karen. Karen was the opposite; I felt as though she had shrunk. Her shoulders drooped as she gazed at the floor, reciting a familiar list: "Birth control," she paused, remembering something. She adjusted her posture and turned directly to Barb, meeting her gaze with a similar intention: "I should tell you I have Turner Syndrome. Do you know about the condition?" Just as Karen graciously responded to Barb's immediate deviation from the script, Barb was ready to play along with what Karen offered. “I’m somewhat familiar,” she responded, “but I’d love a reminder of what kinds of issues you’re worried about.” Karen was suddenly energized, speaking with confidence as she continued: “Well, I’m short. I’m at higher risk for needing heart surgery. And I’m on hormone replacement.” Karen has had this conversation before, and it appeared Barb had, too: she nodded along with vigor, although it was impossible to tell if it was Barb, Doctor, or both displaying their agreement.

From the outset of our first role-playing activity, Barb and Karen each adopted new body language that not only communicated their characters, but also their relationship to one another. Karen, after all, was playing herself, and yet she instantly transformed in the presence of Barb as Doctor. Drawing from their personal experiences with healthcare professionals, Karen and Barb’s embodied changes reflect the roles we perform in response to immediate social encounters, which are situated within recognized cultural standards (Goffman 1959; Butler 1990). At the same time, their identities within the exercise were not clearly delineated from their identities outside of the rehearsal space. Even the distinction between Doctor and Barb, who herself is not a doctor, became blurry as she nodded along with Karen’s list of concerns.

Feminist theorists Catriona Mackenzie and Natalie Stoljar (2000), in their delineation of relational autonomy, emphasize the fundamentally interpersonal nature of selves and suggest the potential of memory and imagination to shape feminist models of agency. In her ethnographic work on the Japanese introspective practice of Naikan, Chikako Ozawa-de Silva (2006, 2007) similarly highlights the role of memory in cultivating interdependent formulations of the self. Elisabeth De Schauwer, Inge Van De Putte, and Bronwyn Davies’ (2018) study of collective memory in the social construction of disability further demonstrates the multiplicity of selves as a shared, intra-active process. As they articulated and embodied their shifting experiences with normalcy and difference, Barb and Karen exemplified a mutual constitution of identity through their willingness to adjust their performances in immediate response to one another, even when what was being offered was not so much grounded in reality as it was in hopeful imagination.

After Karen finished recounting the medical impacts of Turner Syndrome, Barb responded with gravity, “I think I need to educate myself.” She erupted with laughter. “Wow,” she continued, now out of character, “I wish I had a doctor who said that!” Karen laughed with her, signaling her agreement with Barb’s statement. “Can I offer a suggestion?” Barb asked, turning to me. “Of course,” I said. “When we switch roles, I want Karen to ask about my mental health. I don’t know why they always skip over social and psychological concerns.” Karen smiled, “I can do that!” Karen took a moment to prepare herself to transition into the role of Doctor, briefly consulting her copy of “Scripted” to consider the directions I outlined for the exercise. Satisfied with one of the prompts, she offered to Barb, “I feel pain when,” pausing for Barb to continue. Barb responded without hesitation: “I don’t have chronic pain. I feel pain when I’m left out.” Karen listened intently, taking careful notes as Barb began detailing her experiences with anxiety, isolation, and social belonging.

With Barb’s proposal and Karen’s openness to her suggestion, the purpose of “Scripted” felt fully transformed. Karen and Barb were no longer recounting their experiences with doctors; instead, they were projecting their desires onto the medical encounter—aspirations that were rarely met outside of the transient rehearsal space we had created together. As João Biehl details, subjectivity is the “material of politics” through which “the agonistic struggle over being takes place” (2005, 16). Barb and Karen reenacted numerous struggles during our time together, creating room to imagine different outcomes of transformational events and interactions in their lives. “Scripted” demanded both distance and proximity, where Karen and Barb could safely revisit these moments through critical reflection and shared, embodied knowledge. As they articulated understandings of their past experiences, they simultaneously worked through new potentials for meaning. Operating within a dialogic of reality and imagination, our rehearsals collapsed temporal and spatial boundaries to create opportunities for Barb and Karen's multiple and co-constituted selves to come into contact. Just as these moments of subjectivity formation become particularly evident through Karen and Barb's role playing, so, too, do the social, cultural, and political conflicts that situate and complicate our ongoing realizations of selfhood.

