



Sick Futurity

a zine collaboration by
Lyndsey Beutin &
Cal Biruk

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Cover includes image of Queer Tarot deck by Ashley Molesso and Chess Needham

we1come

This zine showcases experimental methods and embodied forms of knowledge production that challenge dominant discourses about chronic illness and common methods of quantifying care, with specific attention to living with diabetes in North America. We problematize the narrative of “surveillance for care” in diabetes management by utilizing photo-elicitation interview methods that give type 1s space to imagine thriving futures beyond living-by-numbers (A1C tests, blood sugar monitoring) used in healthcare settings. In so doing, we challenge narrow definitions of wellbeing that naturalize neoliberal healthism and racial capitalism. The project envisions what a future of wellbeing for all would look like if sick and disabled people’s perspectives were centered. This is sick futurity for everybody’s freedom.

Sick Futurity is inspired by an organic collaboration that has prioritized queer care over biomedical technology during five years of conversations between Lyndsey (a type 1 diabetic for 20+ years, and more recently a media studies & Black studies scholar) and her partner Cal (a non-diabetic medical anthropologist and science and technology studies scholar). Our collaboration is itself an experiment in what we call ‘radical interdependence as method.’



This is Cal’s drawing of a koala. Cal started calling everything related to diabetes “koala” to make sick talk feel warm, cute, and playful instead of sterile, medicalized, and like constant accounting.

Before there was 'method': On orientations and beginnings

Lyndsey: Let's talk about what brings you to the project.

Cal: what brought me to the project was you, because the universe brought us together and that's how I came to understand what some of what it's like to live with type one diabetes and all of the ways in which the various technologies impinge on the everyday, linear flow of life that many people take for granted.

One of the earliest memories I have of you and type one is the first time that we slept together and you took your [insulin] pump off. I asked you about it because I hadn't really seen one up close; it was lying there detached from you on the bed. And I remember you seemed kind of ashamed of it and didn't really want to get into why you had to wear it. Since then, I've learned so much from our conversations about bodies, health, technology, care, and chronicity.



As a medical anthropologist, I've always been interested in assumptions about what health is. **The idea that health is something that should be achieved as if it's a merit system has always bothered me.**

As a transmasculine person who doesn't always fit into the world, I think a lot about medicine and discourses of health and bodies and norms and how they inevitably impinge on us and our self-conceptions. I've really appreciated how you live in a way that confounds or challenges dominant neoliberal ideas of health, rooted in ableism, heterosexism, racism. Just through living your life, I've witnessed you doing all of the theoretical and methodological work and thinking that decades of medical anthropology and science studies literature and scholars are working out, often in a more abstract and less embodied way.

Cal: What about you? What brings you to this?

Lyndsey: I'm glad that you brought up the beginning of our relationship because one of my memories of our early dating life in Philly is a time I came back from the endocrinologist and I was really upset about my A1C being high. I was in...I almost said Tim Horton's but, no, I was in a Wawa, haha. I called you on the street corner and I was mad and frustrated about getting a bad grade for diabetes management, so to speak.

And then, you took an approach that I had never experienced before. You said **it's just a number, it can't tell you what your health is like.** I remember you said something about me being grounded, or balanced, and an interesting thinker and that was part of good

health. I remember feeling so cared for in that moment.

I haven't thought about that in a while, but it speaks to this long burning hunch that we have co-developed through conversations about numbers and diabetes. So much of my daily life is living by the numbers, and especially before I met you, that was the **predominant way of understanding success, failure, shame, and blame in illness.** This one number [A1C] stands in as the indicator of everything else: how you're doing, how you're managing, what your future outcomes will be in terms of complications [from diabetes].

What is A1C?

A1C is a measurement of your average glucose levels over the past three months.^{1,2} It's used by healthcare professionals to measure how well your diabetes is being managed and is given as a percentage.¹

The goal for most people with type 1 or type 2 diabetes is an A1C below 7%.³



But what brought me to this project initially was that I wanted to do something about surveillance. When I was in grad school around probably 2013, I took a surveillance studies class, and I remember that the visiting professor would always respond to my critiques of surveillance by saying, **“surveillance can also be used for care.”**

She would inevitably use health surveillance as the example of surveillance for good. I remember

finding this deeply troubling and problematic as a type 1 who was connected to several surveilling devices. Especially in the early 2010s, I was very **worried that the mass collection of diabetic data** through these devices and proprietary software would be weaponized against us by health insurance companies denying claims if blood sugars were out of range, etc.

I also found it very patronizing - here we are talking about all the negative implications of biometric surveillance via wearables but then the rhetorical rejoinder was like, "there's a silver lining: it can also help sick people." And so from that, I have kept this idea in my back pocket [Cal: in your back pocket with your pump!]: to use the experiences of type 1 diabetics who wear insulin pumps, and who have lived through different iterations of diabetes technology, as a way to **push back against this really simple idea of "the good part of surveillance is to help sick people."**

And relatedly, I wanted to use a creative **ethnographic visual method to create broader visions of what diabetic freedom could mean**, could look like. Annemarie Mol, in her book *The Logic of Care*, does a nice analysis of how diabetes technology advertising mobilizes a discourse of freedom - look how normal and untethered your life can be if you use our device! - but in reality, the technologies, and diabetes management in general, is very demanding. It controls your life [pun intended].

Cal: Right.

Lyndsey: So, I wanted to use a photo elicitation method where diabetics would take photographs of

what freedom could look like or does look like for them, and then use the photos as prompts in an interview process, which would create a visual archive of **life beyond the numbers.**

What connects this project to my research in critical race studies is the desire to imagine broader horizons of freedom for everyone, including sick people.

The different racializations of the figure of the type 1 and the type 2 diabetic are very revealing. The type 1, racialized as white and middle class, uses technology to turn them into a complete, otherwise wholly rational liberal subject, who just needed a technological "fix."

