

KNIT TOGETHER: CRAFTING SOFT SUPPORT STRUCTURES WITH YARN,
PAIN, STICKS, AND STORIES

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ABSTRACT

This thesis is an exploration of how knitters with disabilities connect with one another through a shared project, and how the reciprocal effects of chronic illness and creativity inform the ways that knitters move with their materials throughout the project. Using and queer theory and cripistemology to inform a feminist ethnography I consider what it means to live on “crip time” and be productive in a society that champions able-bodies that are not sick or in pain. Over the course of a year, I worked with five other knitters who have varying degrees and types of disabilities, to create six shawls. During this time I was able to experience how internal and external stresses cause shifts in the ways that each knitter chooses and works with various yarns and needles; the way we engage with each other both as artists and as people experiencing chronic illness; and how each of our understandings of time, productivity, and success become necessarily blurry and mobile. By making these stitches together this group of knitters created space where chronic illness and disability are no longer understood as Other. Exchanging normative time that our capitalist society demands for crip time is liberatory, and isolating all at once. Through the isolation and liberation however, crip productivity through this last year has resulted in solidarity, beauty, and strength.

CONTENTS

ACKNOWLEDGMENTS	2
ABSTRACT	4
GLOSSARY OF KNITTING TERMINOLOGY and ABBREVIATIONS	6
List of Illustrations	8
CHAPTER ONE: GATHERING MATERIALS	11
Introduction	11
Creating with Disability	12
Yarn, Needles, Orientations and Pains	13
Illustrating points and Drawing questions	18
Methodology	21
Outline of the Thesis	27
CHAPTER TWO: CAST-ON	29
Yarn and Yardage: Stitches, Lines, Belonging, and Becoming	33
Needles: Wood, Metal, and Making Meaning	41
Notions: Tools, Meds, and Support	48
Gauge: Size, Shape, Hegemony, and Knowing How	53
CHAPTER THREE: SPECIAL TECHNIQUES	65
CHAPTER FOUR: CAST-ON and KNIT (THE BODY ON CRIP TIME)	78
Instructions: Your Time	78
Section 1: Normie Time	80
Section 2: Productivity and Success	82
Section 3: Crip Time	88
CHAPTER FIVE: SHAWL BORDER and BIND-OFF	89
Border	89
I-cord BO and Blocking	90
BIBLIOGRAPHY	91

GLOSSARY OF KNITTING TERMINOLOGY and ABBREVIATIONS

Bind-off (BO): The process of removing stitches from needles in such a way that they cannot unravel, making a finished edge.

BOR: Beginning of round, used in circular knitting

Block: The process of wetting or steaming your final pieces of knitting to set the finished size and evening out the stitches to achieve a comfortable fit and polished appearance.

Cast-on (CO): The process of winding yarn around a knitting needle to create the foundation row of knitted fabric.

Crochet (Cr): A process for creating fabric out of yarn using a single hook.

Dropped stitch: Instead of knitting or purling a stitch, it is dropped from a needle, resulting in a run in the fabric, and a ladder appearance. This is sometimes a mistake, but it can also be an intentional design element in a pattern.

Fade: A process of alternating rows of color in order to create a color-shift or ombre effect.

Frog: Unraveling a section of a project, or an entire project. (This is a play on the word rip. “Rip-it, rip-it”)

Garter: Fabric that is created by knitting each side of the fabric when working flat, or alternating rows of knits and purls if working in the round. Creates a distinct ridge in the fabric.

Gauge: The combination of knitting needle size, yarn weight, and tension to create a fabric with a consistent and predictable size, measured both by stitches and rows.

Row gauge: the number of rows in 1 cm/inch with a given needle and yarn

Stitch gauge: the number of stitches in 1 cm/inch with a given needle and yarn

Knit (K): The v-shaped stitch generally associated with the “front” side of knitted fabric, made when working yarn is behind the left-hand needle.

K2tog: Knit two stitches together to reduce the number of stitches in a row, a right-slanting decrease

Lifeline: A spare piece of thread that is guided through a line of stitches to create a physical barrier that prevents stitches from unraveling. Lifelines are particularly helpful when making very complicated textures.

Marl: A color effect, achieved by holding two strands of yarn together which are of different colors, resulting in a wobbly, uneven blend.

Needle: Straight stick with a stopper, point or cable at one end, and a point at the other end, to be used for knitting.

Circular needle: two needles that are connected by a single cable attached to each end, only one circular needle is needed to knit most things.

Straight needle: a needle with a stopper at one end and a point at the other. Two needles are necessary to knit.

Double-pointed needles (DPN): short needles with a point on each end, used for knitting small circumference items such as socks, hats, and sleeves. Typically four or five needles are used to knit.

Purl (P): The round, bumpy stitch most associated with the “back” side of knitted fabric, made when working yarn is in front of the left-hand needle.

PM: Place marker

Rip: Unravel work that has been done which is too extensive to tink, but does not need to be frogged entirely.

RS: Right side

Stockinette: Fabric that is created by alternating rows of knitting and purling, when knit flat, or all knit stitches when knitting in the round.

SSK: Slip one stitch purlwise, slip one stitch knitwise, knit those two stitches together to create a left-leaning decrease

TBL: Through the back loop

Tink: Knit backwards, or un-knit

Unfinished-object (UFO): knitting project that has been set aside

Hibernation: UFO that has been abandoned, may never be complete

Time-out: UFO that is not being worked on, but has not be abandoned

Work-in-progress (WIP): knitting project that is being actively worked on

WS: Wrong side

Yarn-over (YO): a method for adding an additional stitch to a row in order to increase the overall size of the fabric

List of Illustrations

Figure 1. Fiber Arts Glossary

Figure 2. Biomedicine and Phenomenology

Figure 3. Knitting and Disability

Figure 4. Migraine/Status Migrainosus

Figure 5. Amy's Story

Figure 6. Colorshifting Yarn

Figure 7. Amy's Shawl

Figure 8. Treeline Sweater by Camilyn Crane

Figure 8. Anatomy of a Swatch

Figure 9. The Round-Robin Shawl-Swap Plan

Figure 10. Jess Teaches Knitting

Figure 11. Flora's Request

Figure 12. Flora's Story

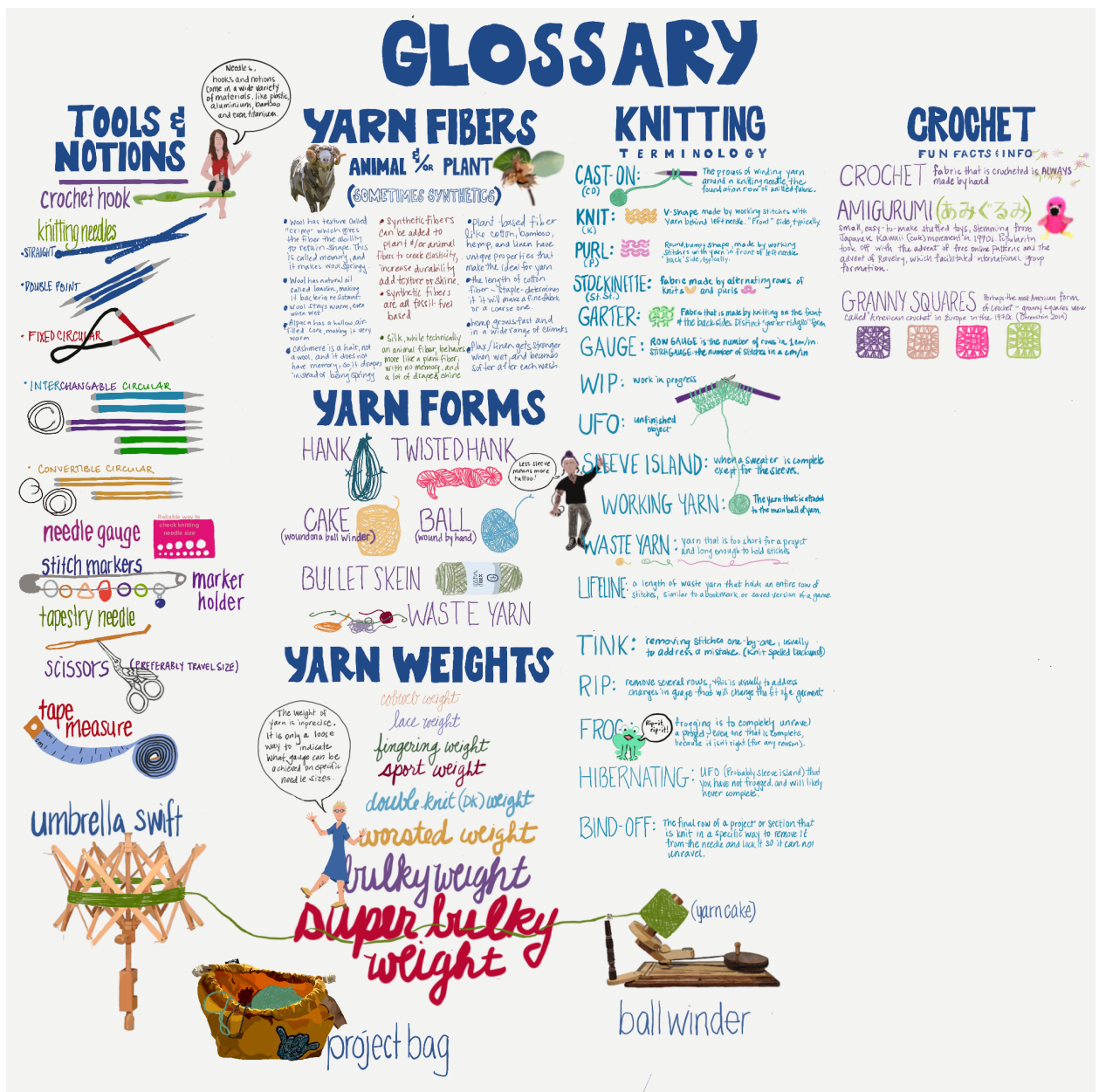


Image 1. Fiber Arts Glossary

CHAPTER ONE: GATHERING MATERIALS

Introduction

You might be surprised how many people I have never met reach out through social media to me to talk about yarn, or my knitting projects. When it comes to textiles, my first love is yarn; knitting is simply the thing I do with yarn. After years, decades even, of practice, I have learned that I am a process knitter; the end product is only a perk of the process, not the goal. Imagining how yarn might look or behave in various conformations is a never-ending process for me, resulting in little piles of yarn all over my home, always. A quick examination of my social media profiles, on Ravelry and on Instagram, show countless partially complete projects, known in the fiber arts world as works-in-progress (WIPs), and those little process piles of yarn. These are the posts that generate the greatest response—and they are the posts where I make the most friends. An interesting occurrence happens: it's not just the yarn my newly acquainted friends want to discuss, it's also bodies and chronic pain. I get messages from people I do not know that say things such as '...your knitting is lovely. I too have several autoimmune disorders and pain'; 'I sometimes forget that we are not alone, even though it may feel that way'; and 'I am a knitter and knitwear designer who has an autoimmune disease and suffers from chronic pain, so if you want you can get in touch with me...' (personal correspondence 2020).

Hi, I'm Rita. I'm a knitter and a chronically ill person with invisible disabilities. I share this information freely in my social media biographies, owing to my own understanding of how isolating pain can be, and the value of solidarity. Both of these aspects of me have become integral parts of my identity, and together or separately they inform nearly every decision I make about how to exist in the world. The process of making opens up possibilities to explore reciprocal relationships between materials and bodies involved in creative work. Understanding

that relationship creates room to consider and appreciate the knowledge of materials and of the body which emerge throughout the act(s) of making. Throughout this project of purposeful engagement in fiber arts, in the form of a group knitting project, with people who live with chronic illness and pain, I've sought to improve my own understanding of how experiences of health and wellness are interwoven with skills of creative expression, to create a rich, complex social fabric. In other words, my goal was to learn more about how pain and materials move with each other, what it means to be a disabled knitter, and why it is important to better understand the processes of a disabled knitter.

Creating with Disability

Anthropologist and maker Stephanie Bunn, who works with wool to create felted fabric and willow to create baskets, has identified a need for anthropological and ethnographic studies which examine the embodied processes of making, the effect of embodiment on materials, and bodily responses to fluidity and change in the material as it is worked (Bunn 2011, 23). I've extended the research she has already done on the process of making, in order to explore how makers who experience chronic illness and pain move with their materials and each other through the acts of making. In order to accomplish this I organized and hosted a knit-along (KAL) with five fiber artists, who all experience some measure of disability, whose skills encompass the whole range of textile creation; though for this project the focus was on knitting. Jess is a knitter, crocheter, designer and botanical dyer, Amy knits, crochets, and works in non-textile arts, Michelle is a knitter, crocheter, and sci-artists who regularly has installations in museums and art galleries, Jacqueline is on again-off-again knitter, and Flora is a knitter,

crocheter, sewist, and dyer. Each participant is a skilled maker, and all of them are proud to share their names, stories, and work for this project. In addition to knitting I also crochet, hand-quilt, and sew. We chose to knit a shawl, Garter Abyss by Stephen West, a pattern which accommodates all skill levels, and is both memorizable and forgiving of missed or dropped stitches, as well as modifications. This allowed each knitter to exercise their creative expression with low stakes in the event of imperfect stitches and stitch counts.