Following their respective interpretations of Doctor, Barb and Karen alternated playing themselves and Mother. As Mother, Karen immediately adopted a sweet tone, moving closer to Barb as she looked at her warmly. Barb played a younger version of herself, speaking in a high-pitched voice and exaggerating her movements. With youthful energy, Barb didn't hesitate to share: "I have a hard time in school, but I feel good when I figure things out." Like many individuals with Turner Syndrome, Barb's character faced a learning disability. Karen took note and transitioned to other issues of potential concern: "Honey, I want you to know that you won't be able to have babies of your own, but you can still adopt. And you may not be as tall as your friends, but that's why you use growth hormone." Barb crossed her arms, looking at the ground. "I wish I had more friends. I try really hard. Maybe I try too hard?" She looked to Karen, who smiled as she gently replied, "Just keep being yourself."

Barb broke character, admitting, "My mom made a lot of mistakes, but she let me be me. I'm so grateful for everything she did." Karen nodded in agreement. "It was harder back then," Barb continued. "My mom had no one to go to. She even tutored me herself." Karen and I remained in rapt silence, maintaining a space for Barb's vulnerable revelations. As she detailed her complicated feelings, Barb also acknowledged the forces beyond her and her mother's control. The actions of her mother—and Barb's response to them—can only be understood in the context of the 1950s and '60s, when doctors still new little about Turner Syndrome, and school systems were poorly equipped to attend to students with the condition. As Barb detailed, "Doctors didn't really know what would happen to me. When I was born, the doctor told my mother there was nothing she could do but take me home and love me."

Anthropologists recognize that emotional lives are not just internal but culturally shaped and socially appraised (Luhrmann 2006; Ozawa-de Silva 2021). Barb's character demonstrated the political dimension of emotional expression when she wondered if she was trying too hard to fit in at school. Wearing her emotions on her sleeve, she realized, was inappropriate with her classmates, marking her as a social misfit. As she discovered, interactions at school were driven by social politics, which influenced her emotional life at the same time her performance of selfhood informed the dynamics with her peers. Dorine Kondo (1990) notes that subjects are always resisting and reproducing oppressive forces of domination, particularly when crafting their selfhoods. In addition to Barb's early social experiences, the politics of medical and educational structures presented constraints for Barb and her mother, providing the substance through which they improvised their approach to gaining knowledge about and resources for Barb's condition. As Barb's testimony highlights, the ability to improvise presents creative solutions to conflict at the same time it reveals contradiction in our lives, like Barb's complicated relationship with her mother. Creating opportunities to improvise and role play through real-life scenarios, therefore, enables investigation of this duality of experience, through which socially-situated tensions become fertile ground for self-understanding.

Once we finished "Scripted," I opened up the floor for discussion. "What did you think of the exercise?" I began. Karen excitedly looked to Barb: "I feel like we know each other better."

Barb enthusiastically agreed. Karen and Barb have been friends for years, first connected through their shared experiences with Turner Syndrome. In less than an hour, they had deepened their knowledge of one another and, in turn, themselves. Through their enactment of a range of characters, Barb and Karen participated in a practice of interrelational discovery that mirrored the improvisation necessary for social life. As they explored instances of care in their relationships through the characters of Doctor and Mother, they cared for one another, listening to each other's experiences and working together to make sense of the past and to reimagine their present. To do so, Karen and Barb remained open to the unanticipated and asked me to do the same. After changing the format of the exercise at the beginning of our rehearsal, Barb caught me off guard again as we wrapped up our work for the day. She wondered, "What about your mom? What did she do for you that made you who you are?" Opening up about my estranged relationship with my mother forced me to confront the same vulnerability I had asked my interlocutors to embrace. In organizing, facilitating, and documenting our rehearsals, I was an active participant in Barb and Karen's self-formation; in turn, they maintained a space where they could similarly contribute as I participated in my own process of self-discovery.