The type 2 is figured as non-white, poor, a 'bad subject' who puts themselves at risk through their pathological choices, and is to blame for their poor health. The imagined race of the type 2 figure also shifts in relation to the cultural context and the national imaginary of marginalization. In the U.S. the "bad diabetic" type 2 figure is predominantly Black women, and in Canada, it's predominantly Indigenous people.

Since I think about race and liberal subjecthood a lot in my research, the **relationships among freedom, technology, and race become crystal clear in the discursive construction of diabetes.** I also write about the memory of slavery, so I see a lot of historical and structural connections with **sugar.**



NUMBERS, MATTER

The black case on the desk, opened to reveal
a sword to prick a finger, to slice a
number from skin

"What is THAT?" "Are you okay?"

High/low, number-centric beating heart &
breathing lungs

A monkey's prehensile tail wrapped around
enumerated states

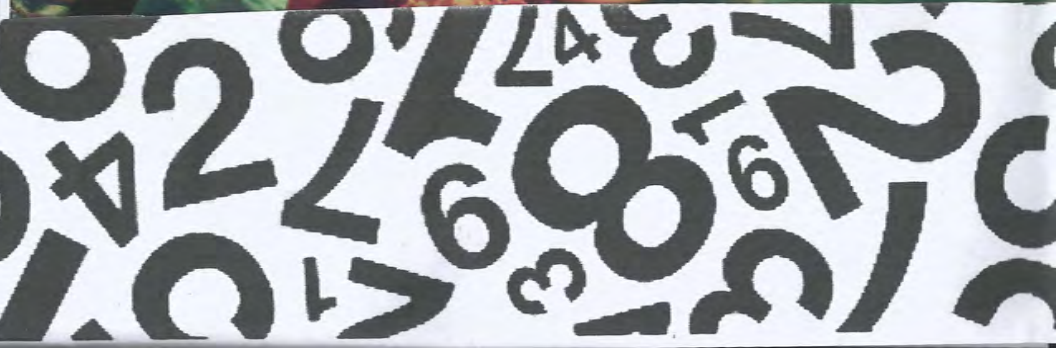
HEALTH, metrical enigma

A joey wrapped warmly in a koala's
pouch

making room where the world doesn't.

poem: cal Biruk

blood: Lyndsey Bentin



field notes

March 18



today was terrible
i was feeling bad + grumpy +
tired on my bike ride over thinking my
sugar was high. but just checked
and it was 145 after 2 pieces of
pizza so YAY! today was terrible
i had a meltdown on the phone
with cal atx. trying to make all my
doctor's appointments + none of them
worked out. CGMS still is not
scheduled, eye dr. not available to
june 2 ~~dr.~~ dr. cardillo booked so long
+ now wont be able to go because in
LA - nobody helping me!!! but everybody
blaming me for not doing better. its all
terrible. theres nothing to be done. →
powerless ness. Plus ive been feeling
like crap + my skin is all rashy

Vietnamese Shrimp Lettuce Wraps

with Cucumber Slaw and Peanuts

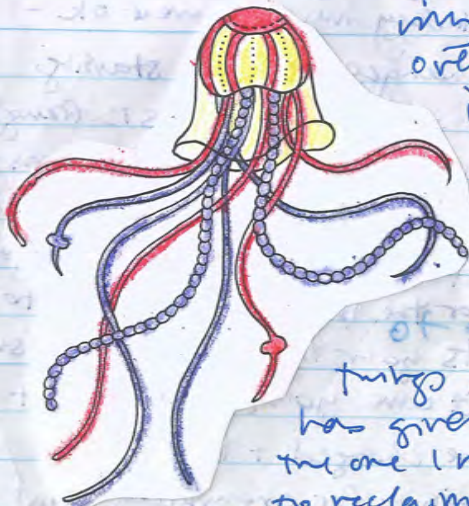
Koala 59
pts

June 2, 2016

EYES ALL OK!

writing big because still
dilated + cant really
see - today's insight:

most want to reclaim +
re purpose is
my



overactive
imagination
of the
future

of all the
things diabetes
has given me
the one I most want
to reclaim + re purpose
is my overactive im

#ethnographersheart



Steak Bulgogi Bowls

with Kimchi Pickled Cucumbers and Crispy Rice

51 Koala pts.

Reimagining 'method': On photo elicitation, interdependence, and moving beyond numbers

Cal: Since it sounds like the genesis of the photo elicitation method for you comes from a frustration with limited constructs or imaginary of freedom, I wonder if you could talk a little bit about how you see those ads you mentioned constructing freedom or how you see dominant discourses about technology and diabetes constructing freedom and how it relates to your broader interests in the liberal subject and its conscription into other projects? And speculate maybe on what kinds of things do you think people will take pictures of or what, for instance, might you take a picture of?

PHOTO ELICITATION METHOD

Research participant takes photo in response to prompt

for example, what does a future of freedom look like to you?

amazing insights to conversation results

image is viewed by researcher + participant

researcher asks "how does this image depict [concept] for you?" during interview

Lyndsey: I love using creative methods and after I learned about photo elicitation, I've always wanted to have a project that uses it. I think its theoretically interesting in this project because it destabilizes photography. Visual studies and Communication studies have known for a long time that the photographic object, that objectivity itself, is constructed. But the idea that photographs capture reality objectively remains very prominent in society. So, I like the idea of asking people to **take a picture of an imaginary future**. By photography's logics, that should be impossible, right?

I thought that prompt would lead to some interesting conversations. I assume people will take very abstract pictures, but I am also hoping that people will take pictures of mundane aspects of their life. I could imagine someone taking a **picture of the bathtub, which is a place where you have to disconnect from all of your devices** in order to go in. I don't think any type ones necessarily want to be disconnected from our devices. They are literally what keeps us alive, but I could imagine someone taking the prompt in that direction.

