ENACTING THE POLITICS OF CARE WITH CHRONIC AND CRIP TECHNOLOGIES

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This panel contributes to studies of chronic illness, impairment, and disability as embodied and systemic ways of thinking about, and with, technology and the forms of care that chronically ill, impaired, and disabled folks do for themselves and others. Issues of care – and what we *mean* by care -- are increasingly centered in studies of disabled and chronic living with technologies. This panel places the politics of care at the heart of analyses of technology and the forms of intimacy and socially transformative work people do with and through technologies and their informational and data infrastructures. Care is a capacious concept in studies of chronic and crip technologies: covering "an action (to perform in ways that support others), an affect (to feel empathy or compassion), a mode of engagement (to 'care about' a person or situation) and politic (to insist on the importance of caring), and even a tool for social change (whether for subverting hegemonic norms or justifying discrimination)" (Ruberg and Scully-Baker 2021, 656). These practices and feelings vis-à-vis technology are

situated between "enclosed regimes of self-care" and their individualizing models of selfhood and "collective communal care" frameworks. The latter reveal conditions familiar to those of us living chronic, impaired, disabled, and differently embodied lives and the "uncompromisingly tethered nature of human dependency," its contingencies and mutual precarities (Sharma, 2017, para. 20, para. 4).

Each talk examines the situated, contextual politics and strategies of care enacted by those living with chronic illness, disability, and impaired difference in their relationships to technologies and their related infrastructures – of information, medical oversight, and platformed communities. Panelists build on Hamraie and Fritsch's (2019) conception of "crip technoscience" and the "practices of critique, alteration, and reinvention of our material-discursive world" to examine the politics and practices of care that Type 1 diabetics, breast cancer survivors, and Deaf HIV positive folks do with chronic and crip technologies. Their uses of technology and the internet trouble notions of the "chronic" and the "crip" and the ways they can both pathologize while also naming, articulating, and strategizing around their conditions of living (see Bennett 2019). These terminologies are not unproblematic; as Jonathan Sterne argues, chronic illness, disability, and impairment each signal "the different work of metaphors" and how they can be used to trouble relationships between "human and system impairments" (Sterne 2021, p. 35, p. 34).

For folks who live these metaphors and their materialities, they experience how the fleshy "affordances of human bodies" interact with material-discursive technologies in ways that vividly reveal their "human/data assemblages" (Lupton 2020, p. 18) and "intimate infrastructures" (Forlano, 2017). Drawing from feminist and queer technoscience studies, the talks on this panel examine the constitutive entanglements of bodies, technologies and systems in Type 1 diabetic continuous glucose monitoring and the intimate feeling of their numbers and data visualization; in the politics of displaying the physical marks of mastectomy in Instagram selfies and the platform vernaculars people use to make the grief of breast cancer's gendered loss representable; in the ways Bay Area Deaf AIDS activists in the 1980s and 1990s remediated their access to information through infrastructures of care they built for themselves and others; and in the ways Type 1 diabetics navigate the material culture of insulin pump treatment as both compulsory and liberating. Thinking across their research on breast cancer, Type 1 diabetes and Deaf AIDS activism, the panelists examine what it means, and *is*, to care for oneself and others in relation to what it feels like to navigate technologized, datafied, and materially marked lives.

References

Bennet, Jeffrey. (2019). *Managing diabetes: The cultural politics of disease.* New York, NY: New York University Press.

Forlano, Laura. (2017). Data rituals in intimate infrastructures: Crip time and the disabled cyborg body as an epistemic site of feminist science. *Catalyst: Feminism, Theory, Technoscience 3*(2)*.* Special Issue on Science out of Feminist Theory. Retrieved from https://doi.org/10.28968/cftt.v3i2.28843

Gibbs, Martin, Meese, James, Arnold, Michael, Nansen, Bjorn & Carter, Marcus. (2015). #Funeral and Instagram: Death, social media, and platform vernacular. *Information, Communication & Society*, 18:3, 255-268, DOI: 10.1080/1369118X.2014.987152.

Hamraie, Aimi & Fritsch, Kelly (2020). The crip technoscience manifesto. *Catalyst: Feminism, Theory, Technoscience, 5(1),* 1-34*.*

Lupton, Deborah. (2020). *Data selves: More than human perspectives.* Polity Press.

Ruberg, Bonnie & Scully-Baker, Rainforest. (2021). Making players care: The ambivalent cultural politics of care and video games, *International Journal of Cultural Studies, 24*(4), 655-672.

Sharma, Sarah. (2017). Exit and the extensions of man. *Transmediale: Art and Digiculture*. Retrieved from https://transmediale.de/content/exit-and-the-extensions-of-man

Sterne, Jonathan. (2021). *Diminished faculties: A political phenomenology of impairment.* Durham, NC: Duke University Press.