"Now you try it": Experimenting with Ethics

A week later, Karen, Barb, and I returned to our rented rehearsal space. We excitedly chatted as we entered the room. After Barb and Karen followed me in removing their shoes, I passed them each a copy of "Life Course Ballet," our main exercise for the day. Unlike "Scripted," which was grounded in verbal communication, "Life Course Ballet" was centered on movement; no speaking was allowed. The premise of the exercise was deceptively simple, asking Karen and Barb to silently enact, in ten minutes or less, the stories of their lives. The worksheet I distributed outlined a possible trajectory of a life with Turner Syndrome: receiving the diagnosis, going to school, acquiring a job, grappling with infertility, pursuing marriage, meeting others with the condition, and so on. The exercise ended with a nod to the future, asking Barb and Karen to represent any other milestones they had not yet reached. I suggested that Karen and Barb adjust the sketch to best reflect their own experiences.

They each found a spot on the spacious floor, hovering over the script. The silence was occasionally punctuated by the sound of pens making their mark on the page. After about five minutes, they were ready. Unable to use her voice, I could sense Karen's initial apprehension as she stood up to share her short solo performance. She took a moment to survey the space, speaking softly to herself as she made her final preparations. Once ready, she crouched on the ground. Slowly, she stood, lifting her arms above her head and unfolding them with a flourish. Soon, school began, and Karen devised a game of hopscotch, jumping in the familiar pattern on the ground. As she grew into adulthood, her enactment of marriage was unmistakable: she tightly grasped invisible flowers and took slow, purposeful steps as she walked down the aisle. Once her performance was complete, she bowed. Barb and I showered her in applause.

In following my suggested life course trajectory by incorporating recognizable images of events like a wedding, Karen silently communicated the significance of these sociocultural norms as she infused them with her own perspective and experience. Through the choices she made in her ballet, Karen demonstrated herself to be not only an actor in our rehearsal space but also in her everyday life. But rather than flatten Karen's performance as merely a medium for her agency, a concept that can suggest unrestricted free will (Mackenzie and Stoljar 2000; Lambek 2010), I instead turn to practice theory, which underscores that individuals are shaped by the structures they help to generate, producing both constraint and the possibility of change (Ortner

1984). Sherry Ortner locates subjectivity within this productive tension, arguing that “actors are always at least partially ‘knowing subjects’…[with] some degree of reflexivity about themselves and their desires and…the ways in which they are formed by their circumstances” (2005, 34). Simultaneously, our actions and inner worlds are shaped by “the subtle forms of power that saturate everyday life” (Ortner 2005, 46). While Karen’s performance was personal, it was also grounds for the reproduction of certain rigid cultural standards, including gendered expectations of marriage. Karen recognized this need for social legibility immediately after she took her bow, nervously asking Barb and me, “Could you guys understand everything I was doing?” By expressing her vulnerability, Karen extended an invitation for Barb to respond to their shared fears of being understood in her subsequent performance.

Barb began her ballet crouched on the floor in a position nearly identical to Karen’s at the start of her performance. As she continued, Barb borrowed a number of movements and images from Karen, including walking down an imaginary aisle with great fanfare. This was puzzling; while Karen was married, Barb was not. On one hand, Barb’s adoption of the wedding sequence reflected the often unspoken and sometimes explicit assumptions from her family and friends that she would marry—expectations that were replicated in our rehearsal space. However, I do not interpret Barb’s performance as only a response to the immediate social pressure of the performative moment and to the influence of cultural norms in her life; nor do I interpret it as mere mimicry of Karen’s ballet. Instead, I contend that Barb’s performance was a form of witnessing Karen’s embodied narrative. Barb’s use of mimesis revealed the continued interdependence that Barb and Karen forged during our time together, a relationship Barb silently honored through her improvisation skills. She had taken time at the beginning of the rehearsal to plan movements for her ballet, but Karen and I watched as she followed the new trajectory to which she was suddenly drawn. By accepting an improvisatory impulse, Barb generously returned the vulnerability of Karen's performance and acknowledged her real-life experiences. In doing so, a performance meant to reflect Barb's experience instead encapsulated an empathetic connection with Karen, without her ever saying a word.