I could imagine the opposite direction as well. People who are the quintessential figure of the successful type one who isn't slowed down in any way, despite having to wear all these devices and stuff. You always hear these heroic stories about type ones. They are supposed to be our models for overcoming [Ca]: This reminds me of Eli Clare's discussion of the dominant image of the supercrip in "The Mountain"], and I could imagine someone taking a picture of doing something amazing while having all their devices

on them or something like that, you know beating the disease through the technology.

I would probably take pictures of practices that ground me. I could imagine taking pictures of my garden, and then **the interviewer asks me: what made you take this picture?** I could talk about medicinal herbs, but not in the hippy dippy way that diabetics hate. (When you first get diagnosed, in activist communities it's very common to hear you should just use herbs, which of course would not work, and you would die.) I think that would be an interesting photograph because the herbs are not about a cure for me. They are about a connection to the land. Gardening does actually lower your blood sugar numbers it turns out, and why does it do that? Because you're calm, and anything that reduces stress can be a really powerful way of managing diabetes. Doctors and nurses are starting to talk about the connection to stress, but for the majority of my time as a diabetic, it was not discussed, which I always found ironic because living with diabetes is stressful!

In terms of the construct of freedom, my favorite continuous glucose monitor is called the Libre, right, literally "free" in Spanish. The company that makes the Libre is called Freestyle. Free, free, free. So it's all of this construction of trying to free you from the imprisonment of being sick or disabled or something.

But the funny part is that **all of this freedom actually means being tied to all these devices which are produced through, you know, massive capitalist industries and have all kinds of profit motives that are not the same as health-based motives.**

Why is there incentive to care for type ones? Because it's such a lucrative industry to make devices for type ones. So, I think the discourse of freedom is quite interesting and very rooted in liberal enlightenment ideas.

That brings me to something that is really important **about our collaboration**, which is in addition to you taking the approach of a medical anthropologist which has helped me think about my own **sickness beyond the numbers**. You also bring expertise about the literature and interest in the theoretical questions that are being asked. I'm not a medical anthropologist and I'm not very interested in being one, but I know many times you have said to me, "you should have been a medical anthropologist" because of different things I've said about diabetes just from processing my experience. We didn't formalize our co-researching relationship until I had a complete freak out when trying to read the literature about diabetes to work on the surveillance for care project. I didn't like reading it, I didn't like reading about my own illness that I didn't know about and all of these non-diabetic researchers seemed to.

I felt that some of the stuff they were saying was not correct, I felt that some of it overly dramatized certain aspects in ways that if you actually live with it if that's not how it feels.

But mostly I just felt so overwhelmed by reading about all of these horrible futures that await me with diabetic complications. So, I just couldn't do the literature review and I shelved the project.

But having you involved in the project provides an opportunity for not only theoretical intervention, but to do some of that aspect [reading that literature] which is also in line with your training as a medical anthropologist. I see that as a form of **radical interdependence as method**, that lived insights about sickness can make theoretical intervention in the literature with the help of an allied and legit trained researcher on those topics, haha.

Cal: Your interest with coming up with creative methods to think about bodies, health, chronicity, it fits into a moment where people are increasingly conscious of the limits of thinking about health as a thing that is contained within our skin or within our body (here, Michelle Murphy's ideas in "What can't a body do?" especially come to mind).

There is a move toward thinking about **health as distributed in the world by all kinds of structural forces and inequalities**. As an entity that is unequally distributed and constructed to uphold the status quo. So, our method that we're trying out is in contrast to a kind of clinical investment in converting bodily processes, things happening within the body, bodily lack, say, into numbers and then using those numbers as a representation of a person or a person's body. With this project we're interested in thinking differently about the body or even **moving away from this idea of the contained body as the locus of health or illness**.

Photo elicitation – a sample

Prompt: Take photographs of your diabetes supplies, including any old technologies that you still have but no longer use.



This is a picture of the first continuous glucose monitoring (CGM) system from Medtronic. Medtronic's CGMs are the worst and they are way behind the innovations of Dexcom. I have always used Medtronic products and I was an early adopter of its CGM. It was the absolute worst!! Look at that needle!! It hurt like hell, did not insert well, and did not work well. I was miserable wearing it. I couldn't sleep, the alarm was always going off. I decided to stop using it, and I felt so guilty about that. Like, I somehow wasn't doing everything in my power to help myself if I didn't subject myself to that torture device, which was also not very accurate. Thinking back on that mentality now, it strikes me as so disordered – the medical apparatus would have you believe that not sleeping and being miserable is somehow **BETTER FOR YOUR HEALTH**. As much as I hated that thing, I love that I was an early adopter of the technology and that I kept it in my archive of obsolete diabetes technologies. I mean that needle is epic, even for people who deal with many needles, injections, and insertions every day. I want to give that needle an award. **MOST PAINFUL AND LEAST EFFECTIVE BLOOD SUGAR MONITOR award** goes to....

Actually, this photograph gives you an overview of my museum of obsolete diabetes technologies. I am not sure why I find it so fascinating to have all this stuff, but I think it has something to do with how many technologies I have been a part of in my 20+ years of being a diabetic and how they were all promoted as the last hurdle in diabetes management until we get a cure. Well, that cure is not coming. And these technological innovations seem to know no chill, lol.