Yarn, Needles, Orientations and Pains

This project is based loosely on a smaller sweater project I completed with Flora, one of the knitters in this group, several years ago. In that KAL the work was done in sections and swapped between the two of us each time a section was completed. While doing this I learned how she perceived me through the sections she completed, and I learned about my own perceptions of her both through the material selection process for her, and also through her selections for me. At the end of our project both Flora and I had a complete sweater, and deeper appreciation of each other made possible through the yarn which became the strands that connected us. With the shawl KAL swap my goal was to simultaneously engage with both the materials and each other, in order to explore some of the concepts described by Drs. Bunn and Feder-Nadhoff. First, turning inwards, and outwards towards the other knitters, exploring how those actions are played out in material choices and second, to experience what it means to follow the lines of another through stitching together. Through this project, knitters oriented themselves with each other, as we all worked together to make our shawls.

The work of interrogating how anthropologists approach craft and art, is undergoing a shift. Instead of focusing on art as simply a finished object with the process largely viewed as a prescribed means to an end, new work is being done to privilege the process. (Bunn 2011; Ingold 2013). There is very little in the anthropological texts about how acts of making are modified by those who have chronic health conditions and disabilities; turning towards feminist, queer, and crip texts are necessary to even begin locating disabled artists. Connection, along with ableism, and oversimplification was indicated by a group of disabled researchers at ASSETS '20: The 22nd International Association for computing Machinery (ACM) Special Interest Group on Accessible Computing (SIGACCESS) Conference on Computers and Accessibility, to be a core component of accessibility and is a neglected as an important area of study. Understanding the function of connection in the context of disability and accessibility requires a move beyond a myopic focus on impairment, in order to illuminate the critical roles of relationships between disabled people and their allies that form systems of support (Hofmann, Kasnitz, Mankof, and Bennett 2020; Piepzna-Samarasinha 2018; Price and Kerschbaum 2016).

Knitting and crochet both require yarn, though there are no boundaries placed on what 'yarn' actually means. Many knitters, including KAL participants Michelle, Flora, and Jess, knit with yarn made from plastic, raffia, and even detritus found washed up on beaches. I have friends who have crocheted with cooked spaghetti noodles. Often the material a maker chooses most frequently becomes an extension of their identity, so it is quite important to examine the process of choosing materials. What causes you to choose that yarn? What are the rituals performed when working with the specific fiber and tools (e.g., needle or hook material) for the thing being made? Do you have a specific project in mind? What properties do you connect with in material

that a different material may be lacking? How does that connection change as your body goes through varying degrees of illness or pain? In a 2018 embroidery workshop led by artist-anthropologist Michele Feder-Nadoff, a needle, thread, and fabric were used to explore how materials and making allow for a phenomenological analysis of identity through stitching, asking 'What does it mean to follow the line of another person through stitching together?' and 'How can turning into self, turn us outwards, towards others?' She describes the relationship of the material to the maker as 'melody and refrain... working together as trajectories of movement...weaving their own lines of becoming into the texture of material flows comprising the lifeworld' (Feder-Nadhoff 2018).

Yarn, needles, and notions are the knitter's tools that are ready-to-hand, easily taken for granted. Through the often monotonous and meditative repetition of knit and purl stitches it is possible to create an object with yarn that can be seen as a physical representation of embodied sensations. When knitting fabric, changes in tension, mistaken or dropped stitches (and the accompanying effort necessary to repair such errors) could be considered a physical manifestation of pain or fatigue, just as a flawless section of creation can be easily interpreted as a moment or more of joy, energy, or rejuvenation. By examining the orientation of a knitter to their tools it became possible to better understand how seemingly background happenings come into sharp relief in the process of making. The sensory experience of creating with yarn and knitting needles, coupled with chronic fluctuations of disease that is often composed of or accompanied by pain make phenomenology an ideal approach to creating knowledge of how creativity and pain move together.

Phenomenology—the study of how our situated understanding of experience occurs through embodiment—lends itself as an ideal methodological approach for this project. Combined with observer participation, I examined the various processes disabled fiber artists employ which become evident while we shared a knitting project. Based on my time as a disabled knitter, I was not surprised to find that conversation moved fluidly between craft and health. My hope, when embarking on this journey, was to experience the unseen and untold aspects of what it means to be a disabled knitter, and how that identity is inherently political. In addition to the work on making, I drew heavily from feminist, queer, and crip theorists in order to create a multi-faceted approach to creativity and disability.

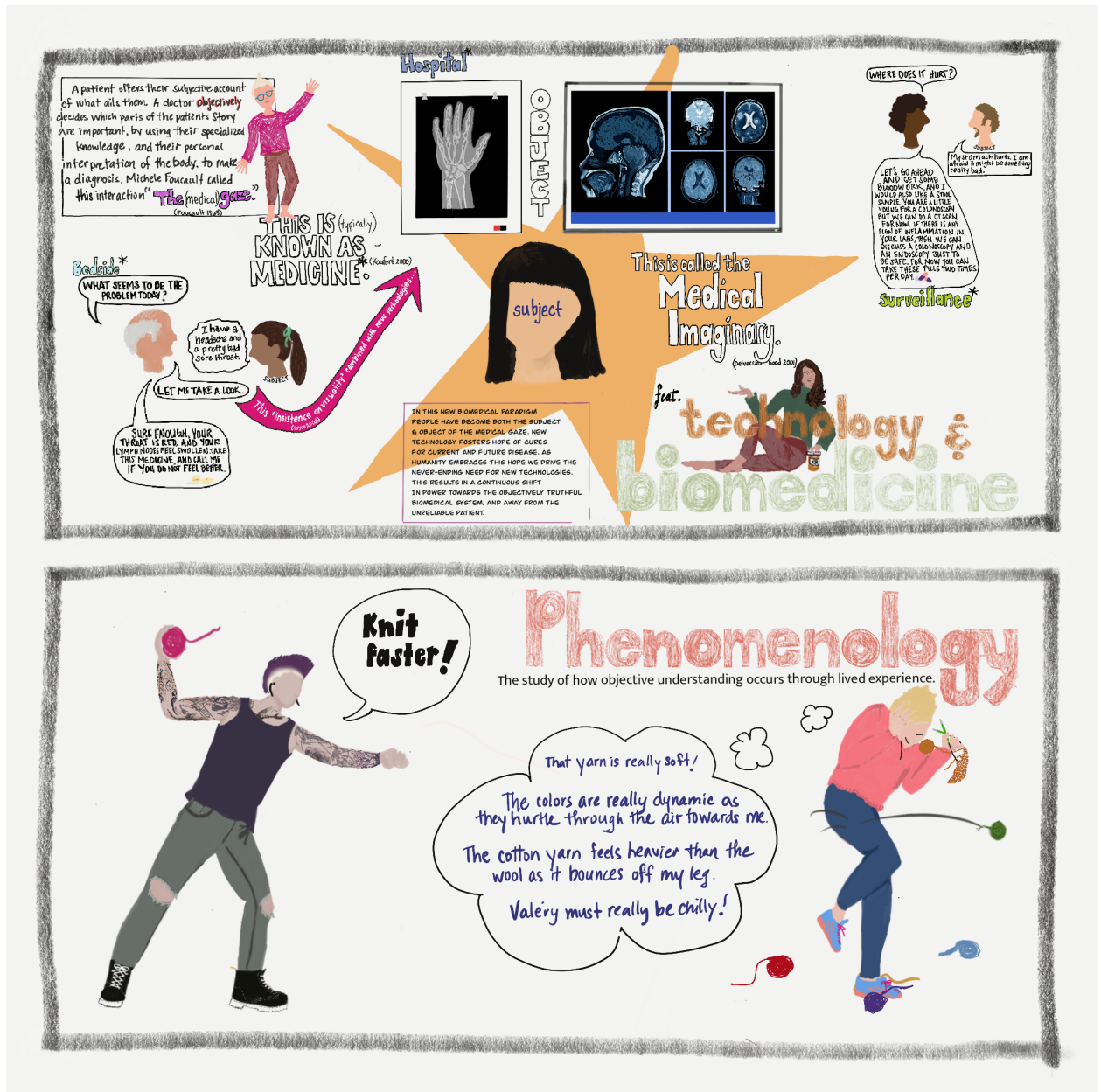


Image 2. Biomedicine and Phenomenology

One of the limitations of conducting an ethnography which utilizes phenomenology as a primary research method, via digital platforms WhatsApp, Instagram, Messages, and Zoom, is that the visual backdrop of daily life often is blurred, obscured, or not present at all. This is an

instance where turning to queer theory, and critical disability studies yielded a constructive way forward:

Queerness, queering disability studies, or claiming disability in and around queer theory, however, helps create critically disabled spaces overlapping with the critically queer spaces that activists and scholars have shaped during recent decades, in which we can identify and challenge the ongoing consolidation of heterosexual, able-bodied hegemony” (McRuer 2006, 19)

By queering phenomenology I was able to examine all that had been erased from sight, resulting in a better understanding of how actions shape our bodies, and change our orientation towards the objects we work with (Ahmed 2007; Kojima 2008). To be disabled in a society that champions able bodies, and bodies that are not sick, is to be queer in that society. After careful consideration I have concluded that one meaningful way to represent important aspects of life that a distance ethnography misses is to create illustrations—to present the world as it is described and depicted as I spend my time talking and making with the people who are sharing their experiences with me. Through the course of the KAL restoration of the background in this project stopped being about a physical location, instead venturing into far more abstract realms of pain and process.

Illustrating points and Drawing questions

Illustrations as information have been used successfully by nurses, physicians, and professors to communicate complicated concepts in such a way that even lay people can easily understand (Squier 2015). These illustrations can be fully composed graphic novels, blog posts, pictures on napkins or spare scraps of paper, or even using hands or other body parts as demonstrations. The purpose of illustrations in this project is to bring into focus aspects of

chronic pain (or absence of pain) and aspects of creativity that can be communicated more accurately through non-verbal descriptions, in a similar way to how knitted stitches can become an expression of lived experiences. Illustrating sensations which are unsaid, and therefore left in the background, can help to create a more robust conception of the intersection of pain and creativity, making illustrations helpful in the pursuit of better understanding what it means to be a disabled maker.