In their ballets, Karen and Barb enacted some of the structures through which their subjective states were given meaning; however, their performances were ultimately grounded in their relationship to one another. By nurturing their already established friendship, Barb and Karen carved out alternative avenues for meaning-making grounded in shared vulnerability rather than oppressive structures of normativity. In contrast to a "dark anthropology," which emphasizes the power, struggle, and oppression that lies on one side of the agency-structure dialectic of subjectivity (Ortner 2016), anthropologists including Joel Robbins (2013) delineate an "anthropology of the good" that emphasizes the relationality of experience to embrace everyday instances of empathy and care. Rather than articulate abstract manifestations of power in the lives of our interlocutors, a shift toward the "good" in anthropology prioritizes lived moral experience (Zigon 2014; Zigon and Throop 2014) and what Michael Lambek (2010) and Cheryl Mattingly (2014) describe as the ordinary ethics of daily life. Emerging in response to the dark side of practice theory, an anthropology of the good foregrounds the moral practices in our daily lives that enable relational autonomy and self-understanding. In turn, an anthropology of the good underscores a direct lineage between ethics and subjectivity.

In their work explicitly outlining an anthropology of ethics and morality, James Faubion (2011) and Cheryl Mattingly and Jason Throop (2018) draw from robust histories in anthropology and related fields. I further highlight how sociologist Emile Durkheim's influence on anthropological thought extends into theories of morality, for which he was deeply invested throughout his career. As he defines, morals are the norms and values of a society, which possess "a double character of external social sanctions and internal motivation" (Hall 1978, 53). Durkheim's early articulation of morality reflects contemporary understandings of subjectivity, including Sherry Ortner's description of the simultaneous "ensemble of modes of perception, affect, thought, desire, fear, and so forth that animate acting subjects" and "cultural and social formations that shape, organize, and provoke those modes of affect, thought and so on" (2005, 31). Durkheim's distinction between morality and ethics is similarly echoed today in the arguments of medical anthropologists, including Arthur Kleinman (2006) and Byron and Mary-Jo DelVecchio Good (2012), who contend that morals are local while ethics are transcendent.

Michel Foucault offers a nearly opposite formulation of morality and ethics, defining morality as "a vantage point," and ethics as an "active experience" (1994, xix). As "a practice, an embodiment, a style of life," a Foucauldian ethics describes an individual's constant work toward an ideal self (1994, xxvi). Anthropologist Jarrett Zigon (2011) expands this definition, arguing that ethics involves working toward an aspirational self that is always shifting and unattainable. James Faubion (2011) further emphasizes that these ethical practices are clearest in moments of rupture that force an individual to care for themselves as they contend with the unexpected and incongruent. A Foucauldian ethics, therefore, reinforces the claim that subjectivity is a process through which we endlessly aspire toward meaning (Biehl 2005). As Michael Lambek (2010), Cheryl Mattingly (2014), and Tamar Kremer-Sadlik (2019) highlight, daily ethical practices inform even the most ordinary and mundane of experiences.

As Karen and Barb translated their past, present, and future experiences into performances, they simultaneously engaged who they have been, who they are, and who they expect to become. They actively participated in a relational process of striving for a meaningful self as they revisited some of the rupturing experiences that shaped and continue to shape their understandings of the world and their place in it. Karen did so when she reenacted an awkward date during her life course ballet. She impatiently tapped her foot on the ground, holding her hands close to her body as she silently disclosed her infertility, only to shake hands with her invisible date as he departed. She was left anxiously awaiting her next potential romantic partner to arrive, preparing for the same conversation while hoping for a different result. As she performed an interpretation of hearing her diagnosis of Turner Syndrome for the first time, Barb mimed picking up a phone, her eyes darting back and forth in confusion as she listened in on a conversation between who she later revealed to be her mother and endocrinologist. Just like their lived experiences outside of the rehearsal space, Barb and Karen's expressions of defining moments were frequently punctuated by uncertainty and contradiction. Karen interrupted her own performance multiple times, freezing in place as she carefully considered her next step. Barb crafted a tale that only loosely reflected her actual experiences, ending her performance cradling an invisible baby in her arms. Barb happily lives childfree; her character represented a version of herself who does not and cannot exist.

Elizabeth Carpenter-Song (2019) reframes moral failure as part of the process of everyday moral striving in the lives of our interlocutors, which in turn helps prevent solidifying the "suffering subject" as the discipline's most recent Other (Robbins 2013). Barb has accepted her childlessness, sharing with Karen and me that she recognized infertility to be both a loss and a foundational component of who she is. As she laughed, rocking her imaginary child back and forth, Barb literally and figuratively embraced what could not be and acknowledged different possibilities of the self, spontaneously creating a moment for meaning-making while Karen and I looked on. As we come to make sense of the messiness of our lives, I argue, we engage in these moments of moral striving and inevitable failures—which frequently take the form of indecision, inconsistency, and conflict—to cultivate ethical interactions. This is equally true for ordinary experiences and the fieldwork encounter; in both instances, our attempts to understand ourselves and others are always necessarily “good enough” (Scheper-Hughes 1989).