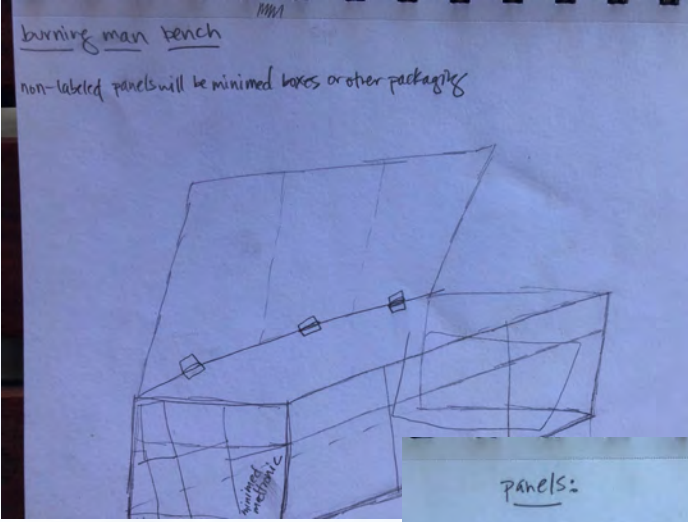
There's something about living on the cutting edge of technological innovations that never quite work well enough and definitely never live up to the hype. Experiencing this cycle year after year, innovation after innovation, gives you a real insight into the **mystique of technology for freedom** – it's complete bullshit. At different points I have really resented having to lug all these supplies around. I used to keep the old ones as backups, like even if they are old, they would work in a pinch, if I lost access to health care for any reason. It was a burden because I've mostly lived in collective houses or small apartments without any storage space, so I have often fashioned my diabetes boxes into furniture. Like this trunk.



Actually, one year I went to Burning Man and designed a diabetes bench as part of our camp's installation that was reimagining NYC's Astor Place as car-free (this was circa 2007?). The bench was a resting place to check your sugar and treat a low. Inside it had all the supplies you would need to change a pump site or give an injection. I thought of it because I hated lugging my supplies everywhere, but I always went low in NYC from long days of walking all over town and if by chance my pump ripped out and I needed a new insertion, I could be an hour+ by subway to where I lived in Brooklyn.

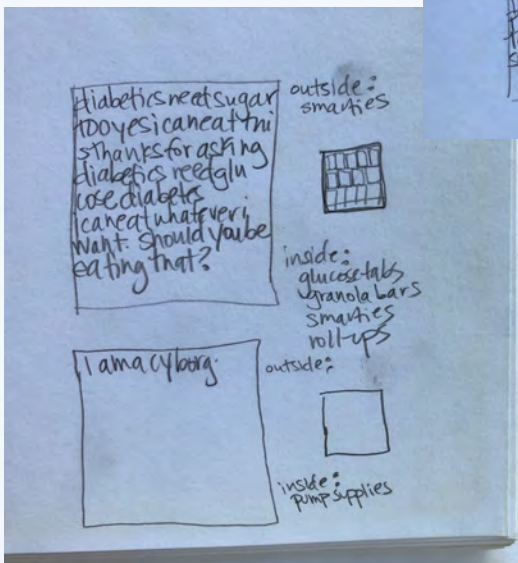
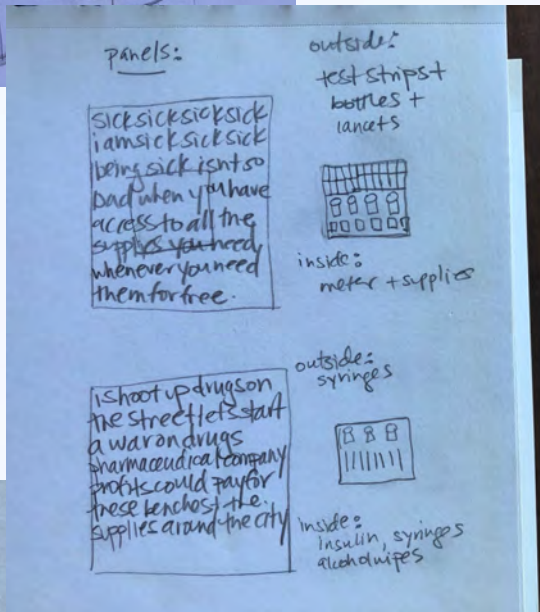
All of this to say that **the collecting of this archive did not start as an archive, it started as protection in the face of health care precarity and then it turned into mutual aid design for access and now twenty years on it feels like a museum or at least a collection of knowledge waiting to be mined.**

I'm not sure what to do with it, but I've been wanting to do some kind of diabetes art installation for years – the stuff is so much a part of our everyday – so I am hoping this project and talking to other diabetics about their stashes and archives of old technologies will guide that project.



Sketches for
Burning Man Bench

circa 2007



free medical
supplies in all
benches everywhere!
places to sit down,
eat a sugar,
take a rest
for all

Interviewer: What does this image depict for you? What were you hoping to capture in this image?



When I was pulling out all my supplies for this photo project, I saw these two laying in a drawer next to each other. The Freestyle Libre is the absolute best CGM. It was kind of my gateway drug to getting back on the Medtronic sensor for the third time.

(Every iteration of sensor, Medtronic claims it is better than the last, and they all suck, ever since 2012 or so. It confuses me to no end why they can't make it better when there are so many other styles that work better on the market. This is a point I often make to diabetes drug reps – **if diabetes management wasn't a for-profit business, they could share and integrate technologies** which would give diabetics better care than what we currently have. What we currently have incentivizes long-term pump brand loyalty because you have a stockpile of extra supplies and you can't mix and match supplies across companies, and each company's pump + sensor has some positives and some negatives. None of them have every good thing, which they could have if they worked together for care instead of for profit and market

share, sigh. It's really so simple, but it's points like this that make me know there will never be a cure, which they told me when I was diagnosed in 2001 that would be DEFINITELY here in 5 years. I blamed Baby Bush and his maniacal fetal cell/stem cell shit for a while but now I think it's just fucking capitalism, baby).

OK, back to the Libres!! My first Libre was when I lived in Ohio, it was a 10-day and it cost about \$225 US for 3-month supply with good insurance for the sensors, the scanner was also like \$200, I think? My first scanner was a total dud!! It did not work properly and the scanner took forever and I was like WTH here we go again with false promises of technology helping me!!