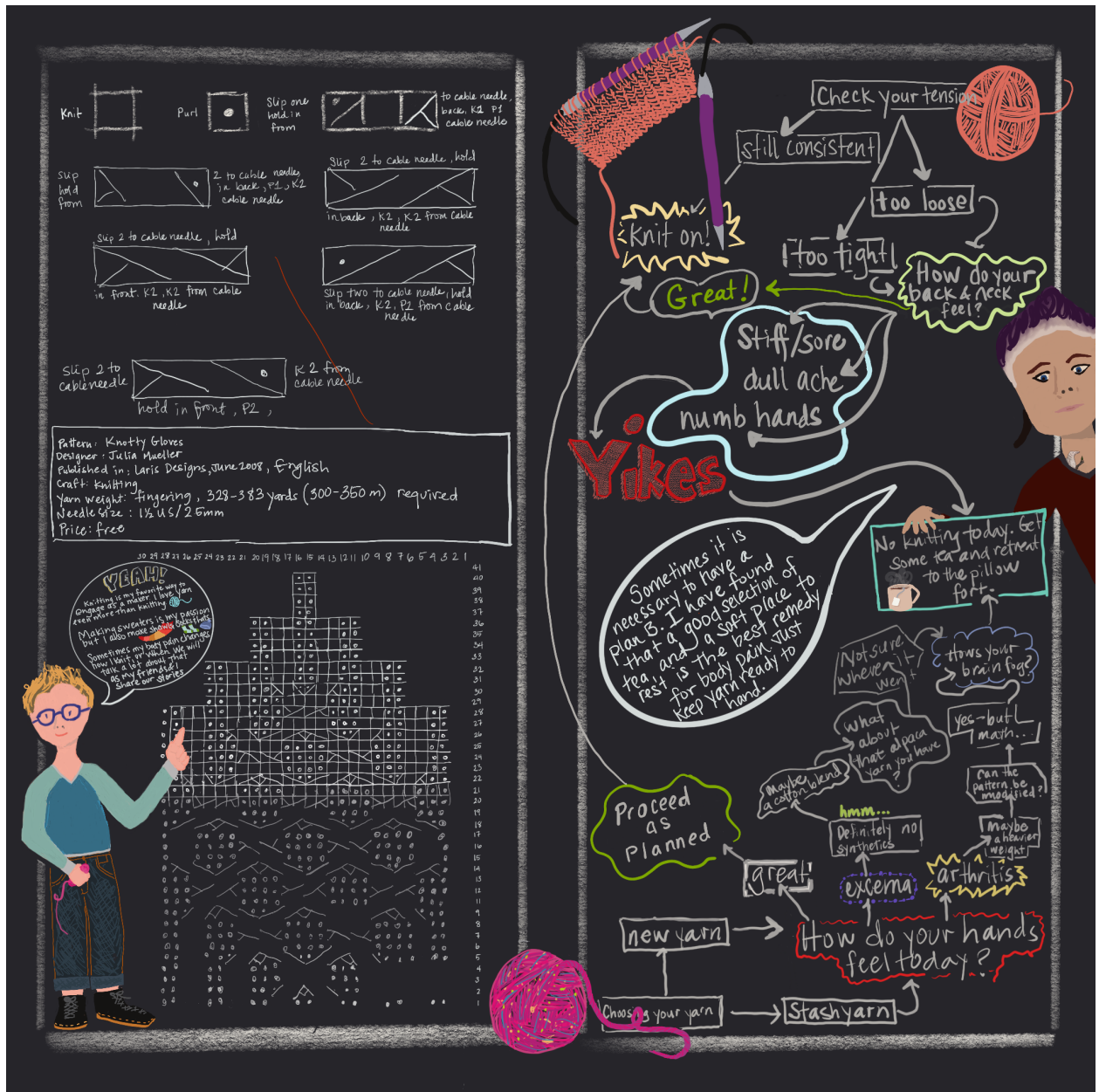


Image 3. Knitting and Disability

Drawing can be used as a way of expressing complex ideas, a means to resist normalizing discomfort borne of vulnerability, fear, pain or any number of experiences that arise in fieldwork, and as a way to queer ethnography (Campbell Galman 2014; Czerwicz 2015; Jain 2019). Comics

and graphic novels often use a specific and highly recognizable form made of frames, and the spaces between those frames, which are known as gutters. In *Graphic Women* Satrapi explains how stories and passage of time can both be shaped through the use of these forms. Unlike words on a page, the reader can transgress the order of the narrative by choosing to look at drawings out of order, and spending unequal amounts of time on each illustration, just as the artist can transgress the norms of illustration by extending their work beyond the visual demarcations. Sally Campbell Galman terms the production of iterative, non-linear illustration 'process work.' In *The Brick* she demonstrates how a story can be told, read, and understood in multiple ways, through a three-panel comic that deals with transgender violence. Other examples of this process-work method, which queers the way ethnographies are told, viewed, read, and understood can be seen in works like *Becoming Unbecoming* by Una, and *Monsters* by Ken Dahl (a pen name used by Gabby Schultz). This proposed KAL project privileges process, and the process work of illustration as a means to communicate embodied sensations and experience associated with making will act as an extension of knitting and the process of following the lines of self and others through stitching.

Methodology

This project was created through a “combination of collaborative and singular voices” (Price and Kerschbaum 2016, 19). It is the result of the creative and physical handwork and stories from each knitter, coupled with inspirations drawn from work done by disabled performance artist Leah Piepzna-Samarasinha, and anthropologist-artist Michelle Feder-Nadhof. “The purpose of arts based research is to raise significant questions and engender conversations

rather than to proffer final meanings” (Barone and Eisner 2012, 56). While attempting to unsettle the limited discourse occurring at the intersection of disability and creativity through disabled research, our conversations engendered discourse on such topics as craft, creativity, health, grief, loss, and fulfillment. My interview approach was intentionally unstructured, because the importance of each answer were in the glimpses they provided into the creative process of artisans who are able to manifest their expertise into tangible objects alongside, not despite, pain and disability.

Medically, pain is considered a symptom of a pathology; idiopathic pain, therefore, could be viewed as a backgrounded feeling which has already been brought into clear relief, without a foreground object present (Ojala et al., 2015). However, pain exists only as a sensation, not as a tangible object. Instead of trying to understand pain as an object of which dimensions characteristics can be known, a more appropriate approach is instead to view pain as a “creative force...that can powerfully organize relationships” (Jain, 2013, 233). Through this paradigm it becomes possible to see the connections between disabled knitters and their materials, and each other. Embodied sensations of pain create room to ask how these women envision their own relationship to pain, and how that relationship allows for the creation of new meanings of pain, productivity, and new ways of being, knowing, and inhabiting the world (Saraswati 2021,118). This reimagination of pain as a way of knowing and being has been termed *cripistemology*. (Johnson and McRuer, 2014).

Feminist standpoint epistemology, or more specifically situated knowledge, is one part of my research tapestry, and an essential component of cripistemology. However, queer feminism, crip theory and methods are the predominant theories that I turn to for this project. Said of queer

feminism: “... meaning cannot be fixed permanently, it can be, indeed it must be, constantly negotiated for reference in particular contexts (Marinucci 2010, 144). People who live with disability often have a unique relationship with time. Just as the theoretical meaning that Marinucci was referencing must be constantly negotiated, being in a disabled body that undergoes periods of remission and exacerbation, the same task may take substantially more or less time from day to day, or even hour to hour. In *Feminist, Queer, Crip*, Alison Kafer says “rather than bend disabled bodies and minds to meet the clock, crip time bends the clock to meet disabled bodies and minds” (2013, 27). To occupy a crip position in society, as each knitter in this project does, a far more mobile situation is called for than feminist theory alone can offer.

“Which woman? What kind of feminine?” (Abu-lughod 1990, 21) has been on repeat in my head since the very first time I encountered it. Her question(s), which are posed not once but twice, help to illustrate how reductive early feminist theory could be. More considerations, more voices, and more positions are critical components to creating robust situated knowledge. Each participant in this study identifies as female, and was assigned female at birth (AFAB), though selection criteria only considered ability to knit and long standing health condition. I followed the logic Emma Shepherd used when choosing participants for a study on chronic pain:

‘Thinking about chronic pain through a crip lens thus reveals—and acknowledges—not just how bodies are marked as normal or abnormal but also how conceptions of normality and abnormality interact with gendered and racialized bodies. It also makes plain that the causes of chronic pain are disparate and not neatly organized. My awareness of this, along with the wish to distance myself from a purely medical conception of disability and place importance instead on a political-relational model of disability, informed my decision not to specify a particular diagnosis when looking for participants...’ (2018, 57).

The political-relational model of disability is a way of creating a clearer distinction than either the social model of disability or the medical models can offer. The medical model, which

is the most widely understood way of considering disability, casts it as pathological, and therefore a solvable problem, through correction (medical or surgical), normalization, or elimination . While the social model offers a sharp critique of the medical model, it ‘relies on a distinction between impairment and disability’. Impairment refers to ‘any physical or mental limitation’ which neglects the societal aspects of disability. Examples of societal disconnect would include poor accessibility design in building architecture, such as stairs with no ramps or elevators, or inaccessible event planning that fails to reserve spaces for assistive devices like canes and wheelchairs, or the creation of websites that do not have readable versions for low-vision or hearing impairments (Kafer 2013, 5-7)

The fact that my participant group is exclusively female showcases both the gendered aspect of handicrafts, like knitting (Barber 1994), and the substantial difference in prevalence of chronic illness between those who are ASFAB, and those who are not. (Marshall et al. 2014). Among those with chronic illness, there is further discrepancy in certain diseases like lupus, that occur along ethnic lines, where Black and Hispanic women are impacted at significantly higher rates than their white counterparts (O’Rourke 2022). I want to acknowledge that the term *woman* is politically charged, and can be used inclusively as easily as it can be used to exclude. Because each knitter in this project is both ASFAB and identifies as a woman I will be using the term woman to describe each knitter. To be clear, my use of that term is inclusive of any person who identifies as a woman. Further, I acknowledge that the use of woman/women, particularly in medical literature, is not always inclusive, but there is ample research at this point that demonstrates that *all* people who identify as women experience gaslighting and dismissal in medical practices (Hoffman and Tarzian, 2003; Kempner 2014).

This thesis is as much an auto-ethnography as it is an ethnographic collaboration among six knitters. I participated not only as a researcher, but also as a knitter and the host/coordinator and through the project I drew on my experience as a knitter and a disabled person to create a vibrant reflexivity. (Koopman, Watling, & LaDonna 2020) We began the KAL in July of 2022, and ran through August 2023. In addition to verbal exchanges, the yarn and needles became a locus of knowledge, as they were used to form shawls in segments, shared through the US Postal Service. Fieldwork for this thesis was conducted using a patchwork approach to ethnography in order to adequately and accurately cover numerous locations of interactions, including occasional face-to-face interactions, email, text messaging, WhatsApp, Facetime, Zoom and Instagram. This patchwork approach is modeled after Anna Tsing's ethnographic patches of knowledge found both in journalistic archives and ethnographic field sites which served to make up her global ethnography (Tsing 2005). The use of patchwork ethnography proved to be a necessary component of doing fieldwork during the first year of the SARS-CoV-2 pandemic, when a good portion of countries around the world instituted some form of lockdown, or restriction on movement. (Fratini et al 2022). We have a primary chat thread on WhatsApp, though the chat feature on Instagram is also utilized on a semi-regular basis. I messaged participants directly every week or so to see how they were feeling, how the project was going, and to coordinate the next swap. At the beginning of the KAL, we set up a schedule where swaps were meant to occur every third week, with one week of transit time, however, the rate of swaps has fluctuated based on a variety of factors, including travel, work schedules, and, most frequently, illness or fatigue. It's worth noting here that the fatigue experienced by someone who has chronic illness is rarely the same as the type of fatigue a person might feel after physical

exertion. Some, not all, fatigue from chronic illness can be so pervasive that it resists distraction, and can even create a “loss of the intact self” (O’Rourke 2022, 52) I kept the discussions open-ended and intentionally casual, because my primary goal was to better understand how each knitter felt as we progressed through the project, an undertaking that does not occur through specific questions or pointed answers.

I would like to note here that the nature of communicating primarily through a mobile messaging platform, WhatsApp, comes with its own norms and cultures. Each participant relies on short messages that contain spelling errors, omission of punctuation, and emojis to facilitate fast and easy communication. I have made a decision to retain these affects, in order to maintain accuracy in storytelling. Therefore, direct quotes that come from apps are presented in the font, size and color found in that application. I used OtterAI to transcribe conversations recorded by using voice memos, Zoom, and FaceTime. Quirkos was the software I chose to code all of the transcripts, its visualization forward interface was a better fit than most of the other available software choices.

Three of the five participants reside on the island of O‘ahu, so there have been a number of face-to-face interactions for swapping. The only instance of knitting together occurred on August 27, 2022 when Jacqueline and I spent some time reviewing the techniques necessary to begin the project. Jacqueline expressed some anxiety about her skill level when compared to the other participants, and we reassured her that someone would be able to spend some time either over video or in-person going over the pattern and techniques. In the instances of all face-to-face interactions appropriate precautions were taken to protect the health of each knitter. High-quality

N95 masks were worn, meetings took place outside, or indoors in well-ventilated spaces with open windows and a cross breeze.

Outline of the Thesis

There is a great deal of information that is accumulated, created, and circulated among members of knitting groups. While a substantial amount is centered mostly on yarn-based activities such as knitting and crochet, some is medical in nature. As we knit together, we became more closely knitted together as a group, and sharing stories of experiences, including some in the healthcare systems, became as intrinsic to the project as discussions of colors and materials. It is in these non-craft centered conversations where the effects of health on creativity, identity, connections, and time can be appreciated.

Chapter Two: Cast-On is where I consider the raw materials used in this project. Each knitter has a specific type of needle, cable, cable stopper, and yarn that they prefer to use. I will also briefly describe the different ways a person can knit (English, continental, combined, etc.) and possible assistive devices that are available. Symptoms that often accompany chronic illness and autoimmune dysregulation are considered here as raw materials- the vague, transient, and sneaky experiences like fatigue, joint and muscle pain (to name a few) which rarely show up in images or tests for biomarkers. These raw materials of chronic illness confound health providers, and can leave those who experience them feeling isolated and abandoned. Just as the way yarn is considered for a knitting project, and accepted or rejected due to a multitude of considerations, so then is fatigue or brain fog examined and puzzled in and out of a multitude of possible diagnoses.