Barb finished her ballet and grinned up at me: “Now you try it.” Yet again, Barb’s improvisation caught me off guard. Despite my years as a performer, I was momentarily frozen. I felt my heartbeat pound in my ears, my mind racing with a million excuses as I tentatively placed my notepad on the floor and rose to take center stage. I already felt like I had failed Karen and Barb last week, having created a version of “Scripted” that they could not, or had deliberately chosen not to, follow. And I could not fathom why Barb had made this request of me; I do not have Turner Syndrome. While I rapidly constructed a narrative in my head, a new thought occurred. Twice now, Barb and Karen had come to rehearsal without knowing what I would ask of them; it was easy to imagine that they might expect the same flexibility from me. I took a deep breath and curled into a ball on the floor to begin my ballet. As I continued to improvise my way through the performance, I returned to Karen and Barb’s performances, infusing ideas from my imagination with their playground antics and ceremonious walks down the aisle. Nervous at first that I could not participate in the exercise without sharing the diagnoses of my interlocutors, my ballet instead transformed into an opportunity to pay embodied witness to Barb and Karen’s interpretations of Turner Syndrome. As I concluded, I took a luxurious bow, met with enthusiastic giggles and applause from my interlocutor-audience. The fear of failure had disappeared, replaced by a feeling of relief—not because the improvisation was over, but because it had opened the door to a shared vulnerability between Karen, Barb, and me. For the first time since beginning my research, I felt a true sense of collaboration, motivated largely by the desire for me to extend the same care Barb and Karen had shown for one another.

“Can I add something there?”: Caring for Change

Karen called me unexpectedly. “I’m here with Barb,” she told me over speaker phone, “we’re going over the script and have some ideas.” Since our first rehearsal, Karen and Barb had been focused on the intended final product of our exploration. After debriefing “Scripted,” Barb and Karen read aloud short, de-identified quotations from my other interlocutors. “I’ve heard these kinds of stories,” Barb shared, prompting her and Karen to reflect on the concerns they had frequently seen others express on Turner Syndrome nonprofit Facebook pages. Recalling a post by a woman who lost her pregnancy with a Turner Syndrome fetus, a flash of inspiration darted across Karen’s face: “What if we wrote something from the viewpoint of a baby with Turner Syndrome who didn’t make it?” Like in their scenes together, Barb took Karen’s suggestion as her cue, listing off critical moments we should include as I frantically jotted them down in my notebook. By our third meeting, I had drafted *More Than Just the Two Percent*. A week later, Karen was calling me, she and Barb full of ideas to mold the play to better fit their ambitions. As they confidently and casually made suggested edits to my writing, I felt the visceral weight of frustration tug at me, suddenly unmoored from my role in our collaborative process.

Disclosing an explosive argument with one of his interlocutors, Paul Rabinow (1977) details the conflicts and subsequent emotional and ethical revelations inherent to building relationships and understanding with our ethnographic subjects. After Karen ended our call, I struggled to understand why I had felt so immediately defensive, my frustration now replaced with guilt and uncertainty. With consideration of the context of our rehearsals and Karen and

Barb's goals for our performance, I understand this unsettling realization through the framework of care. As Arthur Kleinman (1988) contends, caretakers place an impossible demand on those in their care to be simultaneously submissive and independent. While Barb, Karen, and I were not interacting in a traditional caretaking context, I felt protective and responsible over them and our work together. And although I encouraged Karen and Barb to act as equal contributors and to openly share their thoughts, I simultaneously held fast to ownership of the play and its creative vision. When Barb and Karen embraced the former, they in turn revealed to me the latter, and therefore the inherent contradiction of my expectations for our collaboration.