I called the company and they sent a new one which worked great and I was LITERALLY IN LOVE. It was easy to insert by myself, no tape, no calibration, and I loved the zing! Of the scan – funny for an anti-capitalist, but I always wanted to be a grocery check-out girl when I was a kid, so I **took perverse pleasure in scanning myself like a check-out item.**

But then, FreeStyle discontinued the 10-day and changed to a 14-day sensor, so now I had to RE-BUY a new scanner (which just a few months earlier was a “one-time investment”) and my burgeoning stockpile of extras (you can make your stash last a little longer if you skip 1-3 days in between changes, which over time builds up very slowly to have a few extras) was no longer compatible with the new scanner.

Then, a few months after that I moved to Canada to start a new job. They had the Libre in Canada, but my U.S. scanner was not compatible with the Canadian sensors and I couldn't get the U.S. sensors here. **So, I had to buy ANOTHER Libre scanner.** The products are identical. You can see from the package in the picture. There is literally NO REASON why they should be incompatible. The same corporation is making

money from it, it's the same model. The problem would be very easily solved by making all diabetes products have two modes – the European sugar number system (mmol)—the one used in Canada—and the US sugar number system (mg/dL). In the early days when I was first diagnosed, the glucometers had both modes and you selected which one at set-up. I think they've done away with that now, so dumb.

The good news about the Canadian Libre is that they were covered by my supplemental pharmacy insurance (which is paid through my academic job), so I went from paying \$225 USD for Libre sensors to paying \$3.99 CAD/3-month supply. I cried the first time I picked them up at the pharmacy.



But, because the devices are literally identical, I had to mark the two boxes USA and CANADA to not get them mixed up. **I've been a border abolitionist since the early 2000s when I first got involved with migrant farmworkers in the U.S. South, and I think this story is a simple example of why all diabetics have a vested interest in destroying all borders and global capitalism.**

How to Live with a Pandemic: A guide for people just discovering the contingency of the future



1. Trust that no one is taking care of your future except you.
2. Stockpile your supplies little by little until you have enough to survive the revolution.
3. Share your resources and fight like hell to dismantle health profiteering.

Covid and Diabetes, Colliding in a Public Health Train Wreck

Nearly All Patients Hospitalized With Covid-19 Had Chronic Health Issues, Study Finds

Who Is Most Likely to Die From the Coronavirus?

NOT US, motherfuckers!!
We've been keeping ourselves alive IN SPITE of you...

Coronavirus Threatens Americans With Underlying Conditions

Those with chronic health problems are more likely to develop severe illnesses and to die, research shows.

"Joy is the
delighted feeling of
kicking it with friends on
a sunny afternoon, legs
splashing in the
water."



ten bottles

* The Collective Tarot
(2008, Eberhardt Press).

On COVID, underlying conditions and sick futurities

Cal: You had a very strong reaction to discourses about 'underlying conditions,' especially in the early days of the pandemic. Being that diabetes was one of the most prominently mentioned underlying conditions, do you want to talk about that?

Lyndsey: I had a very strong reaction to the COVID discourses because I felt like there was discussion around saving and protecting the most vulnerable, which seems like the right thing to do, and was. In many cases, it was a narrative mobilized by disability justice activists and people on the left, to tell people, presumably non-sick people, that the reason they should care or wear a mask is because of someone else's vulnerability. That really infuriated me, because, you know, **I know how to survive a plague already!** I already have had to come to terms with an unknowable and uncertain future.

And the fact is, everyone has always had an unknowable and uncertain future. But if you haven't had something in your life that's forced you to grapple with that - it could be a breakup or divorce or chronic illness or state violence or family members in jail or yourself in jail - If you haven't had to think about the future, through one of those experiences or positions, you likely have this mirage that you can save your money for retirement and that retirement will come and that you will be healthy in your retirement and that you know that there's this future that's waiting for you, waiting for you to arrive, fully able to participate in it.

For chronically ill people and for type ones in particular, **all of this medical obsession with good numbers is in pursuit of fending off an unpleasant future;** all the stuff about numbers is to prevent diabetic complications, such as going blind, losing feeling in your extremities, amputation. Things that won't kill you but will change your life significantly.

Complications are constructed by the medical establishment as the ultimate worst thing in the world. And that's not to make light of diabetic complications. I get nervous about losing my sight. I know for sure that I will not live long.

I know for sure that whatever my quality of life is in the moment is as good as it's going to be. But what that means for me is that you have to seize the moment, you have to take care of what you can, when you can, you have to do your best, don't put too much pressure on yourself, go on vacation, live your best life, you know, all of those things have to happen now. There's no delaying it for this kind of white middle-class notion of once I retire I'll travel. I think what we're seeing with climate catastrophe and with COVID, more people are having this sense of a secure future destabilized. A lot of people coming to terms for the first time with not having full control over their bodies or over getting sick or protecting themselves.

For people who live with chronic illness, that's our everyday, we already deal with that all the time. In my case, in particular, because I've often had precarious employment in one way or another, in the US context, meaning nonprofit work that's short-term and low paid, insurance benefits that aren't great, or that are great but that could change at any moment. It means that I've had to come up with a lot of strategies for creating a backup supply of insulin and medical stuff.

Cal: Yes, we notice that stuff, those boxes, every time we move! You have brought them with you from place to place.

Lyndsey: And because I'm also an activist and anarchist, I have for a long time been trying to make sure I have a **steady supply of devices, so that I can last as long in the revolution as possible.** By which I mean the fall of capitalism that we are fighting for will also have very extremely urgent, negative effects on my ability to survive. I take it on myself and through community to take care of these things beyond the state, beyond the corporation, beyond health insurance. With the COVID narratives, I was so mad: How dare you people who consider yourselves healthy, the ones who make insurance, primarily in the US context, more expensive for sick people. How dare you people do this and tell people to take these precautions [like wearing a mask] in the name of *keeping me safe* when nothing that you do historically has kept sick people safe. In fact, it has structurally harmed us. On top of that mutual aid became a big thing during the pandemic on a wider scale, which was great. People were getting hip to it. But again, from being chronically ill, and from being involved in mutual aid-based projects in many different forms for many years it was annoying

watching these normative, status-quo-preserving people waking up to the fact that the state will not protect them, but then congratulating themselves for being the heroes to save sick people. No, absolutely not. I know some other disability justice activists have said: we've been asking for work from home accommodations for forever and it was never possible and now it is because everyone needs it. This is an example of the type of thing I'm talking about in a way. It's frustrating because it reinforces that all these other worlds are possible and that they are withheld *because* marginalized people want them.