Chapter Three: Special Techniques addresses the way we engage with each other both as artists and as people experiencing chronic illness; and how each of our understandings of time, productivity, and success become necessarily blurry and mobile. By making these stitches together this group of knitters created a space where chronic illness and disability are no longer understood as Other, as per Simone de Beauvoir (1972). I will explore various rituals surrounding the use of tools and materials to create swatches, which help mitigate any uncertainty as to how they will work together. Because these projects are for one another, as well as self, I examine how knitter's choices change as their relationships are strengthened through daily chats, and physical body conditions, such as pain or brain fog. As in knitting, this is also where we consider how biomedical supports from health providers work together with medications and assistive technologies to alleviate discomfort and uncertainty in the wake of chronic illness.

I will explore aspects of agency and identity as they emerge through knitting, covering topics of biomedicine, and the political economy of hope. It looks at ways that people with chronic illness can participate in, or reject and refuse interventions offered within the medical system. I look at specific ways harm can occur within the healthcare system from mismatched doctor/patient relationships, and how neoliberal policies and deregulation have created an unsustainable system for providers and patients.

Chapter Four: Cast-On and Knit (The Body on Crip Time) looks at how disability and how time requirements become both flexible and modified can create literal and metaphorical dropped stitches within the fabric being created. I discuss specific instances that stressed the KAL timeline, often throttling it, instead of accelerating it. Such instances include acute illness,

painful flares, depression, death, and more mundane things like postage issues, travel, and brain fog. I will also look at how these knitters find in each other the knowledge and support needed to feel “less broken” (Amy, 2023).

Finally, in Chapter Five: Border and Bind-off I conclude this thesis, along with the KAL, and consider what it means to be a disabled knitter among a group of disabled knitters, all creating stitches that move together to create an entire life world.

This thesis follows the format of the knitting pattern we used, and often will include a portion of the first line or two of the pattern (care was taken to not share anything that would infringe on copyrighted material). I chose to structure the project this way in an attempt to include the reader in the process of creating a knitted shawl, and also to acknowledge the amazing skill of each participant. Despite the simplicity of a piece of string and two sticks, knitting -especially in a group- requires a lot of attention, calculation, and of course, communication. Throughout the entire thesis there will be interplay between the nature of knitting and aspects of biomedicine, and the overriding theme will be how chronic illness and disability crip time. There is a noticeable, and occasionally jarring difference in chapter lengths, which maps to both the pattern sections and the experience of how disability can crip time.

CHAPTER TWO: CAST-ON

In general, the relationship between maker and [...] material is not one of imposing form onto substance or making it do what one wants, but rather of knowing the life-cycle,

habitat and potential of the material and listening to the wisdom that it may impart (Bunn and Mitchell, 2020, 2)

The opening line of a newly published book on knitting declares that anyone can pick up a pair of needles and a ball of yarn, and I am inclined to agree, but the interesting stories can be found in the creative movements and gestures, and in the ‘inscriptions they yield’ (Ingold and Janowski, 2016, preface) . At its core, knitting is a series of simple motions, using tools and materials which do not require industrial processing. The work of raising sheep, shearing wool, cleaning, carding, and spinning are all intense and critical to prepare yarn that is ready to knit, crochet, or weave. These are all tasks that can be completed outside the confines of high-volume, at-scale production, due to generational knowledge that has been passed on for thousands of years (Barber 1994; ; Kruger, 2002; Malkki, 2015; Nargi, 2008) Contemporary knitting, in reality, looks very different, with ready-made material choices too abundant to iterate. Of course, the thing that makes knitting special is how those series of gestures can create something so critical to human existence that it is on par with food, water, and air. Human beings require barriers between our fragile skin and the harsh elements in nature. Whether fur pelts, tanned leather, or fabric that has been woven or knitted, life and textiles are intimately connected. The steps to make a knit stitch: insert right needle into the first loop on the left, wrap the working yarn around the right needle, pull a new loop up from the left side and move over to the right needle. There does not appear to be room for creativity, but when repeated enough times even the most simple fabric, stockinette, begins to display the hallmarks of a specific knitter. Knowledge,

stored in the bodymind¹, intermingles with joy, pain, and artistry, resulting in fabric that will provide the protection that is critical to our survival. Knitting can be thought of as a series of “generative movement(s) that remembers the past even as it presses forward, since to go forth along a line of life is simultaneously to retrace the paths of predecessors (Ingold 2000, 148). The importance of gestures and their generative nature is present in anthropological literature almost as frequently as references to fabric and knitting. For example, Tatiana Rabinovich describes an interaction between two muslim women, Zarema, her mother Madinat, and Shahnaz, an Azeri friend of Zarema, in the family atelier in St. Petersburg Russia, where they made and sold clothes. After noticing a frayed, stained area on Shahnaz’s blouse, Madinat put aside her knitting, rustled through some blouses and handed Shahnaz a gold blouse to try on, simply because she thought it would look good on her. Modest and eloquent, this interaction demonstrates one way threads can connect people, and exemplifies how gestures move beyond mere motions, generating support, acceptance, generosity. “In a similar way —stitch by stitch —Madinat and her daughters knitted intimacies with their Muslim sisters.” (Rabinovich 2023, 6)

Before we even got to the place of beginning to knit, we had a lengthy discussion about what type of project we should do, given our wide range of expertise and experience. Among the patterns we considered it was necessary to talk about ability to read the pattern, adaptations for body size, accounting for the differences in gauge between each knitter. At one point Jacqueline exclaimed:

¹ Margaret Price used the term *bodymind* in a 2015 essay in *Hypatia* entitled *The Bodymind Problem and the Possibilities of Pain*, in which she discusses how the body and the mind give rise to each other, and generally act as one entity, even though conventionally they are separated into two. She grew tired of saying 'body-and-mind' so the amalgamation of the two was a comfortable solution.

oh geez. i may be way out of my depth. i can knit squares and scarves and basic rib and cables as long as they're not too complicated or don't have a lot of increasing or decreasing. i only know one crochet stitch and have never attempted a crochet pattern. in fact i can't ever crochet a circle successfully

She went on to apologize in advance for all of the mistakes she was certain she would make. Offers of help came flooding in almost immediately. Flora reached out with “Noooooooo it's gonna be great!!!” simultaneously with an offer from Jess to do a virtual lesson if it would help. Michelle cheered her on:

'Nonsense, Jacqueline! You rock! (Having just spent time with the 2014 Spalding House yarnbombing project you helped assemble, your work is much appreciated — and it's still going strong after all these years!)'.

This early interaction is indicative of the amount of support and cheering on everyone offered each other. This type of encouragement and solidarity extended well beyond knitting, to include illness, the grief of loss, and successes. Jess offered reassurance to everyone as we prepared to begin

I'm currently 7.5 months pregnant with two toddlers and of course autoimmune disorders. I'm not trying to think too much 😊

And so began the process of engaging with each other as knitters and as people who each live with chronic conditions that might (and did) interfere with the ability to stay connected through stitching.

The similarities between seeking medical care and knitting a shawl are a bit surprising. For instance, filling out an intake form in a doctor's office is one of the first steps in a ritual, where the desired outcome is to be (and feel) cared for, and choosing a knitting pattern was just one in a number of rituals that surround the start of a project. Much like that intake form, the amount of consideration that went into pattern choice was borne of a goal to care for each

participant, to consider not only their knitting skills, but also to honor the particular needs that arise with chronic illness.

Yarn and Yardage: Stitches, Lines, Belonging, and Becoming

In terms of human needs, textiles are of key importance, alongside food, drink and shelter. Our relationship to our second skin is profound, yet we very rarely know exactly how and where our trusted materials were made. Our attraction to certain colors reflects our mood and this changes throughout our lives. Our choices in textiles tell us much about who we are and “the culture that we live in. Noticing the interdependence between color, texture, nature and human skills can deepen our relationship to the entire universe (Matthews 2023).

As soon as the decision to make a Garter Abyss shawl by Stephen West was made, the rituals surrounding material choices became evident. I asked each knitter individually if there were any fiber sensitivities or allergies, in order to place limitations on material choices that might harm another knitter. Only two fibers were eliminated, alpaca and mohair. Both of these fibers have a structure that includes guard hairs, which can give knits a fuzzy “halo” and can also be very itchy on sensitive skin. These two fibers are in numerous yarns that have more than one fiber, which meant everyone had to be diligent in their choices, always checking to make sure not to include those two fibers.

Even when fibers that make up yarn are not problematic due to allergy or sensitivity, the possibility of bodily insult still exists. In one of the first rounds of swapping I was chatting with Amy, and mentioned that I was really enjoying knitting with a type of wool called Blue-faced Leicester (BFL), named after the species of sheep who provide the wool.

Amy: Sounds way better than the Wool of the Andes tweed I'm wrecking my hands on!

I don't generally have issues with wool but it dries my hands out pretty intensely. I don't have a problem with it once it is knit up, and it makes for an economical sweater that wears well.

The yarn that Amy mentions is from a company called KnitPicks (KP), who are known worldwide for making available yarn that is less expensive than yarn that is highly breed-specific, like the BFL I was using, or yarn that comes from small, independent dyers. This is an example of a type of built-in knowledge that occurs throughout the project- it was not necessary for Amy to tell me anything more about the yarn, because a knitter in the US who has progressed beyond a novice level has heard of, or interacted with KP yarn. This type of shared knowledge

At a different point in the KAL Jess also noted that working with yarn, in this case weaving instead of knitting, caused pain in her hands. She deals with autoimmune inflammatory arthritis, though she was not taking any immunosuppressant or anti-inflammatory medications through the course of this KAL.

Jess : So I did a weaving work shop and my hands are killing me today
Achy
All I did was sleigh the warp
Or whatever that terminology is 😊

Knitting as a process, and its resultant fabric, is largely absent from historical scholarship, not for lack of importance, but rather because of its vital importance to those who could not afford finely woven or embroidered fabrics. Knitted garments were often worn threadbare, owing to their position as the garments closest to the skin, and as such, their preservation was not a

priority or a privilege (Glazzard et al. 2023). Needlework, which is to say women's work, is both invisible and ephemeral, much like the undergarments that were worn beyond use or repair (Barber 1994; Jones 2022). By using the bits of historical needlework that remains, it is possible to examine all manner of women's lives, including (but not limited to) class divisions, thoughts on the body, work, leisure, and even death (Ulrich 1990, 205) This has proven to be true so much so that many scholars now view textiles as a form of text, a product of a what Ulrich describes as "a creative tension between pens, and needles, hands and tongues, written and non written forms of female expression (202). Knitting is frequently used as a metaphor to describe social phenomena, but the ongoing devaluation of knitting has led to metaphors that are devoid of a "conscious awareness of the complexity of making practices' (Pérez-Bustos et al. 2019, 370) One example of the devaluation of knitting can be found in a discussion about the neediness that often accompanies charitable knitting, because the knitters themselves are perceived as needy, not just the recipients of the knitted items.

"It is against a background of unremitting social and affective neediness that the people whom I call "the old women" knit. Many do so in an effort to "keep busy" and "useful" in a world that sees them as useless (or simply does not see them), and to have the dignity of giving something to an anonymous person somewhere in the world [...] who may need it—or not" (Malkki, 2015, 10)

Despite a resurgence of engagement with fiber arts among millennials and generation Z, the image of a needy, or mere, elderly woman is indelibly linked with knitting. Crochet is no different, as evidenced in the description of a very popular crochet motif, the *granny square*. Of course, there is some truth there, nearly everyone in our little group learned to knit from an older woman in their lives, mother, grandmother, aunt- we all participated in what Loretta Napoleoni

calls “an ancient ritual of initiation, a ceremony immune to time and technology” (2020, xii).

Jess described her first encounter with knitting with everyone:

Jess: I always had a desire to knit as a child. Pretty sure I saw it in a very old episode of Tom and Jerry cartoon. I thought to myself, I want to do that. Then maybe a year or so later I stumbled upon some plastic knitting needles, going through my moms dresser, like the curious little child I was. She apparently knew how to knit and crochet. So I asked her to teach me. It apparently runs in the family on both sides of my family. My uncle, and grandmother say I remind them of my great-grandma. Prolific maker and always giving away her makes to those that need it.

Jess: The desire to make is still there. I feel like it's in my dna 😊

Tim Ingold encourages a move beyond material culture, which understands making as an *imposition* of a specific design by an agent (knitter, in our case) onto material, to instead consider making a *process of growth*, where maker and material undergo continuous synthesis and distillation throughout the project, not entirely positive what will emerge (2013, 21-22, emphasis added). Jess is working on making as a process of growth, as she teaches and observes her own children, as making becomes a part of their growth:

Jess: I'm in the process of teaching Ariella. I've tried finger knitting with her. She can chain stitch with a crochet hook, and she can knit with assistance

They all seem interested in it. Stealing my work, yarn, or tools, and pretending to knit/crochet

One time I caught Ariella hiding under a blanket with my test knit swatch. Likely she didn't drop anything but she she was clicking the needles back-and-forth like she was knitting.