FEELING NUMBERS AND DATA INTIMACY IN TYPE 1 DIABETES

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This talk examines the ways some people with Type 1 diabetes relate to continuous glucose monitoring (CGM), its assemblages of sensor and receiver technologies, and its quantification of sugar in diabetic bodies, as numerate forms of self-intimacy and self-knowledge in relation to other diabetics. Ways of knowing diabetes through its quantification and data visualization powerfully shape what it means to be diabetic; it is also a large part of what it is to "do" diabetes as a set of increasingly data-driven health management practices in relationship with technology (Mol and Law 2004). Being Type 1 diabetic and knowing oneself as diabetic are inseparable from the methods people with Type 1 diabetes do to quantify their sugars (in blood, and in interstitial fluids via the CGM), and the devices they use to track and visualize their management of living with this disease around these measures. Type 1 diabetics lead, as Evan Calder-Williams (2014) puts it, a "biopolitical life, in which all food is quanta and [our] blood speaks in numbers" (para. 30). If living with diabetes is a "condition of being metric" (Williams, 2014, para. 29), we ask whether and how some Type 1 diabetics experience this condition (defined by their bodies' lack of insulin production) as forms of intimate feeling and self-knowing; intimacies that emerge through their entanglements with glucose sensors, mobile app receivers, and networked insulin pumps and in relation to other people with diabetes, medical professionals, families, and their communities.

The authors of this paper analyze their own long-term experiences of living with Type 1 diabetes, its devices and quantification practices via transcripts of interviews they conducted with each other to assess the different, diffractive ways they interpret their self-understandings of living a quantified chronic life in relation to multiple networked medical devices. Knowing diabetes intimately has enabled the authors to tune in to some of the similarities and differences that other Type 1's express in relation to how they "feel" their numbers, and what kind of relationality this creates between the person and their diabetes, between diabetics, and between diabetics and others (Kennedy & Hill, 2018). We draw on a feminist technoscience framework for our interview methodology to center ourselves as subjects who are "living chronic" (Arduser 2017), mobilizing our experiential and observational knowledge of Type 1 to examine, as well, the structures of inequality and the enactments of exclusion that diabetics face, name, and participate in over the course of their lives.

In addition to drawing on their own interviews, the authors also analyze how other Type 1s represent what it feels like to quantify themselves and to engage with the visualization of their sugar measures via their medical devices, focusing most directly on Type 1 diabetes blogs and posts made in Type 1 Facebook groups and on Instagram. Across these materials, we examine the ways people with Type 1 diabetes talk and write, as well as the things they post (such as screenshots of data visualizations of their sugar measures), about the quality and kinds of relationships they form with the datafied results of their sugar measures. Responses to the line graphs of sugar measures that CGM technologies provide via mobile apps and integrated insulin pumps, for instance, reveal the ways in which CGM users may "judge and invite normalizing prescriptions" (Webb, 2003, p. 225) about their own and others' diabetes management. It also reveals the ways some people celebrate "good numbers" or even identify their own happiness with the "flat line" of overnight CGM glucose measures, as one of the authors experiences, in ways that can also function socially to exclude or marginalize those without good numbers, and for whom good numbers might be a constant struggle.

In examining the patterns in how people talk, use, and interpret data visualizations from their CGMs, we aim to understand how people feel about theirs and others' numbers, and how that feeling shapes their chronic and crip epistemologies in relation to non-diabetics and other diabetics. "Feeling" in relationship to diabetic numbers refers to "the emotional dimensions of engaging with data and their visualisation" (Kennedy & Hill, 2018, p. 834); we examine not only how individuals feel about *their* numbers, but how they feel in relation to *others'* numbers. Drawing on Margaret Wetherell (2012) we approach emotion in our study as "relational patterns" that form between diabetics, and between diabetics and non-diabetics, via affectively experienced modes of practice (p. 21). In our interview transcripts with each other, and in our collection of online Type 1 posts about data visualizations of their sugar measures, the authors examine how Type 1 diabetics talk about, represent, and deploy their "datafied body doubles" – their "device-produced numerical stand-ins" (Horrocks 2019, p. 9) – in ways that are deeply felt in relation with others.