Cal: Yeah, and it seems that by virtue of the title of our zine, sick futurities, you're thinking about the fact that **sometimes the solutions, or the most creative ways of thinking about a problem, don't necessarily come from authoritative or validated methods.** with COVID, you and other sick people already knew how to survive a pandemic. You've already had a stash of all your supplies.

This was useful when everyone was hoarding and buying up all of the alcohol wipes that we were looking for in the pharmacy section of the grocery back in 2020 for your injection or insertion sites. Luckily, you have creative and tinkering methods of your own to be able to access things like that in a moment driven by a mindset of scarcity rather than sharing.

Some of what you were saying made me think about how the terms method and methods always presume something formal and visible and validated. We've had a lot of discussions about seeing all these talks people are giving about COVID advertised to us in our inboxes. They're all, or mostly, rooted in "proven" methods like surveys and interviews. Public health researchers, clinicians, sociologists, what have you. I was just thinking about how I hope that **our study comes from a place of the pre-existing knowledge set** that doesn't view the people who might talk to you as research subjects whose data or numbers or stories we want to extract. Wanting to think of them as interlocutors or view the 'interview' more as an exchange where there are kinds of common ground that exist. (Of course not completely common ground because it's not like everyone even in Ontario has the same experience living with type one).

NPN
80029421

Stérile, Moyen

TAMPON D'ALCOOL
ISOPROPYLIQUE ANTISEPTIQUE

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ALCOHOL PAD

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Stérile, Moyen

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Alliance®

ALCOHOL PREP

ANTISEPTIC ISOPROPYL
ALCOHOL PAD

Sterile, Medium

Imported by / Importé par:
Medical Mart Supplies Ltd
6200 Cantay Road
Mississauga, Ontario L5R 3Y9

NPN
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Stérile, Moyen

TAMPON D'ALCOOL
ISOPROPYLIQUE ANTISEPTIQUE

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Lyndsey: Yeah. I think of the alcohol wipe shortage as a perfect example of the type of rage that I was having. Everyone is invoking this mythical figure of the diabetic who can't take care of herself, who needs other people's care, who is just the sad sap hunk of fat who can't help themselves. As if everyone's going to mask up to save us because we can't save ourselves, but then **in the same breath, those people are buying up all of the alcohol wipes.** Alcohol wipes are one of the really basic things that diabetics need to make sure that we have clean injection sites.

This goes into your argument in the article you wrote, Cal, "COVID containers' in pandemic mediascapes," that people were never trying to help diabetics, they were always just trying to containerize and purify their own self or their own space or their own family. Don't invoke us and then actively do things to make it harder for us to live! I've gotten infections before from injection sites. It can cause a fever, it can cause an infection. And imagine getting infected sites during COVID before we knew more information. You're getting a fever and you can't get to the doctor and you need antibiotics. It's such a small thing that alcohol wipe, but you couldn't find them anywhere and I remember you and I even asked the pharmacist, "next time you get a shipment can you hold some back for diabetics who actually are the ones who need them." What the hell were people doing with alcohol swabs anyways?

Cal: Swabbing their phones and wiping off their groceries. Blaming the Uber drivers who brought their groceries for potentially giving them COVID. [Laughter]



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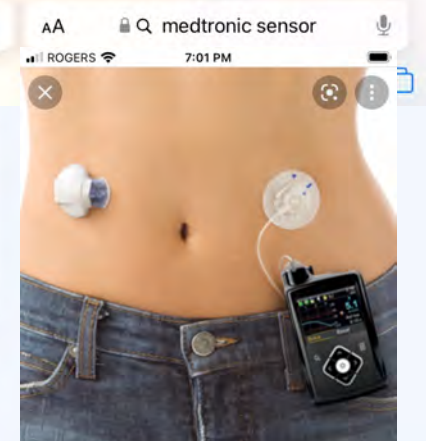
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The Medtronic Paradigm insulin pump and continuous glucose monitor

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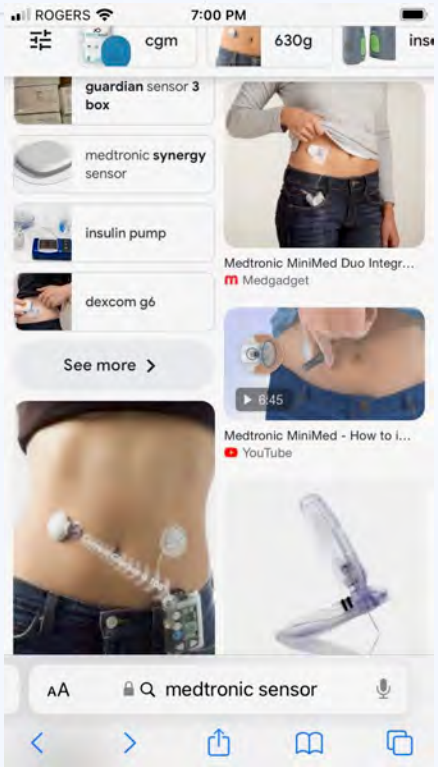
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the figure of the perfect white type 1 is everywhere - just add technology.

with this many perfect white girl stomachs to populate with medical devices, who needs a cure?!

not medtronic!! to a tune of \$5 BILLION in net income in 2022 alone.