Faye Ginsburg and Rayna Rapp (2001) emphasize that ambivalence is always present when we care for others. As we create opportunities to understand ourselves and deepen our relationships through interdependency, the roles we inhabit as caretaker and cared for exacerbate the differential power dynamics that shape human interaction (Murphy 2015). Karen, Barb, and I juggled multiple objectives as we embarked on an experimental process that we each hoped, in our own way, might promote education of and awareness for Turner Syndrome, and therefore improve the lives of those with the condition. As we navigated the bounds between hope and finitude that Michael Lambek (2010) finds central to care as a means of ethical striving, we were left to reckon with the limitations of our roles and aspirations while attempting to meet the needs of one another. We strove to do good, working through tensions that created possibilities for us to reflect on ourselves and to contribute to change. Care is therefore not a static relationship within clearly defined medical or therapeutic boundaries but rather an opportunity for ethical growth woven into our daily interactions. Arthur Kleinman (1988) resolves that care is a lopsided power struggle; it is also fundamentally human (Kleinman 2015).

In 2021, Turner Syndrome Foundation presented us with an opportunity to revisit *More Than Just the Two Percent* for a livestreamed performance. During our first virtual reunion, Barb and Karen already had new ideas. Not far into our read-through of the script, Barb stopped: “Can I add something there?” I nodded for her to continue. “I think we should emphasize that pursuing pregnancy is dangerous for most women with Turner Syndrome. Can we add that disclaimer before the bit about talking to your doctor about IVF?” Barb made an important point: for the few women with Turner Syndrome who can conceive, the risks can be great, as pregnancy places additional strain on potential pre-existing heart conditions. Now more familiar with Barb’s thoroughness and passion, I was not surprised by this suggestion, and was grateful for it. Karen and Barb had demonstrated their unwavering dedication to the Turner Syndrome community since we sat down to outline *More Than Just the Two Percent* in 2019. Before I could say anything, Barb asked, “What kind of audience are we envisioning for the play?” Karen agreed: “Maybe that will help us figure out the purpose of the performance. We want it to be educational, right?” Although I had designed our rehearsals primarily to better understand their experiences, and therefore to inform my research, Barb and Karen were always focused on our future audience. By transforming the expectations of our process to meet their desires of helping other families and individuals with Turner Syndrome, Karen and Barb carved out surprising moments for self-discovery. Their care for others, in turn, created opportunities for them to better understand themselves and one another, enriching our shared project in unexpected ways.

At the end of our Zoom rehearsal, Barb and Karen examined their rooms to ensure the spaces would work for the performance. Karen noticed a photograph on the dresser behind Barb. “What’s that a picture of?” she asked. Barb fetched the small frame and held it up to her computer camera. A photo of Barb and her siblings came into view. “I never realized this before," she started to tell us, "But this is the last of my family. None of us have any children, so this is the end of our lineage." Everyone was quiet for a moment. "Now that you mention it," Karen broke the silence, "That'll be the same for me." Karen is a self-described "bonus mom" to her stepson but has no biological children. Earlier in the same rehearsal, Karen and Barb expressed their concern to provide accurate information about infertility and pregnancy risks to those who would attend our performance. Now, they came face to face with the rupturing realities of their own experiences with infertility. Considering the gendered history of care as women continue to supply the majority of care-oriented labor in the United States, including raising children and looking after elderly relatives (Susser 1989; Diquinzio 1993), the relationship between Barb and Karen's dedication to the welfare of future generations and reflections of their own legacies becomes all the more poignant. Caring for others with Turner Syndrome does not supplant Karen and Barb's lived experiences with the condition; rather, their long histories of activism with the community are a means through which they make sense of their own narratives and create new models of feminist care practices outside the bounds of traditional conceptualizations of mothering and family.

Whether engaging in self-care as a process of ethical transformation or providing resources and support for another, care is an everyday practice. Michael Foucault (1994) frames curiosity as one such "technology of the self," as it encourages us to examine what exists and imagine what might be possible as we cultivate our identities. Driven by uncertainty and the potential of the unknown, ongoing practices of self-cultivation are always an experimentation. As Andrew Irving (2017) details, the root *peira*, meaning to test, attempt, or put into peril, is shared between *experiment* and *experience*. In other words, we experiment as we attempt to make sense of our experiences; similarly, Arthur Kleinman (2015) highlights how caring for others demands fluidity and improvisation. Healthcare workers and therapists constantly improvise and intuit how to meet the needs of their patients (Kleinman 1988; Mattingly 1998). As Cheryl Mattingly (2014) illustrates, parents must similarly extemporize as they strive to build the best possible lives for themselves and their children, especially when raising a disabled child. Across extraordinary and mundane interactions, both those providing and receiving care must embrace their vulnerability as they face the unknown and try their best to work through it. For anthropologists interested in studying subjectivity, care not only provides a theoretical backbone for understanding the messy ethical practices of daily life but also illuminates the creative, improvisatory, and ultimately vulnerable interactions through which we forge meaning. When we foster opportunities for curiosity and experimentation, the ethnographer finds similar moments for growth, and, by extension, humility, as a researcher and as an individual.