Our analysis focuses on how data visualizations of Type 1 diabetic self-quantification feel to people with Type 1s in contexts where Type 1s are primarily talking to one another, but in ways that are also often visible to non-diabetics under the felt

surveillance of "monitored performance" (Lucherini, 2016). Type 1s talk and self-present this quantified relationship and its visual and graphical representation in view of others, and they feel this monitoring. Data visualizations produced by CGM mobile apps and insulin pump software translate minute-by-minute automated glucose readings into colourful graphical representations of glucose readings over time, from 1-24 hours in the daily use of CGMs, and from 2 weeks to 3 months in the online graphical interfaces provided by companies that do online CGM data management. The set of data visualizations we analyze are drawn from the authors' own corpus of CGM glucose data and other examples drawn from Type 1 diabetes online forums. We are especially interested in how Type 1 diabetics differently deploy data visualizations of their glucose measures in the process of keeping records for themselves and presenting themselves to others, through mobile phone photos of the graphical line marking one's sugars on the screen of one's insulin pump, screenshots of the CGM mobile app interface and its line graph representation of glucose measures, and downloadable color graphs of glucose measures over longer time periods, alongside other forms for declaring and depicting one's number (e.g. via verbal or textual report, for instance). On social media, these uses of data visualization can become key avenues for qualifying the self and accounting for diabetic selfhood (Humphreys, 2018).

There are technologized forms of intimacy at the heart of diabetic self-quantification practice and data visualization over time: affective, felt epistemologies of chronic, and sometimes "cripped," relationships diabetics have in relation to their diabetes technology and other diabetics. While the data visualization of CGM measures might bring diabetics into closer relation to themselves, this relational device-driven dependency can also feel unwanted, imposing, and unchosen (Forlano, 2016). Diabetics *feel* their practices of quantifying diabetes: sometimes they feel really bad, and sometimes they feel great, and everything in-between. They demonstrate and express these feelings through how they relate to, talk about, see, and show their glucose numbers and their data visualizations to others. These practices can, in turn, also obscure or even amplify how experiences of diabetes continue to be conditioned by entrenched structures of inequality and lack of access to full healthcare. They sometimes "feel bad" because other's numbers are so good. How these "data sensibilities" (Lupton, 2020, p. 76) feel emerge over the long time periods in which Type 1s (ideally, at least) live and continue to live chronic lives, revealing crucial archives of chronic and crip technologies that can both reveal and conceal some of the specificities of diabetic identity and experience.

References

Arduser, Lora. (2017). *Living chronic: Agency and expertise in the rhetoric of diabetes.* Columbus: Ohio State University Press.

Forlano, Laura. (2016). Hacking the feminist disabled body, *Journal of Peer Production*, *8*. Retrieved from http://peerproduction.net/issues/issue-8-feminism-and-unhacking-2/peer-reviewed-papers/issue-8-feminism-and-unhackingpeer-reviewed-papers-2hacking-the-feminist-disabled-body/

Forlano, Laura. (2017). Data rituals in intimate infrastructures: Crip time and the disabled cyborg body as an epistemic site of feminist science. *Catalyst 3*(2)*.* Special Issue on Science out of Feminist Theory. Retrieved from https://doi.org/10.28968/cftt.v3i2.28843

Horrocks, Stephen. (2019). Materializing datafied body doubles: Insulin pumps, blood glucose testing, and the production of usable bodies. *Catalyst: Feminism, Theory, Technoscience, 5*(1), 1–26. Retrieved from https://doi.org/10.28968/cftt.v5i1.29613.

Humphreys, Lee. (2018). *The qualified self: Social media and the accounting of everyday life.* Cambridge, MA: MIT Press.

Kennedy, Helen & Hill, Rosemary Lucy. (2018). The feeling of numbers: Emotions in everyday engagements with data and their visualization, *Sociology, 52*(4), 830-848.

Lucherini, Mark. 2016. "Performing Diabetes: Felt Surveillance and Discreet Self-Management." *Surveillance & Society, 14*(2), 259–76.

Mol, Annemarie and John Law (2004). Embodied action, enacted bodies: The example of hypoglycaemia, *Body & Society, 10*(2/3), 43-62.

Webb, Stephen A. (2003). Technologies of care. *Information and communication technologies in the welfare services,* ed. Elizabeth Harlow and Stephen A. Webb (pp. 223-238)*.* London: Jessica Kingsley Publishers.