389
S23



Pancetta BLT Pasta

with Lacinato Kale, Cherry Tomatoes & Bucatini

Pâtes BLT à la pancetta

avec lacinato, tomates cerises et bucatinis



10 min



Nutrition Facts		Valeur nutritive	
Per Serving (471 g)			
par portion (471 g)			
Calories 820		% Daily Value*	% valeur quotidienne*
Fat / Lipides 33 g		44 %	
Saturated / saturés 12 g		63 %	
+ Trans / trans 0.5 g			
Carbohydrate / Glucides 103 g			
Fibre / Fibres 9 g		32 %	
Sugars / Sucres 10 g		20 %	
Protein / Protéines 31 g			
Cholesterol / Cholestérol 70 mg			
Sodium 1200 mg		52 %	
Potassium 1000 mg		21 %	
Calcium 225 mg		17 %	
Iron / Fer 7.5 mg		42 %	

942 g R389S23 1030

Rethinking carb counts: Carbs as relational

Lyndsey: The notion of a carb is relational. It is not an objective scientific count of something. It's a relationship to my pump, my ratios, my body, and my life.

A recipe could say that a meal has, for instance, 103 carbohydrates, which is calculated by some scientific measure, I am sure.

But, it's possible that I will appraise a meal that says 103 carbs and tell my pump that I am actually eating 75 carbs, because I have an embodied sense that estimating 75 instead of 101 will prevent my blood sugar from dropping too low, and I'm usually right. So, then, **did that meal have 75 carbs, or did it have 103?**

The number itself is relational. Diabetics rely on what we call the “carb ratio,” which is the ratio of the amount of insulin your body needs to synthetically process the carbohydrates you eat. The standard ratio is 1 unit of insulin covers 15 grams of carbohydrate. So, you need to learn how to count carbs in every meal that you eat. If I eat a sandwich for lunch, that is usually 15 carbs per slice of bread + a few carbs for the filling, so I might estimate 35 carbohydrates. You then multiply your carb count by your ratio to figure out how many units of insulin you should take with the meal. In insulin pumps nowadays, the carb ratio is put into the settings, so you just type in 35 carbs, and the pump delivers the appropriate amount of insulin.



Insulin (“one of the best known Canadian medical innovations”), image from Canadian \$100 dollar bill.

But, carb ratios vary dramatically by person, by food, by activity, by stress, by literally every other thing in addition to the content of the food. In order to calculate your carb ratio, you eat something pre-packaged like a Lean Cuisine frozen lunch. Then, you test your blood sugar two hours later. If your sugar is high, that means your carb ratio is not giving you enough insulin, so you need to adjust the ratio. A lot

of time is spent learning how to more accurately estimate carbs and fine-tuning your carb ratio. But, what all of this misses, is that **carbs are not a universal thing that exist outside or beyond the body that can be empirically measured.** It's all made up. It's all a proxy for a much more complex relation.

For instance, if you were drinking alcohol with your carbs, your blood sugar will spike and then drop, so less insulin is better. If you sat on the couch while eating, if you got in an emotional argument over dinner, if you have your period, if you ate right before or after exercise, your ratio will be different in all these scenarios. Doctors would be the first to say that carb counting is not an exact science, we do our best and it's a rough estimate. But, nevertheless, what people imagine is that we're trying to overcome our human flaws to get closer and closer to the real, objective carb amount that is outside the body waiting to be counted.

This assumes the real carb exists and we, just because of human error and complexity of life, we haven't yet mastered these complex carb ratios. I don't think that is what is going on. You said earlier that **we should move away from arbitrating whether numbers are good or bad and instead see data as part of the self.** I think this approach would help us see that there's no such thing as carbs, there's only a relationship to carbs.

Cal: what you've just said makes me think of Karen Barad's ideas (*Meeting the Universe Halfway: Quantum Physics and the Entanglement of Matter & Meaning*). I don't know if you've ever read her work; here, your method—the process by which you have come to your ideas about carbs

relational—is embodiment, not reading the existing literature. This idea that things do not exist except in relation to and entanglement with other things and processes is what she calls intra-action. Your ideas about carbs as relational make me recall that when we lived in Oberlin [Ohio], we started doing these meal delivery services. We wanted to do this bougie meal service but we also thought it would be helpful because it gives the full carb count for the meal on the recipe sheet.

The idea was it would help you with accurate carb counting. And now we've continued these meal deliveries with a Canadian based company that also sends us the recipe cards. I always read you the number of carbs on the recipe before I throw the recipe away when we finish cooking it but I think how you're articulating it is really great because it turns out the carb count on the page is not as helpful as it seems.

The carb itself is this unit, this metric that's so moralized. It's caught up in so many different discourses. The fact that most diets have people obsessing over not eating carbs, for instance, or the feminization of certain kinds of alcoholic and other kinds of drinks that are carb-free or low carb. There is also this assumption that carbs are bad for diabetics which we've talked about in terms of the low carb meals we order. They're terrible for you, because there's not *enough* carbs, but they are marketed as healthy.

Lyndsey: And funny enough, I rarely ever put the exact carb number that they say on the recipe card in my pump. The carb ratio and the carb counting is a lot of math, like

constant math. Some of that is taken away if you have a meal kit or if you have the pump that does some of the math for you.

But nevertheless, **it is a felt embodied relationship to what a carb is for your body that you accumulate through experience over time.** You know I have been feeling for a while that my carb ratio [pre-entered into pump] is kind of off. But we haven't changed it because my doctor looks at my numbers and is like you never go high after meals so your carb ratio is perfect.

What she doesn't factor in is that I'm creating some kind of coefficient, in my calculation, to offset it. I know that if I put 103 carbs for a bowl of pasta that I have historically estimated was closer to 75, I would go low, even if 103 is actually the "correct" carb count. I am able to make the mental coefficient adjustment because of embodied practice. The carbs might total to 103 by some dietary metric, but that is not what that amount of carbs is to my body. And that could be true for various reasons, because of recurring lifestyle patterns of drinking, exercise, eating late, or whatever it is. But you don't necessarily need to know why or what causes it if you let go of the idea of the external objective carb. If you let go of that, **you can learn to trust your embodied knowledge and accumulated intuition that you know what any given carb is for YOU in any given moment.**

Cal: Right. That's your method. And it's kind of like you're beating the algorithm in a way but the algorithm never knows because you're always correcting it. I think this example helps us contest the idea that numbers somehow reach the threshold of 'real data' and that stories or

embodied experience are just a fluffy complement to this real data.