Amalia rolls up the yarn in her hands she think she's knitting 😊 it's cute.

Antonio was more of a hooks kinda kid.

I've also attempted to teach my niece and nephew

Taking time to understand and appreciate creative processes can prove to be a useful skill when we find ourselves at the places that require an interface with the biomedical system. That knowledge of the creative processes may be of assistance when it is time to assert agency in the

wake of refusals and rejections by healthcare systems, professionals, and insurance companies. Biosociality— a means of socializing and crafting group identity around a shared medical diagnosis— works to help describe this group of disabled knitters, though it draws an incomplete picture. When Paul Rabinow theorized biosociality in the late 1990s, he imagined group coalescence around a genetic phenomenon called a single nucleotide polymorphism (SNP), and indeed there are a plethora of publications which demonstrate that very happening (Rabinow 1996). Liisa Malkki wrote about a similar phenomenon, which she called an 'accidental community of memory' wherein groups drew together based on shared experiences of trauma as refugees, despite considerable distance in time and location (1993). While the participants in this KAL project are not bound by an easily identified genetic mutation, they are bound as a community through the shared social process of living with chronic conditions, making biosociality and accidental communities of memory is a useful theoretical framework to understand how the social dynamic of this community results in physical and material manifestations (Bunn 2020; Diamond et al. 2015; Halverson et al. 2016). Not only is the act of making a Garter Abyss while managing health and life our SNP, but also having the same type of embodied pain. In this case we learned that nearly everyone in the group experiences migraine headaches.

Amy experiences debilitating migraine headaches. While she was living in Hawai'i (this was prior to this project) her migraines began lasting longer and longer, until she was having headaches that would start, and take days or more before they receded. She actually began knitting seriously when her migraines went from occasional to constant. Knitting, she told me, is soothing, and a lot can be done with closed eyes. The constant migraines, which are called *status*

migrainosus, coupled with medical gaslighting, caused a lot of anxiety on top of the debilitating pain.



Image 4. Migraine/Status Migrainosus



Image 5. Amy's Story

As I was making these illustrations we learned that nearly everyone in our knitting group gets migraine headaches. As we shared our thoughts, the shared experience of migraines became

a part of the thread that connects us. Not long after this conversation, Michelle shared that she, too, gets migraine headaches.

Rita: @Amy does this begin to capture get weeks of unrelenting pain?

Amy : It does. It's a weird thing to give a heart to but yes

Rita: there will be more, but pain is a tough one

Flora: Amy for your migraines do you get visual aura? And if so do you take a rescue med at that time? Idk if it's brain fog or I've never confirmed with my neurologist besides the pain onset if I should take rescue meds when I get aura... 🤔

Jess: I do and I take foricet

Amy: Yes I do, visual aura as well as other sensory fuckery. My neurologist has said to take rescue meds at aura onset

Flora : Thanks!!! I just had aura and was like should I take it now?!!

Flora : Brain fog is so real

Flora : Thanks everyone !!! 🙌🙌🙌🙌🙌

Jess : I've been getting migraine and headaches since I was a kid. Always had brain fog. Worse after kids. Mommy brain is real too lol

Flora : It's crazy right to look back and realize the migraines as a kid? Like I didn't know what was wrong. They were def not as severe as adult but now I'm like wow I did get headaches often but I just thought that was normal bc my dad did and I also thought oh you just nap it off bc that's what my dad does still to this day even though my sister and I both have gone to the neurologist and gotten all the meds

Flora : He claims he doesn't get migraines

Flora : It's bananas 🍌

Needles: Wood, Metal, and Making Meaning

Can yarn tell stories of health? Certainly it can be a conduit through which health-related aspects of life can be shared, and perhaps even a vehicle for modulating experiences of health (Bunn 2020; Goerendt et al. 2003). Yarn born of plants, animals, and insects can show us the health of the soil, water, and plants which nourish and sustain them, and the flocks and herds which house them. The health of shepherds, and shearers can be glimpsed in the quantity and quality of fibers produced in a season. Natural colors which adorn yarn can indicate the health of watersheds, plants, lichens, invertebrates, and insects. Yarn can carry the stories of trauma and even death, as textiles hold on to the DNA of those who wear, or simply even touch them (Linacare et al. 2009). Our knitted shawls have become “long records of hands,” moving through the possession of each knitter who incorporated kindness and love into each stitch for one another (Dahl, de la Paz, and Scott, 2016, 100).

Amy’s shawl arrived today, I’m the third person to add to it. So far it’s a thing of beauty, the jewel tone colors she started with are gorgeous. The shawl starts with a green-ish grey color, which progresses into a purple-gray. This effect is due to how the yarn, called Dyed in the Wool which is made by a team of women owners of Spincycle Yarn, is spun, with two strands of wool which are each dyed with multiple colors that shift over long lengths.



Image 6. Colorshifting Yarn

Just before the purple-grey begins to shift into a blue color, there are a couple of stripes of **vibrant** pink.

I started my own ritual of pulling yarn that might work, and photographing it. Taking a picture of colors, and converting the picture to black and white is a trick used by many artists to decide if there is enough contrast between colors to meet their needs. I decide on a color, which is no small feat. At first I thought I wanted to use a gold-colored yarn, but as I held each skein of golden-colored yarn up I realized that it needed to be a red of some sort. The gold colored yarn fought with a vibrant fluorescent pink color that punctuated the subtle green-gray base color for attention. The red yarn felt more like an acknowledgement of how emphatically the pink existed in the fabric of the shawl.



Image 7. Amy's Shawl

Ultimately, I chose to add a few rows of a terra-cotta color from AVFKW (local yarn store, A Verb For Keeping Warm, referred to often as Verb) as a start to my section. As I started stitching, everything else faded away, including the increasingly intrusive back pain I've been dealing with. I'm not sure I will ever stop being amazed at how a good enough diversion can bring pain relief, at least for a time. I set up the Knitter's Pride needle that each knitter received at the start of the project, but quickly realized that it was going to snag, and the tips felt so dull compared to my preferred Signature needles. Over the years I have become accustomed to aluminum needles, which facilitates a quick movement of yarn across the needle, and a very

sharp point. So I found my US5/3.75 mm Signature needle, and transferred the whole shawl over. The most mundane aspects of knitting, like the cable attached to your needle, or the sharpness of the tips reveals a substantial amount of ritual that is performed by each knitter.

Rita: I'm on the 7th repeat of Amy's shawl, and I'm using a Signature needle which has a floppy cable, and very pointy tips. Normally this combo works great, but there are so many stitches, (almost 700!) they have become hard to move on the floppy cable. A rigid cable would be so much more useful.

Flora : Yah. It was a weird thing that I didn't expect Rita bc I adore the sigs but once I changed I was so much less annoyed!!

Rita: I would love any and all stories from you about instances where time needed to be flexible or rigid, and how the reality of time worked for or against you.

Amy : I like the coated wire type of cables. But I do have an interchangeable set that came with firm cables and soft cables which I thought was an interesting idea. I don't use them often because the needles themselves are much longer than what I generally find to be comfortable

Flora : I need time to be flexible all the time because i live in chaos?!?
Jk jk. But time management is not among my top skills anymore

Jess : What is this time management you speak of



Honestly think I've got ADD.

When we started this project a year ago, my body possessed a nearly innate knowledge of knitting needles, and yesterday, as I gave myself two different injections, it occurred to me that I now have an intimate knowledge of hypodermic needles as well. My rituals of choosing knitting needles now parallels my decisions about medical needles. So in a way, knitting tools and prescriptions (and their adjacent tools, like a hypodermic syringe) can appear to parallel each other. I find that the idea that “writing a prescription can best be described as a closing ritual

which is intended—and often succeeds—to send the patient away with hope and positive feelings towards his medical problem, himself and the doctor” is not far off from casting off a finished knitted item. (Pellegrino 1976). Both have a finality that is ephemeral. The knitted item will eventually wear out, and most medications (or other medical technologies) will eventually stop being effective as the body changes and the disease progresses.

I could not tell you the last time I did not have pain, a sentiment that is woven through my friendships with knitters who have non-conforming health. Dr. Arthur Kleinman (2020, preface) has articulated beautifully the need to continuously strive for a clearer understanding of chronic disease and occasional health when he says, “illness has meaning; and to understand how it obtains meaning is to understand something fundamental about illness, about care, and perhaps about life generally.”

Early on in our project, Amy told me she was knitting a sweater for her husband.

Amy: My husband is really tall and likes cables, so finding something that is affordable in giant amounts is a plus.

Rita: What pattern are you using for the sweater?

Amy: Treeline sweater by camilyn crane

Wool of the Andes Tweed Worsted » Treeline Sweater



Treeline Sweater

by Camilyn Crane

Image 8. Treeline Sweater by Camilyn Crane

Rita: Oh wow, that's gorgeous. You've got a lucky husband.

Amy: It took about ten years of marriage for him to be deemed sweater worthy 😊

In what looks like a really short exchange, we touched on several aspects of knitting that are laden with meaning. When she told me he is tall and likes cables, it caused me to adjust my own internal estimate of how long it takes to make a sweater². A garment that is very plain, like

² Making a sweater requires roughly 1000 yards of yarn, or 4-5 skeins, and around 40 hours of work to make even the smallest size.

stockinette or garter (our shawl is garter) for someone that is shaped like me 5'8"/1.7 m tall, 135 lbs./61 kg, takes around 40 hours using a sport or DK weight yarn, on US6/4mm needles. Of course this is a knitter-dependent estimate, I am not particularly speedy, so someone else might be able to make a sweater like that faster, but it is my experience that this is a relatively common time frame. Making a sweater for a man means no waist shaping, so there is automatically more fabric- and tall means not only will the body of the sweater be longer, but the arms will as well. Cabling, a process of rearranging stitches on a needle to twist them over and around each other, requires more yarn, more time, sometimes extra needles, and more expertise in general. Finding a knitting pattern with cables is easy; a lot of designers will use a motif both to make a project more interesting, and to make a more textured fabric. Creating a pattern that utilized an all-over cable pattern requires a substantial amount of calculations in order to keep consistency in sizing, and requires a lot of attention as a knitter. I have not ever made an all-over cabled pattern, for myself, let alone anyone else, and I am an accomplished knitter. By telling me that she was making an all-over cabled sweater for her husband told me that she is generous, expertly skilled, and incredibly patient without ever saying any of those words.

As we wrapped up this KAL, I asked after the sweater she was making for her husband.

Amy: Sorry I've been disconnected lately, some health stuff and a hard pet death anniversary. I'm not sure which sweater for my husband I was working on at the start of this that you might be thinking of but he has several sweaters I've knit for him, he's knitworthy ❤️

Thus confirming everything I had presumed from our first conversation about making sweaters for him, much like Donna Haraway so aptly said:

It matters what matter we use to think other matters with; it matters what stories we tell to tell other stories with; it matters what knots knot knots, what thoughts think thoughts, what descriptions describe descriptions, what ties tie ties. It matters what stories make worlds, what worlds make stories (2016, 11)

Notions: Tools, Meds, and Support

Pain does radiate out into the social world, because it changes the person who feels the bodily pain, which in turn cannot but affect those to whom she relates. (Crosby 2016, 33)

The conversations that took place over the course of the year-long KAL became a framework.

The topics of conversation wandered in and out of health and creativity, and the longer the project progressed, the more comfortable the participants became with each other. As knitters oriented themselves amongst one another, the vibrancy of conversation increased. Much like we follow patterns, or a set of directions, when making specific knitted items, as you read through the following exchange you may start to see how we become comfortable offering our own experiences, which can be considered a form of providing support (or a lifeline) in the form of directions.

Rita: You know how everyone has advice when you have chronic health stuff? Do yoga, eat paleo, take these supplements. Did any of you try the suggestions you got? Did any of it help?

I have ulcerative colitis, and fibromyalgia, and I ate low FODMAPs for almost two years. I spent so much money on supplements. I wanted so badly for those things to work that I told myself they did.

Now I get steroid injections in my spine, and honestly, I'm not sure they help much, but I get a week's worth of narcotic pain meds- and those actually do work. But i'm not willing to ask my doctor to make real pain medicine part of my regimen of therapy, because i'm only 45 and I want that to continue to work for a long time.

(yes, I am hurting pretty bad this morning, does it show?)