Williams, Evan Calder. (2014, December 17). The honeyed siphon, *The New Inquiry.* Retrieved from https://thenewinquiry.com/the-honeyed-siphon/

#MASTECTOMY ON INSTAGRAM: SELFIES, PATIENT VISIBILITY AND GENDERED LOSS

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This paper approaches people's creation of #mastectomy selfies on Instagram through the conceptual and analytic framework of gendered loss and the platform vernaculars breast cancer survivors use to represent themselves and their scars. It approaches the mastectomy–a surgery with directly gendered implications–as forms of gendered loss. On Instagram, people living with breast cancer and its post-surgical materialities post "autopathographic" photos that both perform and reckon with such loss (Tembeck, 2016), but in ways that do not look like illness. In autopathographic photographs, the subject depicted has a specific desire to be identified as a person who not only has but who also continues to live with the illness in question (Tembeck, 2016, p. 9). In the corpus of hashtagged and captioned #mastectomy selfies I analyze, mastectomy

photos function as public proclamations of having had breast cancer, in ways that seem to suggest the surgical intervention was, in part, the end of their illness. They reveal the physical markings and comportments of women who have had one or two breasts surgically removed – the *signs* of breast cancer -- but for the most part, the women depicted do not look sick. #Mastectomy selfies tend to communicate "I have had a mastectomy" but they rarely say, "I am sick," even as breast cancer -- like so many other cancers -- is increasingly recognized as a chronic illness.

 #Mastectomy selfies, I argue, portray the condition of breast cancer and the surgical intervention to remove one's breasts less as a sign of existing and chronic illness, and more as a sign of having had and lived through a mastectomy. They serve a documentary function, indicating recent patient status, but also a certain milestone in treatment, in the sense that surgery might be one of several steps in their medical journey. They consist of more than texts to be read and suggest an encounter with the subjectivity of another, which cannot be expressed solely through language. As Alessandro Delfanti and Salvatore Iaconesi (2016) suggest, "In the face of illness and disability, digital cultures often imagine and perform technologies as social and relational prostheses, as opposed to bodily prostheses" (p. 126). In sharing these selfies, current and former patients become visible to each other in an online space and contribute to the development of an online community of women with mastectomies. In this sense, the hashtag #mastectomy acts not only as a label, but as a unifying tool: the hashtag is a link, literally and figuratively, to a community that may prove invisible in offline spaces.

Many of the selfies I analyze do not appear, then, exactly like the autopathographic photos of breast cancer that Tamar Tembeck (2016) so powerfully analysed. They may "attest to personal experiences of illness or hospitalization" (p. 4), but their point seems in general to be to *not* portray illness per se. What they do reveal, perhaps, is the ways women navigate the experience of loss and grief from mastectomy in the context of breast cancer through the processes of making, posting, and commenting on #mastectomy selfies on Instagram that communicate something else. The gendered loss of the mastectomy in these selfies, then, does not generally appear in the form of "sad girl" selfies, that is, as something primarily negative, making visible loss via tears, reddened faces, and other signs of affective burden typical of sad girl Instagram selfies (Holowka, 2018). Instead, as this paper analyzes, #mastectomy selfies on Instagram serve as potential sites of self and collective affirmation around another kind of articulation of breast cancer loss and grief, one that tarries more directly, but uncomfortably and unevenly, with the happiness politics of breast cancer philanthropy and the "recovery" focused aesthetics of so many self-help-oriented selfie aesthetics.

Selfies posted with the hashtag #mastectomy on Instagram vary, though they may be loosely categorized as self-portraits of individuals who voluntarily expose their mastectomy scars, often in poses that suggest that they have made it through surgery and are now learning to live in their adjusted bodies. Picking up on the gestural nature of selfies – as photos that are meant to communicate and be shared (Senft & Baym, 2015) -- #mastectomy selfies are not just for the photographer but for others who will encounter the images and share them further; selfies "document the self for

consumption by others," (Ori Schwartz quoted in Marwick, 2015, p. 141), or as Paul Frosh puts it, selfies say "see me showing you me" (Frosh, 2015, p. 1610).

While operating within recognizable platform vernaculars and adopting influencer-style habits, #mastectomy selfies also create a networked community wherein patients may grieve their pre-mastectomy selves and honour their post-mastectomy identity. Locating the #mastectomy selfie within Instagram's platform vernaculars (Caliandro and Graham 2020; Gibbs et al. 2015), this talk considers how the optimism of breast cancer culture and the visibility afforded by Instagram converge, and what this means for preconceived notions of grief and mourning. In the #mastectomy selfies I analyze, many are full-length photos of the subject standing in front of a mirror; others are taken with the front-facing camera in which the subject is usually visible from the waist up. Some #mastectomy selfies depict subjects bare-chested with their scars in full view, while others depict their subjects wearing hospital gowns or wrapped in bandages in clinical settings that suggest they were taken just after mastectomy surgery. Many of the selfies appear to be taken at home, where women pose themselves to show their unilateral (one breast) or a bilateral (both breasts) mastectomy scars. Others show women who have undergone breast reconstruction, and some wear bras specially made for women who have had mastectomies. In several, even those in the hospital, #mastectomy selfies depict subjects appearing with happy and cheerful dispositions, posing with their thumbs up signalling "okay" or with two fingers up in a peace sign.