As our 2021 rehearsals continued to offer Barb and Karen opportunities to practice care for themselves, one another, and others with Turner Syndrome, they also offered me the chance to address something I had failed to consider in 2019: the impact of nonverbal learning disability (NVLD) on our rehearsals. NVLD is characterized by strengths in verbal reasoning and communication and difficulties with social cues, spatial awareness, and executive functioning. Although I had been aware of its association with Turner Syndrome, not until a conversation with psychologist and NVLD expert Dean Mooney did I recognize how the disability manifested in my research. NVLD could help to explain why Karen, Barb, and so many of my interlocutors were clearly apprehensive when presented with abstract or movement-based scenes like "Life Course Ballet." In both our 2019 and 2021 performances, Barb and Karen consistently ad-libbed lines where there were none, demonstrating their preference for verbal-based communication. Despite my failure to provide a fully accessible rehearsal space, Karen and Barb had improvised.

In creating better accommodations for themselves, they silently communicated to me ways in which I could improve our rehearsals and, therefore, my understandings of them.

In 2019, I was bothered by these constant changes to the script; I held onto the belief that theater must showcase equally spoken and embodied performance and wanted to preserve this vision in our work. With a clearer understanding of NVLD, I embraced the necessity of Barb and Karen's initial modifications, which served as an invitation for me to improve as a collaborator and approach our 2021 rehearsals with a different attitude toward the bounds of theatrical exploration. As Karen and Barb increasingly recommended swapping silent sections of *More Than Just the Two Percent* for clearer dialogue, I recognized these changes as a part of Barb and Karen's concern for the audience. When Barb expressed her relief that she would no longer have to manage holding both her script and a clipboard with multiple pieces of paper, which I had asked her to use to communicate to the audience which of the many roles she was playing in any given scene, I understood how listening to Karen and Barb's accommodation requests enabled me to strengthen our relationships. And when, during a viewing of our play for a small group of the Turner Syndrome community, everyone chuckled in recognition when Karen's character forgot to grab her backpack on the way to school, I realized we had succeeded in developing a meaningful dialogue between Barb and Karen, their characters, and our audience, aided in part by a recognition of everyday experiences of disability in the play itself and in our rehearsals.

Conclusion: Toward a Care-Oriented Anthropology

In their contributions to a special issue of *Ethos*, Jarrett Zigon and Jason Throop outline compelling cases to cultivate an anthropology of moral experience from an anthropology of morality, thereby prioritizing lived practices of the moral over abstract, ethical concepts (Zigon

2014; Zigon and Throop 2014). To do so, they call for developing more robust ethnographic approaches to critically examine the slippery concepts of subjectivity, ethics, and morality. I contend that collaborative and creative approaches, like the theatrical explorations I organized with Karen and Barb, encourage us to experiment through meaning-making processes alongside our interlocutors. Already, anthropologists including João Biehl (2005), Cheryl Mattingly (2014), and Sherry Ortner (2016) have reframed subjectivity as a medium of experimentation rather than agency. In doing so, they foreground the foundational interplay between uncertainty and possibility as we work toward meaning. As our rehearsals illustrate, experimenting with the unknown demands we embrace vulnerability, improvisation, and our subsequent failures. Through these failures, we can further explore and actively contribute to the striving that shapes our subjectivities. Furthermore, grappling with failure engages our reflexivity as researchers as we demonstrate respect for our interlocutors and the limitations of our role as ethnographers of their experiences. Reflection and growth, as practices of empathy, are already interwoven into the ethical fibers of subjectivity formation, making care an ideal framework for expanding the toolbox of approaches for a rich catalog of anthropologies of moral experience.