Flora: Supplements have cured me but I do generally feel better when I take iron and vitamin b consistently. Diet has helped some to reduce my joint pain. But exercise has been tricky. Over exercising just leads to flares (like those cardio work outs etc). Low impact strength building like Pilates, or walking and swimming (when I feel up for being wet and cold) are the only things my body seems to not hate.

Haven't **

But I did have a partner who is convinced my problems will all go away if I exercise for two hours a day.

Amy: I am pretty open to trying things that are suggested by my care team but I am also at this point very anti everyone and their mother giving advice that will certainly cure me. To the point where I keep what I experience to myself because if one more person tells me eliminating gluten will cure me I will end up in jail for murder. But I've tried all sorts of supplements, trigger point injections, acupuncture, cupping, TMS, nerve blocks, elimination diets, blah blah blah. The biggest thing that helps me is getting sleep, which can be a struggle

Flora: Amen to sleep

Michelle: Seconding the sleep thing. Tho to my teenager about sleep, it's too often "do as I say, not as I do"

Flora: How much sleep does everyone feel best at? For me it's like MINIMUM 8. But ideally 9-10 hours. Though as my pain increases the harder it's been to stay asleep without being crazy uncomfortable.

Michelle: Last night's five is definitely not going to be enough for me, especially after an unexpected migraine yesterday morning. If I can nap today, I'll have a better chance of functioning adequately for the rest of the week.

Flora: I would say I average 7 hours typically between pain and anxiety. 😊

Rita: I'll third or fourth the sleep. It's a bit of a double-edged sword though, because the longer I lie still the worse the pain in my si joint and lumbar facet arthritis gets. So I slept great last night, and am definitely paying the price this morning.

Amy: I get about 4-6 a night. Same for me, the longer I lie there in the morning, the more I hurt, so it's a game of what's worse. If I get less than 4 everything flares and things get unmanageable very quickly.

Jess: I need to do exercise that's low impact. It does help. I've tried the supplements and they are expensive and don't really help me. The steroid injections are a short term fix. If you feel they aren't doing the job anymore, you're probably right.

I've had doctors completely ignore me, if they didn't know, it was just "stress " Stress doesn't help, but I know when something is off. I'm very sensitive to changes in my body.

Jess: I feel for you Rita, idk what medicine to take and don't really want to be on anything if I can. Has your doctor done genetic testing on you?

I'm having a flare up also. Everything hurts 🗨️

Amy: Yup. I have had medical professionals treat me as drug seeking, lazy, etc. I've had a doctor in the ER give me long acting injected anti-psychotics without consent when I went in (at the direction of my neurologist) for a migraine that lasted greater than 3 days because I must be hysterical if I think a migraine can last that long. When my husband was still active duty I had to register as an "exceptional" family member due to having complex medical issues. The program is supposed to assist you in connecting to services you need, especially when transferring duty stations. The administrator told me I didn't need help with a referral to a provider who could complete a diagnostic procedure that the military treatment provider couldn't do because he was deploying imminently and no one else was trained to do it. What I needed, according to her, was to smile more. I have a lot of medical profession rage. But thankfully I have a treatment team now that is pretty good.

Jess: I can relate 😞 well less military stuff though I have friends with similar experiences. I'm so sorry you've had to go through that. No wonder we flare up with that extra unnecessary crap

Amy: I think my husband would say I'm a professional at rage. When he hears me on the phone trying to figure out why my prior auth that's been in place for years has suddenly been denied he says I get scary calm, what he calls my "documenting" voice. 😂2

Rita: the documenting voice is nothing to be trifled with. 100

I have a dermatologist who is a quietly amazing doctor. She has been trying to get out-of-control eczema on my hands and feet under control with little success. Yesterday we talked about some of my autoimmune things, and I told her that my ulcerative colitis is not being treated at all. She said there's a new drug (a JAK-inhibitor) that can be used for eczema, but is also used for arthritis, spondylitis, and ulcerative colitis. so my UC will now be treated by my dermatologist who is furious at my GI

Flora: Your gi doc 😞

While reading *Queer Phenomenology*, I began to see parallels between Ahmed's discussion of lines and orientation and the work we were doing during our KAL. "Directions are instructions about 'where', but they are also about 'how' and 'what': directions take us somewhere by the very requirement that we follow a line that is drawn in advance. Later she follows this up with "So in following directions, I arrive, as if by magic" (2006, 16). Knitting is not something that is intuitive, and it is not inherent knowledge. Anyone who knits has a story about who taught them, and even knitters who create patterns (directions) first learned by following a different set of prescribed directions. Knitters rarely talk about lines though. We talk about stitches and rows, and very occasionally you'll see mention of a line on a chart (though even there it's far more likely to be called a row)- and I believe this is for good reason- knitting does not produce straight lines. By the very virtue of how a single stitch is made, nothing is straight, except, in the case of a circular needle, the tool used to make it. So then, "how ironic that 'a lifeline' can also be an expression for something that saves us?" (Ahmed 2006, 17). Knitters use lifelines because their rows are fluid, and returning to the place of a mistake can be time consuming and difficult. Unlike the lifelines Ahmed talks about, which are flung from a boat into water, lifelines in knitting are placed in very specific places, with full intention. In the beginning of the book Ahmed asks what difference is made when where we gather, and the ground on which we can gather, change. This question is an ideal place to begin the process of looking at how the movement between bodies and materials change in response to pain or joy. Knitting then, for the sake of this project, is the site where knitters will gather, and the bodymind the ground on which we gather. Both are places where knowledge of the processes and rituals of

making can be evaluated, in order to better address the question of what difference is made to our orientation when stability is in short supply, or the directions don't work.

So then, what happens when we are knocked off course? Events or pressures that have enough force to knock one off course are things like “trauma, anxiety, or the loss of an imagined future” (Ahmed 2006, 19). This idea is not fully explored in *Queer Phenomenology*, because Ahmed was not considering a course deviation as something permanent. However, it's possible to see where critical disability studies take this question and answer and really explore it. For many people who become disabled not only do they have to grapple with internal pressures of lost futurities, there is also the societal pity that accompanies such a loss. In *Feminist Queer Crip*, Alison Kafer talks about the double-disavowment that occurs when the trauma that knocks a person off-course is permanently debilitating: “the value of a future that includes disability goes unrecognized, while the value of a disability-free future is seen as self-evident; and...the political nature of disability, namely its position as a category to be contested and debated, goes unacknowledged” (2013, 2). When I asked Amy about her experience of becoming disabled, this is what she told me:

This is really complicated for me. I basically cut myself off from nearly all the people I knew prior to having chronic health issues. I had always been a high performing person and my whole identity was wrapped up in that and suddenly having everything fall apart was really destabilizing for me. It hasn't been until recently that I have gotten okay with identifying myself as having a disability. The first time I had to ask for reasonable accommodations at work was really difficult. At this point though, I think most of the people in my close circle know that I have illnesses that impact my daily life and are really supportive. I don't know if that answers that, but I feel like the internal struggle in labeling oneself as disabled is important.

The silence of the other four knitters when asked about their own experience coming to terms with being disabled is a powerful indicator that Kafer is right on the money in her assessment of disabled futurities, and assumption of identity in an disabled body.

Gauge: Size, Shape, Hegemony, and Knowing How

...‘knowing how’ extends beyond ‘skill’ to ‘care for skill’, while ‘knowing that’ encompasses ‘knowing when’ and ‘knowing about’ – memories contained and triggered by seeing and interaction handling, touching and making, both materials and artifacts. There is also a ‘knowing through’ how belief and world view can be both articulated through and even generated by basketry moves, patterns, forms and by basketry potential such as containment. (Bunn and Mitchell 2023, 10)

There is a pattern of language of medicalization such as failure, burden, exceeding/excess that reveals the collective will of compulsory able-bodied normativity. Returning to Kafer shows us some examples of this language. People with chronic illness exceed diagnostic categories when there are no labs or imaging that can confirm for the doctor that their narratives of lived experience are true. In a telling of how a disabled professor, Eliza Chandler, trips and falls on the sidewalk, she surmises that “the experience of falling ..leads Chandler to recognize how shame and pride coincide in her body on the sidewalk, a queer awareness of how her body falls into, exceeds, and fails expectations all at the same time” (2010, 36- 37). There is a strand of failure in any good story, and this project is no different.

Within crip theory we hear a different discourse, and a reversal of language that signals compulsory heteronormativity, which reveals a way of operating that rejects the hegemony of biopower. Ideas of mutual aid, care web, wholeness, solidarity demonstrate how crips necessarily come together, because of barriers, like Murphy's violence of stairs, but also because we can

create together. We create shawls, and we create space to be broken, and beautiful, and whole.

This can be seen in a continuation of Kafer's analysis of Chandler's fall:

...it is, at least in part, this link between falling and failure that renders crip temporalities queer. Notions of failure and excess, and acts of failing to adhere to some societal norms while or by exceeding others, run throughout discussions of queer temporality. Chandler knows that by falling she lives up to expectations about what disability does, even as she fails expectations about what the body does; failure and success thus coincide in the moment of falling (36)

Knitting does not escape the mechanism of surveillance present in biomedicine, nor does it fall outside the realm of the political economy of hope. Technological advances in knitting have produced products such as WEALTHY, a wearable item that contains sensors that have been integrated into the fabric. These sensors communicate biometric data collected from the wearer's body to a device called a Portable Patient Unit (PPU), which analyzes the signals and sent to the user's phone or computer in the form of alerts that enables the wearer to make modifications to their behavior, in the hopes of creating the most favorable health outcomes as possible. This project was introduced via peer-reviewed journal in 2005, and is one of many predecessors to the contemporary biometric devices commonly used by people in 2023, such as the Apple Watch and the Fitbit (which also come with optional knitted bands). The aspects of surveillance and subjugation are written plainly, and discussed as a renovation for "health managing system[s]" which help to achieve "long-term monitoring of patients". (Paradiso et al. 2005, 33)

Foucault describes how bodily subjugation can be exacted through strategies, and the control this type of power affords the wielder—be it a person, persons, institutions, or the State—is a means to control the emotions, behaviors, and relationships of the subjugated.

Foucault states very clearly that this power is ‘exercised rather than possessed’. The assumption, then, according to Foucault, is that the only thing one needs in order to exercise or exert this power is some measure of ‘dominion’ or authority above those one seeks to subjugate or control. (Foucault 1984, 174) In *The Economy of Hope* the authors describe hope as “affective, aesthetic, discursive, ideological, motivational, or temporal orientation” and able to “embody some or all of those at once”. The economy of hope, in his estimation, “revolves around the tension between hope and knowledge”. (Swedberg and Miyazaki 2017, .2-3) Hope works well as a political tool because it is paradoxical in nature, often feelings of fear, disappointment, and even despair exist together with a desire or anticipation of something better. Within anthropology the political economy of hope is used to describe how personal and collective ‘hope’, which can be produced through technological advances such as MRI in the case of biomedicine, become part of the social structures that produce an apparatus of biopower. Foucault details the relationship between bodily subjugation and the corresponding resultant obedience and utility of that body, which he terms ‘technology of discipline’, and how that discipline is unique in its ability to create obedience and utility simultaneously. Preventive care, such as routine colonoscopies after the age of 50, or mammograms and PAP smears, are both a product of the technology of discipline Foucault describes, and the hope which fuels the need for newer and better technologies which have the ability to prevent potential disease or future medical malady.

Mary-Jo Delvecchio-Good goes on to describe how these aspects of subjugation, discipline, and technologies are combined not just in US and Western medical systems, but a composite of international cultures and local variants of “knowledge, scientific and medical cultural power, market wealth, products and ideas” that result in the medical imaginary, which

she breaks down into three intersecting categories: biotechnical embrace, the political economy of hope, and the clinical narrative (2001, 362-363). One place where this medical imaginary is fully intact and functioning in knitting is repetitive stress injury (RSI). The internet at large, and discussion forums on the website Ravelry, which is dedicated solely to yarn-related craft, are littered with conversations about how to prevent the development of an RSI, and ways to manage the symptoms of an RSI. There are numerous tools that can be purchased in service of these exercises. Knitting is also considered a method for recovery and rehabilitation for folks who have experienced a stroke, as well as folks who have been incarcerated (Christianson 2003). In a study of hand osteoarthritis (HOA), knitting is used as a tool to increase adherence to exercise therapy in older women, with the goal of reducing the burden of disability within that population (Guitard et al. 2018).

Chronically ill people, particularly women, spend a good deal of time feeling as if they are background objects in a biomedical context: unstable, untreatable and incurable, their illness a sign to their doctors of failure (Rieder 2020; Street 2014; Werner and Malterud 2003). As each knitter shared their histories and embodied sensations, it became possible to consider notions of operable and inoperable subjectivity. A good patient, who participates in preventive technologies, acquiesces to diagnostic data collection, and adheres to the instructions laid out by doctors, is an example of how subjectivity becomes operationalized. In this scenario the biomedical structure maintains a position of authority, resulting in bodily discipline, displayed by a patient's participation in self-monitoring.