Yet despite their perhaps exaggerated looking cheerfulness, something else seems to be at work here besides the hyper-feminized politics of breast cancer happiness and its related images of optimism and hope (Ehrenreich, 2010; King, 2006). Among other things, these selfies reformulate boundaries between public and private through openly sharing medical experiences of mastectomy that otherwise still tend to be so hidden, and even stigmatizing. Analysis of the comments and talk around these selfies suggests there is far more complexity to what appears, a lurking discourse of loss and grief that seeps through the portrayals in the selfies, revealing something more about the genres of #mastectomy selfies, the cultural and political work they could be doing on the platform, and the spaces for talking about and representing the enduring, but under-acknowledged, chronicity of breast cancer. These selfies represent a congealing of social media practices and patient visibilities, and have much to teach us about how gender, loss, and mourning are performed within the current social media landscape. They might prompt us to ask further: What might a politics of gendered loss vis-à-vis mastectomies look like if a fuller representation of its various affective experiences were more readily witnessed in the presentation and production of mastectomy selfies? How could a broader (and more intersectional) range of women's experiences of mastectomy and breast cancer expand the cultural and aesthetic platform vernaculars, and the imperatives that drive them on Instagram, in ways that could more readily portray the embodied loss of mastectomy?

References

Caliandro, Alessandro & Graham, James. (2020).Studying Instagram beyond selfies. *Social Media + Society,* 6(2), 1-7.

Cotter, Kelley (2019). Playing the visibility game: How digital influencers and algorithms negotiate influence on Instagram. *New Media & Society,* 21(4), 895-913.

Delfanti, Alessandro & Iaconesi, Salvatore. (2016). Open-source cancer: Brain scans and the rituality of biodigital data sharing. *The Participatory Condition in the Digital Age.* Eds. Barney, Darin, et al. (123-144). Minneapolis: University of Minnesota Press

Duffy, Brooke Erin. (2017). *(Not) getting paid to do what you love: Gender, social media, and aspirational labor.* New Haven, CT: Yale University Press.

Ehrenreich, Barbara. (201). *Bright-sided: How positive thinking is undermining America.* New York, NY: Picador.

Frosh, Paul. (2015). The gestural image: The selfie, photography theory, and kinesthetic sociability. *International Journal of Communication,* 9,1607-1628.

Gibbs, Martin, Meese, James, Arnold, Michael, Nansen, Bjorn & Carter, Marcus. (2015). #Funeral and Instagram: Death, social media, and platform vernacular. *Information, Communication & Society*, 18:3, 255-268, Retrieved from DOI: 10.1080/1369118X.2014.987152.

Holowka, Eileen Mary (2018). Between artifice and emotion: The "sad girls" of Instagram. *Leadership, popular culture, and social change*. Edward Elgar Publishing.

Jain, Lochlann. (2013). *Malignant: How cancer becomes us*. Berkeley, CA: University of California Press.

King, Samantha. (2006). *Pink ribbons, inc.: Breast cancer and the politics of philanthropy*. Minneapolis: University of Minnesota Press.

Leaver, Tama, Highfield, Tim & Abidin, Crystal. (2020). *Instagram: Visual social media cultures*. Cambridge, UK: Polity Press.

Lorde, Audre. (1980).*The cancer journals*. San Francisco, CA: aunt lute books.

Marwick, Alice. (2015). Instafame: Luxury selfies in the attention economy. *Public Culture,* 27(1), 137-160.

Senft, Theresa M, & Baym, Nancy K. (2015). What does the selfie say? Investigating a global phenomenon. *International Journal of Communication,* 9,1588-1606.

Tembeck, Tamar. (2016). Selfies of ill health: Online autopathographic photography and the dramaturgy of the everyday. *Social Media + Society,* 2(1), 1-11.

DEAF AIDS ACTIVISM AND BAY-AREA TECH HISTORIES

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In the late 1980s and early 1990s, the San Francisco Bay area was home to an emerging tech boom, the most developed AIDS service infrastructure in the U.S., and concentrated disability activism. This paper draws on archival research to argue that this intersection is not only consequential: it is key to advancing knowledge of how HIV left an imprint on emerging communication technologies and to better understanding how sexuality and disability factor in technological cultures. The paper focuses on a specific organization called the Deaf AIDS Center, and their work to advocate for remediation of HIV-related information for the Deaf community. Specifically, we focus on how this organization framed Telecommunications Device for the Deaf (TDD), a technology that used teletype machines and modems to facilitate "telephone" communication using text. The Deaf AIDS Center advocated for wider access to TDD in the AIDS service sector, while also marking its inadequacies as a substitute to the high touch, caring, one-to-one interpretive work needed by many ASL speakers (TDD relies on written English).