As we expand our imaginaries of the kinds of ethnographic methods that can promote self-reflection for ourselves and our interlocutors, we simultaneously practice a discipline-wide reflexivity. Byron Good (2012) contends that subjectivity cannot be studied devoid of historical context; I further argue that it is critical to investigate the longstanding and shifting theories of the term in the discipline. When we delve into its history, we find that an anthropology of ethics and morality has long been entangled in definitions of subjectivity as a deeply embedded, daily process of caring for the self and others. Theatrical explorations, like my rehearsals with Barb and Karen, represent one of many ethnographic possibilities for fostering the kinds of vulnerable and improvisatory interactions that give rise to who we are. While Michael Foucault (1994) maintains that care of the self is more important than care for others, our rehearsals demonstrate that care of the self, care for others, and the self-cultivation that fosters interdependence are mutually constituted practices. It appears that human existence, and our subsequent search for meaning as relational beings, is care (Mattingly 2014; Kleinman 2015). As anthropologists interested in human experience and the ethics of our work, we cannot afford to ignore this fact.

While many of us take care for granted, it is a conspicuous, lived reality for many disabled individuals, some of whom retain caretakers, and nearly all of whom implicitly—if not explicitly—highlight the scarcity of interrelational modes of being as a political resource and social necessity. Importantly, developing a care-oriented approach to disability is not synonymous with a rehabilitation anthropology, which Russell Shuttleworth and Devva Kasnitz (2004) criticize for focusing on medicalized models of disability causes, cures, and doctor-patient interactions. Rather, it demands we prioritize the vulnerable and generative dimensions of human interdependence. Anthropologists including Cassandra Hartblay (2020) have recently called for formulating a distinct disability anthropology. While an anthropology of disability importantly centers the lives of disabled individuals, a disability anthropology situates these experiences within theories of disability to provide a critical scaffold for understanding relational processes of categorization, difference, and meaning-making.

A growing body of work, including contributions from Karen Sirota (2010) and Cheryl Mattingly (2017) examines ethics in the lives of disabled individuals, particularly those with intellectual and developmental disabilities. An anthropology of ethics and morality therefore carves out avenues for expanding a disability anthropology, and vice versa, encouraging anthropologists to equally consider the stories of disabled individuals and the utility of disability theory as they work to understand embodied experiences of the moral. Using collaborative and creative methodologies, we develop compassionate ways to be with our interlocutors that enable us to actively contribute to their ethical strivings for good, if not their explicit activist endeavors. I argue that this recursive process is part of a thorough and integrative approach to accessibility. By striving to accommodate our interlocutors' bodies, preferences, and expectations for our enduring research encounters, we not only care for our disabled and able-bodied subjects; we also challenge ourselves to experiment with creative modes of ethnography. In turn, we make space for theories and lived realities of disability as we expand the horizons of anthropology.

Like disability studies, which reveals the normative representations and environmental designs that reproduce certain bodies as abnormal or undesirable (Siebers 2008; Linton 2010), a care-oriented anthropology can be applied beyond studies explicitly interested in care. It takes seriously the centrality of ethics in our lives, prioritizes accessible research methods, and recognizes how creativity shapes the everyday processes that give meaning to life. In doing so, a care-oriented anthropology requires that we brace for, and ultimately embrace, failures in our work. As Andrew Irving emphasizes, failure is "necessary to all forms of representation—including ethnography—and we might add that failure is also necessary to learning about people's lives, entering new social worlds, and the ethnographic project" (2017, 223). João Biehl (2005) similarly reminds us that our ethnographic products never quite compare to our experiences in the field, especially as we attempt to capture the complex entanglements that give rise to our interlocutors' experiences of themselves and the worlds in which they are situated.

As Jarrett Zigon (2011) defines, subjectivity formation is an ongoing, always incomplete striving toward an ethical self; so, too, are our ethnographies never perfect nor complete. By explicitly engaging collaboration and creativity in our anthropological approaches, we accept the probability of failure. In turn, we contribute to self-reflection and understanding alongside our interlocutors as we leverage the generative powers of vulnerability and improvisation for communal moments of self-discovery. In turn, our approaches not only mirror the ethical processes inherent to subjectivity formation, but also enable us to cultivate empathy as a reflexive interaction with our interlocutors. As we strive to meet the needs of our ethnographic subjects, we practice care as anthropologists. Even if—or rather, when—we fail, we simultaneously make room for more creativity and, therefore, possibility (Kleinman 2006). This is, after all, what we and our interlocutors do every day as we strive toward our best selves.

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