Lyndsey: Yeah, I'm interested in our project discussing how embodiment makes the data better, which is similar to your argument in *Cooking Data*, that the fieldworkers' [in data collection projects in southern Africa] improvisations are what make global health data good.

Cal: Yeah, the invisible kind of tinkering and modifications and **learned corrections are what make these systems work**, even as systems try to eradicate them [the tinkering] because the system wants everything to be smooth and the same and to claim it works on its own and works the same way in every instance and for every person.

Another thing we could also talk about is your **little koala journal where you record down ideas and feelings and notes on appointments**, all related to diabetes. Maybe that could be part of the archive, because you were talking about the blood sugar number logs you did when you were younger, before digital upload technology made them obsolete.

"The body archive is an
attunement, a hopeful gathering,
an act of love against
the foreclosures of reason."

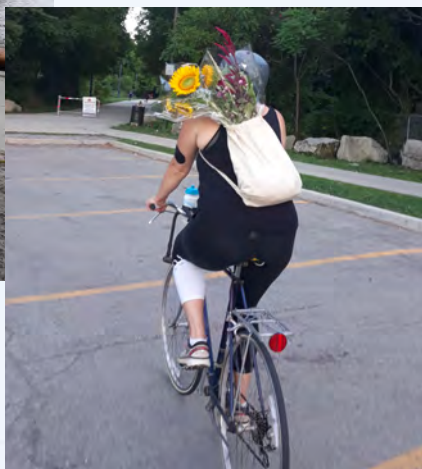
Julietta Singh
No Archive will Restore You
p. 29

But even though you rely on the pump and your closed loop system to do a lot of that work now you still have material artifacts [analog objects that don't get coded as 'technology'] that you seem to really like.

The journal is cute and has stickers in it and it reminds me of why you put radical message stickers on your glucose pills bottle to make the bottle look less 'medical' or 'sterile'. That journal doesn't look like a medical thing. **It looks like a happy little thing that doesn't have anything to do with carbs or numbers.**

Lyndsey: Cal, you made me that journal! with a beautiful inscription from the poem "Health" by Rafael Campo:

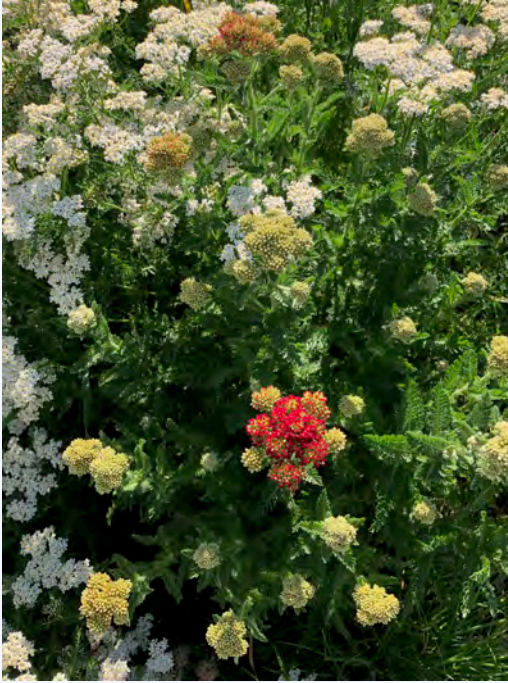
"We need a health pandemic...We'd understand the moonlight's whispering. We'd exercise by making love outside, and afterward while thinking only of how much we'd lived in just one moment's time, forgive ourselves for wanting something more..."



References

- Barad, Karen. 2007. *Meeting the Universe Halfway: Quantum Physics and the Entanglement of Matter and Meaning*. Duke University Press.
- Biruk, Cal. 2018. *Cooking Data: Culture and Politics in an African Research World*. Duke University Press.
- Biruk, Cal. 2021. "COVID containers in pandemic mediascapes: Discursive economies of health, bodies, and race in North America." *Anthropology & Medicine* Dec 21:1-18.
- Campo, Rafael. 2010. "Health" [poem]. Access at: <https://poets.org/poem/health?mbd=1>
- Clare, Eli. 2015. "The Mountain." In *Exile and Pride: Disability, Queerness, and Liberation*. Duke University Press.
- Jacobs, Andrew. 2022 April 3. "Covid and diabetes, colliding in a public health train wreck." *The New York Times*. Accessed at: <https://www.nytimes.com/2022/04/03/health/diabetes-covid-deaths.html>
- Mol, Annemarie. 2008. *The Logic of Care: Health and the Problem of Patient Choice*. Routledge.
- Murphy, Michelle. 2017. "What can't a body do?" *Catalyst* 3(1):1-15.
- Rabin, Roni Caryn. 2020 March 12. "Coronavirus threatens Americans with underlying conditions." *The New York Times*. Accessed at: <https://www.nytimes.com/2020/03/12/health/coronavirus-midlife-conditions.html>
- Rabin, Roni Caryn. 2020 April 23. "Nearly all patients hospitalized with Covid-19 had chronic health issues, study finds." *The New York Times*. Accessed at: <https://www.nytimes.com/2020/04/23/health/coronavirus-patients-risk.html>
- Serkez, Yaryna. 2020 June 4. "Who is most likely to die from the coronavirus?" *The New York Times*. Accessed at: <https://www.nytimes.com/interactive/2020/06/04/opinion/coronavirus-health-race-inequality.html>
- Singh, Julietta. 2018. *No Archive Will Restore You*. Punctum Books.

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