The Deaf AIDS Centre operated out of St. Benedict's Catholic Church for the Deaf from 1988 until it became part of the University of California, San Francisco in the mid 1990s. Led by Darol Vance, a straight, white woman who was deaf and a lifelong advocate, the organization focused on creating accessible AIDS information resources for the Deaf community through resource guides, TDD advocacy, interpretation services, and other forms of outreach. In this focus on outreach, the organization looked like scores of other AIDS service organizations, but made information accessible to deaf people who experienced a lack of access to culturally specific resources, and stigma around homosexuality and substance use from existing deaf services (Gaskins; Stevens; Peinkofer; Gannon). This work took place within a broader national context of deaf AIDS outreach, including similar organizations in other cities, and the National AIDS TDD Hotline.

We undertake a media history of the Deaf AIDS Center, asking how the organization's grounding in San Francisco's Deaf gay life worlds shaped its capacious understanding of information as one facet of a larger caring practice, and modem-supported access provisions as helpful but ultimately inadequate to supporting communication for chronically ill people using ASL. To make this argument, we specifically analyze the Deaf AIDS Centre's advocacy for TDD alongside their record keeping practices. While most activist and service organizations' archives are comprised of file folders containing records of administrative paperwork, the Deaf AIDS Centre compiled their papers, photographs, and other media into five large scrapbooks. Using techniques of bricolage, annotation, and candid photographs, the scrapbooks show how the Deaf AIDS Center facilitated a high-touch care network and interpreting service for Deaf gay men dying from AIDS as an intrinsic part of their access politics and everyday information work. Portraits of men in hospice appear alongside documentation from workshops on ethical ASL interpretation of conversations about HIV, and documentation of Deaf volunteers operating TDD phone lines. Living, dying, and finding information were deliberately entwined; as Vance explained at the annual Deaf memorial service, the organization

was guided by, "REMEMBERANCE for those who have died of AIDS…. HOPE for cure, better treatment, understanding, communication…. ACTION for better services to improve networking and accessibility…. [and] LOVE for everyone." Reading across these scrapbooks, we argue that Deaf culture's intersection with HIV in San Francisco enriches understandings of information as care, and nuances celebrations of modems and computing through a disability studies lens. The research contributes to internet studies work on alternative histories of Silicon Valley, and minor internet histories (Paloque-Berges; Rankin).

Our analysis is grounded in a few intersecting literatures. Recent scholarship has revisited questions about information, access, and HIV from an historical perspective, framing AIDS activist work with information and networks as critical experiments (Lubin and Vaccaro; Esparza, Brewster, and Ruberg). These histories build on media studies written during the North American AIDS crisis (Juhasz, Crimp), and complement recent theorizations of care and care networks developed in and through AIDS and its structures of harm and survival (Cifor; Fink; Watkins-Hayes; Jolly). We bring these literatures into dialogue with media studies of deafness and Deaf culture (Bruegemann; Hickman; Mills; Sterne; Bauman & Murray) and the literature on scrapbooks as affective media in queer and trans archives (Edwards; Moynihan). We ask how the remediation of information through the situatedness of disability reorients our understandings of care, technology, and information.

References

Bauman, H.D.L. and Murray, J.J. eds. 2014. *Deaf gain: Raising the stakes for human diversity*. Minneapolis, MN: University of Minnesota Press.

Brewster, K., & Ruberg, B. 2020. SURVIVORS: Archiving the history of bulletin board systems and the AIDS crisis. *First Monday*, *25*(10). Retrieved from https://doi.org/10.5210/fm.v25i10.10290

Brueggemann, B.J. 2009. *Deaf subjects*. New York, NY: New York University Press.

Cifor, Marika. 2022. *Viral cultures: Activist archiving in the age of AIDS.* Minneapolis, MN: University of Minnesota Press.

Crimp, Douglas. 1987. Introduction: AIDS: Cultural analysis/cultural activism. *October*, 43, 3–16. Retrieved from doi: https://doi.org/10.2307/3397562.

Driscoll, Kevin & Paloque-Berges, Camille. 2017. Searching for missing "net histories." *Internet Histories,* 1(1-2), 47-59. Retrieved from DOI: 10.1080/24701475.2017.1307541

Edwards, Rebekah. 2015. 'This is not a girl': A trans* archival reading. *TSQ,* 2(4), 650–665. Retrieved from doi: https://doi.org/10.1215/23289252-3151574

Esparza, René. 2021. 'Qué bonita mi tierra': Latinx AIDS activism and decolonial queer praxis in 1980s New York and Puerto Rico. *Radical History Review,* 140, 107–141. Retrieved from doi: https://doi.org/10.1215/01636545-8841706

Fink, Marty. 2020. *Forget burial: HIV kinship, disability, and queer/trans narratives of care.* New Brunswick, N.J.: Rutgers University Press.