Hegemony is often credited to the theorist Antonio Gramsci, although there is ample evidence of an understanding and use of *hegemon*, which means leader, in fifth century Greece

and more recently in the 1880s by Russian Social Democrats Plekhanov, a Marxist theorist, and Vladimir Lenin. Gramsci was an advocate for integral hegemony, which can only be obtained through what Peter Ives describes (using a quote from Gramsci's *The Prison Notebooks*) as “‘national–popular collective will’ – [which] is obtained because the ruling group is able to meet and surpass not only its own interests but also the needs and desires of all the major social groups” (2004, 68). Gramsci came to theorize hegemony in this way as a response to an insufficient “Marxist theory of the state” or “the sphere of the complex superstructures: political, legal, cultural” (2000, 189). His goal was to facilitate the creation of a “relationship between leaders and led would not be contradictory or antagonistic, rather it would be ‘organic’ and continuous; an educative and reciprocal relationship” (Ives 2004, 69). This theory, refined by Laclau and Mouffe, also considers how oppositional ideologies become a socially effective means of generating discipline over a population. It embraces the ubiquity of power, the irreducibility of difference, and the perpetual partiality of autonomies and dominations. While the theory of hegemony describes a dispersal of power, it does not ever claim homogeneity. Social groups form articulations with one another, and one result of these articulations are group desires which become political ideologies, and collective will. Put another way, the public becomes a political force. Within the confines of biomedicine, and critical disability studies, it is important to understand hegemony in order to see what is missing, like agency and consent. In 1996 Stuart Hall described “culture is the sphere where consent to political power is perpetually in negotiation” (Swiffen 2009, 241). The self-monitoring that Foucault describes has a number of moving targets that depend on age, race, gender, ability, class, etc., and are doubly complicated in the case of chronic illness. The location in which biomedicine is operating also

becomes a significant modifier. For example, biomedical oversight will look different in Hawai‘i versus in the North American Continent. In the case of Amy’s migraines, it became necessary to leave Hawai‘i because of a lack of resources.

Amy : When my husband and I moved back there (Hawai‘i) in 2012 I had a neurologist there that I really liked, but she had just moved there the year prior. I liked a lot about Hawaii but the medical care was frustrating, though a large part of that is the navy and not Hawaii - discredit where discredit is due.

Jacqueline has run into a similar issue here in Hawai‘i. She was diagnosed with MS when she was living here in Hawai‘i. She has expressed to me her frustration that the neurologist that she has seen for the last several years in Hawai‘i doesn’t know enough about MS to be comfortable treating or advising. So she sees him once a year for an MRI to determine the rate that her disease is progressing.

Knitting, for me, is a location as much as it is an activity. It is where I go to be certain of my movements and choices, and feel okay with my mistakes as well as my successes. When I turn toward the tools and materials that I use to knit, they each serve as a way for me to know where I am, and where I am going — they help me to keep my bearings. Therefore, to knit is to be oriented.

In “Translating the Crip”, by Laura Hershey, some of this language and the way knowing your own positionality, and trying to empathize with others is critical is demonstrated.

Can I translate myself to you?
Do I need to?
Do I want to?

When I say *crip* I mean flesh-proof power, flash mob sticks and wheels in busy intersections, model mock.

When I say *disability* I mean all the brilliant ways we get through the planned fractures of the world.

When I say *living in America today* I mean thriving and unwelcome, the irony of the only possible time and place.

When I say *cure* I mean erase. I mean eradicate the miracle of error.

When I say *safe* I mean no pill, no certified agency, no danger to myself court order, no supervisory setting, no nurse, can protect or defend or save me, if you deny me power.

When I say *public transportation* I mean we all pay, we all ride, we all wait. As long as necessary.

When I say *basic rights* I mean difficult curries, a fancy-knotted scarf, a vegetable garden. I mean picking up a friend at the airport. I mean two blocks or a continent with switches or sensors or lightweight titanium, well-maintained and fully-funded. I mean shut up about charity, the GNP, pulling my own weight, and measuring my carbon footprint. I mean only embrace guaranteed can deliver real equality.

When I say *high-quality personal assistance services* I mean her sure hands earning honorably, and me eating and shitting without anyone's permission.

When I say *nondisabled* I mean all your precious tricks.

When I say *nondisabled privilege* I mean members-only thought processes, and the violence of stairs.

By *dancing* I mean of course dancing. We dance without coordination or hearing, because music wells through walls. You're invited, but don't do us any favors.

When I say *sexy* I mean our beautiful crip bodies, broken or bent, and whole. I mean drooling from habit and lust. I mean slow, slow.

When I say *family* I mean *all* the ways we need each other, beyond your hardening itch and paternal property rights, our encumbering love and ripping losses. I mean everything ripples.

When I say *normal* I don't really mean anything.

When I say *sunset*, *rich cheese*, *promise*, *breeze*, or *iambic pentameter*, I mean exactly the same things you mean.

Or, when I say *sunset* I mean swirling orange nightmare. When I say *rich cheese* I mean the best food I can still eat, or else I mean poverty and cholesterol. When I say *promise* I mean my survival depends on crossed digits. When I say *breeze* I mean finally requited desire. When I say *iambic pentameter*, I mean my heart's own nameless rhythm.

When I say *tell the truth* I mean complicate. Cry when it's no longer funny.

When I say *crip solidarity* I mean the grad school exam and the invisible man. I mean signed executive meetings, fighting for every SSI cent.

When I say *challenges to crip solidarity* I mean the colors missing from grant applications, the songs absent from laws. I mean that for all my complaints and victories, I am still sometimes more white than crip.

When I say anything I know the risk: You will accuse me of courage. I know your language all too well, steeped in its syntax of overcoming adversity and limited resources. When I say *courage* I mean you sitting next to me, talking, both of us refusing to compare or hate ourselves.

When I say *ally* I mean I'll get back to you. And you better be there (2012).

In order to examine inoperable subjectivity, I used the framework set up by Alvaro Jarrin to explore notions of beauty and surgery in Brazil. Jarrin argues that one of the most important aspects of beauty for women in Brazil is the act of sharing information with each other. By sharing personal histories and embodied sensations that women's bodies are brought into operable subjectivity in ways that men's bodies are not (2019). I would contend that this argument can be applied similarly to the chronically painful bodies of knitters and crocheters. The process of knitting or crochet became the space and opportunity for the knitters to share personal histories and embodied understandings of health and disability, the KAL the location for

those exchanges. The ongoing exchange amongst disabled knitters created a form of biomedical expertise which is not available to medical providers, which undermines the authority of the biomedical structure. According to Anne Werner and Kirsti Malterud these women are ceasing to 'keep to the rules of the game' by rejecting the power to maintain their own position of subordination in the patient-doctor relationship, when they cultivate their own medical expertise (Werner and Malterud 2003, 1411). This rejection of the 'rules' results in a chasm which brings these knitters (and countless others) into a state of inoperable subjectivity (Wilbers 2014). This inoperable position is further compounded by the impact of late-stage capitalism on biomedicine, which creates a myopic imperative to be exclusively curative. Inexhaustible demands for new technology are played out in real time by "practitioners and policymakers steeped in biomedical ways of knowing" who "are unable to see influences on health beyond the level of individual biological predisposition and individual behavioral choices" (Wendeland 2010:12).

When a chronically ill person is unable to choose their way out of poor health and into a curable position, they can be (and often are) viewed as in breach of an unspoken social contract to be healthy and productive. In some ways chronically ill people are a necessary part of the maintenance of biomedical hegemony: innovation (as demanded by the economy of hope) does not occur when illness can be cured with a single dose of medicine. However, failure to be cured casts those who remain sick as something abject, a symbol of human mortality. Art, and the connections that form when creativity is shared, help to form a new position where visibility comes not from social failure, but by the successful creation of care, communication, and a more fluid understanding of productivity which includes space to ebb and flow as the bodymind moves

through the various stages of disability. I asked all of the participants about their feelings regarding productivity and knitting.

Michelle: You bet I feel productive! In part because it's one of my modes of working, and because I'm combining creativity and skills to make/design/invent something. Even if it doesn't get exhibited/sold/worn, it's a pathway.

Flora: Yes knitting always makes me feel productive even when I have to frog. It's one of the few things I have almost endless patience for.

Jess: feel productive when I finish a knit, or when I make decent progress on a project

Amy: I am usually trying not to be productive about other things in my life when I'm knitting. Not always, but usually

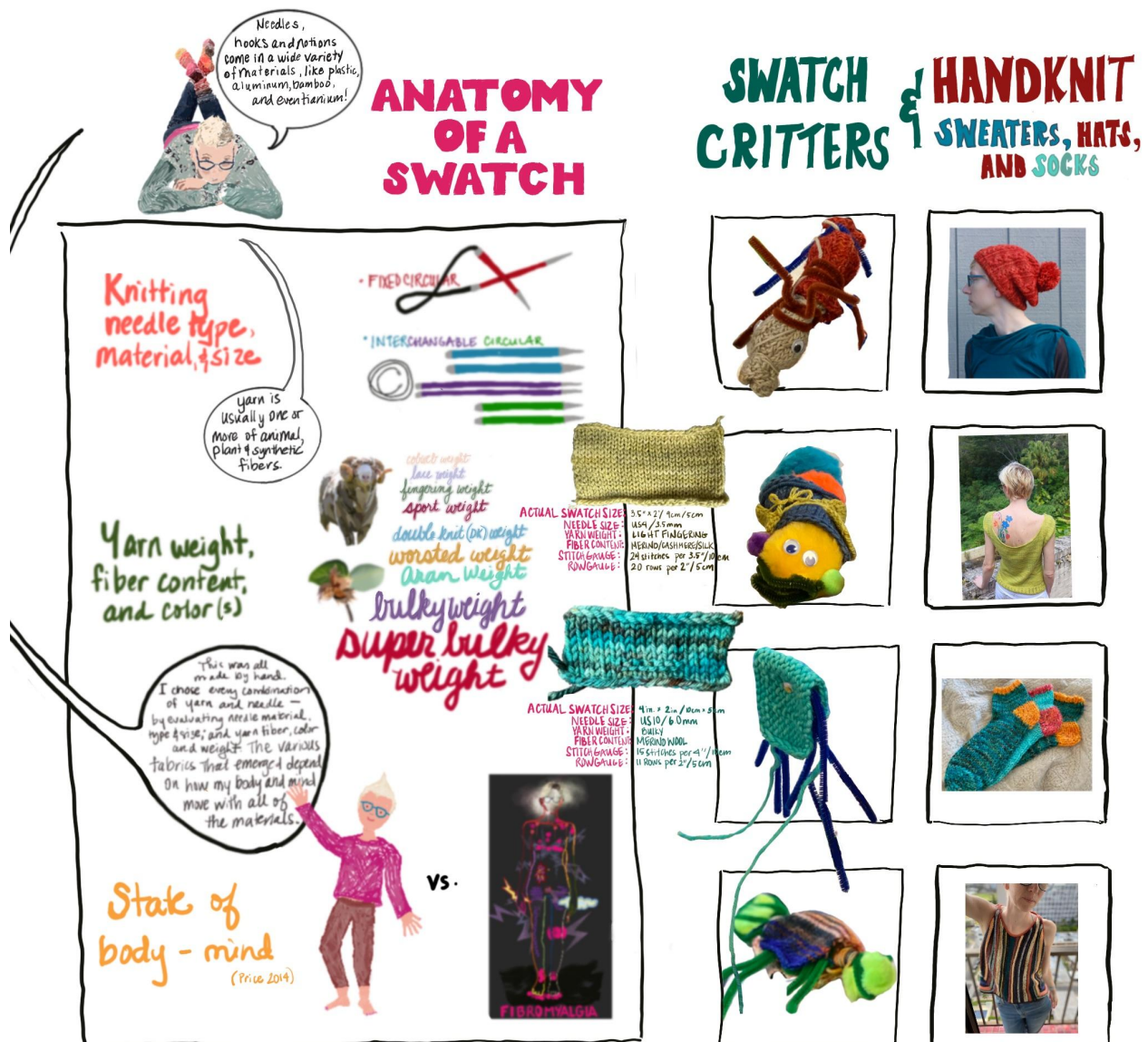
Jess went back to the idea of productivity a few months later when we were discussing the impact that knitting has on her life, and Jacqueline also had some thoughts:

Jess: Knitting keeps my hands busy. I have the need to do something productive while idle. If it's also art that's a plus too. Knitting relaxes me.