Gannon, C. 1998. Developing HIV/AIDS resources for the deaf. *SIECUS Report, 26*(2), 19-20.

Gaskins, S. 1999. Special population: HIV/AIDS among the deaf and hard of hearing. *Journal of the Association of Nurses in AIDS Care, 10*(2), 75-78.

Hickman, L. 2019. Transcription work and the practices of crip technoscience. *Catalyst: Feminism, Theory, Technoscience*, *5*(1), 1–10.

Jolly, Jallicia. 2019. From 'at risk' to interdependent: The erotic life worlds of HIV+ Jamaican women, *Souls*, 21(2-3), 107-131. Retrieved from DOI: 10.1080/10999949.2019.1705084

Juhasz, Alexandra. 1995. *AIDS TV: Identity, community, and alternative video*. Durham, N.C.: Duke University Press.

Lubin, Joan., & Vaccaro, Jeanne. 2020. AIDS infrastructures, queer networks: Architecting the critical path. *First Monday*, *25*(10). Retrieved from https://doi.org/10.5210/fm.v25i10.10403

Mills, Mara. 2012. Do signals have politics? Inscribing abilities in cochlear implants. *The Oxford Handbook of Sound Studies* (pp. 320–346). Oxford, UK: Oxford University Press.

Moynihan, Bridget. 2020. Digital decoupage: Reading and prototyping the material poetics and queer ephemera of the Edwin Morgan Scrapbooks, 1931-1966. PhD Diss, University of Edinburgh. Retrieved from https://era.ed.ac.uk/handle/1842/37005

Peinkofer, J.R. 1994. HIV education for the deaf, a vulnerable minority. *Public Health Reports, 109*(3), 390-396.

Rankin, Joy Lisi. 2018. *A people's history of computing in the United States*, Cambridge, MA: Harvard University Press.

Sterne, J. 2003. *The Audible Past*. Durham, NC: Duke University Press.

Stevens, H. 1998. AIDS, not hearing aids: Exploring the link between the Deaf community and HIV/AIDS. *Health and Human Rights, 2*(4), 98–113.

MEDICALIZED FREEDOM THROUGH CONTROL: A CRIP CRITIQUE OF THE TECHNO-LIBERATION OF TYPE 1 DIABETES

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Approximately 1.25 million people in the United States—9 million worldwide—have been diagnosed with Type 1 Diabetes (Centers for Disease Control and Prevention, 2017). Not to be confused with the more common Type 2, Type 1 Diabetes Mellitus (or T1D) is an autoimmune disorder which eliminates the body's ability to produce insulin altogether. Because the body uses this hormone to break down and use carbohydrates for energy, people with T1D must take multiple daily injections or insulin pump infusions of artificial insulin to process the food they eat and prevent other related health problems from developing (Eisenbarth, 1986; Morran et al., 2015). For nearly 40% of people with T1D in the US, these injections are automated through the use of insulin pumps and networked blood glucose monitoring systems that have proved life-changing—nothing short of a "miracle," as one individual put it—and understandably so (Heinemann et al., 2015).[1] A chronic illness requiring constant attention and awareness of what is happening with(in) the body, T1D can be overwhelming and exhausting. Given the conglomeration of medical, social, financial, temporal, and emotional complications of living with and treating Diabetes, the prevalence of Diabetes burnout is alarming if still unsurprising (Polonsky, 1999). Any respite from T1D's constant presence can be, in a word, liberating.

But that new freedom means constant connectedness with—and repetitively connecting to—multiple medical devices in ways that fundamentally transform T1D bodies, materially and phenomenologically. As people use and engage with these devices, they become embedded within (and extensions of) people, their bodies, and their social selves. That process produces altered people, altered bodies, and altered technologies as medical need and cultural norms make these use acts compulsory. In this paper, I analyze informant discussions alongside quantitative data sets collected from Twitter Diabetes Online Communities (DOC) related to their treatment practices at the nexus of their bodies and their Diabetes treatment devices, first as a material experience and then as a phenomenological or conceptual one, in an attempt to answer two primary questions. First, what does the act of use do to/for informants' material experiences with their treatment devices and their world? And second, how does that material experience influence the ways they *understand* their bodies and use experiences?

The material culture of insulin pump treatment, I argue, constructs and is in turn built by data-centric images of the Diabetic body. The act of using insulin pumps, continuous

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[1] Ashley, interview, female age 26, diagnosed with T1D in 2000, June 1, 2017.

glucose monitors, and blood glucose meters relies on conceptualizing the body as data—what I call Datafied Body Doubles—and through constant connectedness, incorporates these images into people's lives and bodies (Author, 2019). Though these medical devices are frequently framed as technological gateways to users' freedom and independence, those discourses rely on a definition of Diabetes as medically un-free, inflecting people's embodied experiences with ableist assumptions of dependence.

By describing and analyzing some of the most influential locations of device-connected T1D materialities, as identified by informants—namely their infusion sets (where the pump attaches to/under the skin) and their pump devices themselves, this study centers the datafied T1D body in relation to its material lived experience. I then turn to the material traces left by these devices in/on the bodies of patient-users, examining the experience and implications of rashing, scarring, and so-called infusion site rotation. Last, I follow those networked devices in their production and deployment of Datafied Body Doubles: from new measurements systems and blood glucose meters, to technologically produced "freedom" in continuous glucose monitors, and finally to the contradictory rhetorical framework of freedom through control at the site of insulin pump use.

As I will show, material and datafied bodies are also fundamentally social, and these embodied experiences require an agency-centered reframing of bodies/the body—a process common among Critical Disability Studies/Crip Studies scholars such as Alison Kafer (2013), Aimi Hamraie and Kelly Fritsch (2019), Laura Mauldin (2016), and Robert McRuer (2006, 2018), which likewise informs how we can approach the technologies and use acts entangled in these practices—to account for the complexities of *choice* and materiality in T1D treatment and life more generally. The freedom these informants have been promised through their devices, and have in some cases sought out with vigor, is actually a freedom *from* their own bodies and lives deemed unlivable. As one informant offhanded noted, despite the treatment regime requiring control over one's body and one's very self, "you don't control Diabetes, you manage it. There is no controlling it."[2] Yet people with T1D are stuck in a medicalized system both compulsory and unrealistic, both life-sustaining and body-controlling. The tension built into that type of liminal experience can be a lot to handle, especially when added to the experience of living with chronic illness in general. In response, some people use that tense in-between space to push back against the defining and confining that networked insulin pump treatment can produce. In so doing, they call attention to and critique the normalization of ableist conceptions of embodied freedom that discount/devalue life with chronic illness and that permeate cultural understandings of T1D, identifying rich sites of much needed nuance in discussions of Diabetes treatment devices and of medical device use in the US more broadly.

References

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[2] Michael, interview, male age 41, diagnosed with T1D in 2010, May 19, 2017.

Horrocks, S. (2019). Materializing datafied body doubles: Insulin pumps, blood glucose testing, and the production of usable bodies. *Catalyst: Feminism, Theory, Technoscience*, *5*(1), 1-26.

Centers for Disease Control and Prevention. (2017). *National diabetes statistics report, 2017*. Centers for Disease Control and Prevention, US Department of Health and Human Services.

Eisenbarth, G. S. (1986). Type I Diabetes Mellitus. *The New England Journal of Medicine; Boston*, *314*(21), 1360–1368.

Hamraie, A., & Fritsch, K. (2019). Crip technoscience manifesto. *Catalyst: Feminism, Theory, Technoscience*, *5*(1), 1–33. Retrieved from https://doi.org/10.28968/cftt.v5i1.29607

Heinemann, L., Fleming, G. A., Petrie, J. R., Holl, R. W., Bergenstal, R. M., & Peters, A. L. (2015). Insulin pump risks and benefits: A clinical appraisal of pump safety standards, adverse event reporting, and research needs: A joint statement of the European Association for the Study of Diabetes and the American Diabetes Association Diabetes Technology Working Group. *Diabetes Care*, *38*(4), 716–722. Retrieved from https://doi.org/10.2337/dc15-0168

Kafer, A. (2013). *Feminist, queer, crip*. Bloomington, IN: Indiana University Press. Retrieved from http://www.jstor.org/stable/j.ctt16gz79x

Mauldin, L. (2016). *Made to hear: Cochlear implants and raising Deaf children*. Minneapolis, MN: University of Minnesota Press.

McRuer, R. (2006). *Crip theory: Cultural signs of queerness and disability*. New York, NY: New York University Press.

McRuer, R. (2018). *Crip times: Disability, globalization, and resistance*. New York, NY: New York University Press.

Morran, M. P., Vonberg, A., Khadra, A., & Pietropaolo, M. (2015). Immunogenetics of type 1 diabetes mellitus. *Molecular Aspects of Medicine*, *42*, 42–60. Retrieved from https://doi.org/10.1016/j.mam.2014.12.004

Polonsky, W. (1999). *Diabetes burnout: What to do when you can't take it anymore*. Arlington, VA: American Diabetes Association.