Jacqueline: my biggest challenge when it comes to knitting is my never ending to do list and issue with being productive. both of which are i'm sure self imposed. that's why i like knitting that i can do when doing something else like watching tv or visiting cause then i can do both

The first page or two of any contemporary knitting pattern begins with one or two full color photos, and a list of necessary information, starting with the yarn weight and yardage needed for each specific size, gauge, needles, and notions. The pattern we chose to use for this project is no exception- the recommended yarn is fingering weight in 5 colors, which correspond

with the vibrant photos of the designer's versions. Needles needed are US 5/ 3.75mm circular, 13 stitch markers, and a tapestry needle for weaving in ends. Gauge is noted at 22 stitches and 40 rows over 4 inches (22sts and 40 rows = 4" / 10cm in garter stitch, after blocking). However, for our KAL, most of that information was read, and promptly discarded. We used a wide variety of yarn weights from very thin lace weight yarn held double for a marled look to a squishy worsted weight. At the beginning of this project everyone was provided with three needle sizes, US 4, 5, 6 and sport weight yarn which is a bit heavier than the recommended fingering weight. Because a shawl is not tailored to the specific dimensions of a body, the gauge is not a critical part of the pattern, which is how we were able to make so many modifications, changes, and flourishes as we moved our way through the project.



Swatching is a method knitters use to understand their gauge (a counting of stitches per row, and rows per inch present in a piece of fabric that is a set size, usually 4' x 4' / 10cm x 10 cm) indicating the size of the finished fabric. Knitting needle size and type, yarn size, material content of the yarn (cotton, wool, silk, etc.), and the knitter's own muscle function, which is

governed by things such as stress, pain, and happiness, are the major factors that influence the size of a knitted swatch. The result of swatching is a small square of knitted fabric which looks as if it came from the finished project, and can be used to predict the size of finished project (2). For this project a swatch was not necessary, but in order to match gauge from the knitters that came before you, it was important to understand how the yarn and needles would work together to create a harmonious fabric.

Within this approach to knowledge, Kùchler (part 2) shows how practices such as weaving or knotting cords in the Pacific do not so much represent political practices, such as Hawaiian kingship ritual, through resemblance, as make associative and contiguous links. – ‘It is not what the cord looks like that is important . . . It is the processes of binding and opening to which the cord is subjected which constitutes the mystical subject of kingship.’ Knots are, she says, a ‘mode of being’, and according to the emphasis that different Pacific societies place on specific forms of binding, the emphasis on their political and social practices may vary, or vice versa. Reflecting this diversity, indigenous Australian basketry conversely evokes, not temporal events, notions of memory, nor linear history, since for these indigenous makers the sacred is beyond time. Rather, their baskets evoke a notion of country, land, place and belonging. ‘The land,’ they say, ‘inspires us to make things’ (Bunn and Mitchell, 2020, 9).

CHAPTER THREE: SPECIAL TECHNIQUES

Pain brings with it a dour companion, loneliness. I feel an unassuageable loneliness, because I will never be able to adequately describe the pain I suffer, nor can anyone accompany me into the realm of pain. I’ve learned that the recourse to analogy is not solely mine, since pain is so singular that it evades direct description, so isolating because in your body alone. Crying, and screaming, and raging against pain are the sign of language undone. As if is pain’s rhetorical signature, which requires the displacement of

metaphor to signify—its properties can be articulated only by way of something else, and the tropes of pain display the awkwardness of catachresis. (Crosby 2016, 31)

When women with disabilities engage in creative endeavors at any level, from encouraging others to planning and execution of their own projects there is a positive impact on their overall sense of wellbeing. (Riley, Corkhill. and Harris 2013; Håkansson and Ahlborg 2010). Due to the nature of most textile projects, which can be stopped and restarted without a negative consequence (except dyeing), most can be managed even during periods of increased pain, or flares. As a result of this intrinsic flexibility many women who live with chronic pain engage frequently in these forms of making. A plethora of literature exists which demonstrates the ameliorative effect of group support on chronic pain, whether that support is digital or physical. Thus, feeling distanced from their communities can result in increased feelings of pain. (Berkowitz, Baggett, and Edwards, 2019; Huber 2017; Jain 2013; Lorde 1980) A weaving of the two worlds through the use of the internet occurs with greater ease of social connectedness, even amidst periods of increased physical pain and turmoil.

Both the production and maintenance of selfhood for women often center around the social expectation that they provide care as well as their need to receive care. Social and economic inequality are common factors which influence the need for women to receive care, whether it is in the form of support from family, community, or forms of welfare from the State (Murphy 2017; Saethre and Sadler 2017).

The natural extension of the need to care, and the need to be cared for can be seen within the biomedical system in the United States. Medical care shifted in the mid 20th century from medicalization, or a system of disease identification and cure, to one of biomedicalization which

includes a technological shift to create practices of screening and surveillance for disease that has the potential to occur (Clarke 2010; Foucault 1976; Joyce 2008; Taylor 2008). In practical terms this shift can be observed in questions a doctor might ask a patient: What is wrong? becomes Where does it hurt?. Such a shift removes the patient from a subjective position as an active participant, into a passive object to be imaged, biopsied, and surveilled for future disease. (Fourault 1976). Within this paradigm the patient is subject to the privileged knowledge the doctor possesses. A failure on the part of women to be screened for ‘actual, or potential signs, of disease and decay’ can be viewed by society as a moral dereliction of their responsibility to care for themselves (Kaufert 2000, 167). This dereliction in turn has the potential to directly impact their ability to care for others. Chronic illness and disability easily become liminal spaces between biomedicine and the political economy of hope. Chronic means there is no cure, and often even a cursory diagnosis can take close to a decade, leaving women who experience disability from long-term illness in a chronic state of anticipation (Adams et al. 2009). The temporality of disability within biomedicine is so prolific as to have its own vernacular, “prognosis, remission, recurrence, chronic, and/or terminal” (Samuels and Freeman 2021, 245). In this one exchange alone Jess, Amy, Flora and I touch on recurrence, and the chronic nature of autoimmunity.

Rita: so I am getting a shingles vaccine tonight before I start (Rinvoq, for anyone who likes to read about drugs) and I'm not looking forward to the side-effects of Shingrix

Amy: My fingers are crossed for you, when my PCM tried to do something similar when my neurologist dropped all the balls my insurance came back with "nope we won't auth it unless it is signed for by a neuro" which was a whole other infuriation 😞😞2

Jess: Good luck Rita!

My doctor should have had me do the shingles vaccine before I started my biologic. I did end up with shingles after going on it, but they didn't give me the vaccine afterward?

Amy: Yes good luck! I had the vaccine and I felt bad after the second shot but the first was okay.



Flora: Rita 💙💙

Hmsa just rejected my last round of Botox? So I have to sort this out.



Jess: Fighting with insurance is a job 100

Currently sick again 😞

They have me on prednisone

Rita: @Jess sick again?! Is the prednisone helping?

The shingles vaccine is kicking my ass. I'm taking heroic doses of tylenol and aleve just to kind of function.

In that dialogue, you see how pain mediates the ways in which our KAL group moves through discussions on support, unsolicited advice, and medications. While the group centers knitting, our collective gives us tools for dealing with our medical providers, insurance carriers, pesky friends/ family/ partners. In the same way that we choose our tools to knit with, we have chosen each other to be part of our communal toolkit for navigating a world in which our bodies, which reject cure and embrace the fluidity of being chronic, agitate those around us.

Knitting, particularly while disabled, is an act that resists capitalist and colonial hierarchies that value work for profit over work for necessity. It disrupts the hegemony of the heteronormative white patriarchy through an insistence that it is not “only” or “just” but rather intricate, complex, and in many cases made by people who are crip, and therefore queer, as Kafer describes in *Crip, Queer, Feminist* (2010). In 2020 there was a series of three essays written by people disabled in very different ways, who all describe a type of coming out with regards to their disability. One of the essayists, Ryan Haddad, describes a failed hook-up attempt where the potential lover backed out after Ryan revealed that he has cerebral palsy. The response he received was “Sorry, man, I kant b kool w dat.” After that, Ryan, a gay man, understood that his “disability might make being gay more complicated” (Haddad, 2020). In this instance it is possible to see some of the overlap that occurs between being crip and being queer, which can be thought of as a “productive reciprocity”. Of course, one does not presume or preclude the other, but the experiences of people who are queer and who are disabled have a rich and storied history. Both have “pathologized by medicine; demonized by religion, victimized by hate groups, and isolated socially, often in their families of origin” (Sandahl 2003, 25-26).

“...how tacit one’s ... identity is to others is a matter of interpretation and requires that the others interacting with my informants recognize and decode the self-presentation of bodies and the information about them that circulates in family networks” (Decena 2008, 340).

One is not born a woman, nor is one born an organism, cell walls and skin are not a delineation or solid barrier between self and the outside world. Instead they perform as a place of ‘threatening illicit fusions’ (Haraway 1989, 384), extended and unbounded. Our immune system, made up of cells that arise from ‘amorphous’ tissues of the thymus (T-cells), bone marrow (B-cells), spleen and lymph nodes which migrate into the layers of epithelial cells that make up

organs, or circulate in bodily fluids- essentially existing everywhere and nowhere all at once (Delves and Roitt 2000)

Within our knitting group the majority of us have one or more diagnosed autoimmune disorders, including: multiple sclerosis (MS), rheumatoid arthritis (RA), Sjögrens syndrome, Hashimoto's thyroiditis, ulcerative colitis (UC), eczema, and status migrainosus. Present also are endometriosis, fibromyalgia, and asthma, which have not (yet) been classified as autoimmune, but are a result of immune system dysregulation, and demonstrate a close correlation with autoimmune diseases. Worldwide, between 5 and 10% of the total population have autoimmunity, at least 75% of those people are women, and on average it takes 5-7 separate doctor visits over 4 years to be properly diagnosed (Marshall et al. 2014). Sex-based disparity is not isolated to rheumatology or immunology; cardiovascular events in women are more likely to receive delayed treatment, or go untreated. Cardiovascular events in women are often misdiagnosed or disregarded because the symptoms women experience are "atypical," which is to say they do not conform to the male-model (Graham 2016). Women who report symptoms of pain, which is a primary indicator of a cardiovascular event, inflammation from autoimmune disease, or a variety of other life-threatening illnesses, are treated less aggressively than their male contemporaries (Hoffmann and Tarzian, 2003). This type of delay in diagnosis and treatment results in a disproportionate increase in female disability and mortality (Braveman 2003; Moser et al. 2006). Research done by anthropologists that contributes to the understanding of how social sources of health contribute to health differences between men and women can help shape the way educational and system policies are created (Braveman 2014).

Broadly, autoimmune disease is a dysregulation of the immune system. The immune system stops recognizing proteins that make up tissues of the body, and treats them as a foreign invader, mounting an ongoing attack. The attack can be organ specific, like Hashimoto's thyroiditis (HT), or systemic, like systemic lupus erythematosus (SLE) (Ngo et al. 2014). Autoimmune disease is considered idiopathic, which is to say nobody has a clear idea what triggers are involved that cause an immune system to stop recognizing its own tissues (Costenbader et al., 2012). New research suggests that stress-triggers like PTSD, bacterial and viral infections, and chemical exposure play a significant role in the onset of autoimmune disease (Song et al., 2018). Other factors, including sex, environment, and genetics have widely been accepted to be the primary precipitating factors. Between 80-100 discrete autoimmune disorders have been identified; however, a lack of consensus on what specifically constitutes an "autoimmune disorder" means that many other diseases, like asthma and endometriosis, could potentially be classified as autoimmune (Pilli et al., 2017).

There was a point in history when the female body was considered standard, and the male body was simply a deviation from that standard. Archibald Pitcairne, an influential physician in 17th century England, is paraphrased as believing that a man is simply a woman without a uterus (Churchill, 2005). In Western medicine, the shift in perception of viewing women as separate and equal in the medical model to a male-centric model occurred in the late 1800's. In the late 1800s and early 1900s medical technology started including laboratory-based analysis of blood and other human tissues as a diagnostic tool (Berger, 1999). The social structure in the US at the turn of the 20th century was patriarchal. Government was composed entirely of men, the majority of scholars were men, scientists and doctors were men (Khelghat-Doost and Sibly

2020). At the time, the criteria for selection into a study to establish reference intervals in a laboratory were: “To qualify for the Reference State, individuals shall be 20-30 years of age, of ideal body mass, fasted for 10 h[ours], taking no medication, consuming less than 45 g[rams] alcohol per day, smoking less than 12 cigarettes per day, and with no apparent illness (Petitclerc and Solberg, 1987). When the reference values for laboratories were created, they were a reflection of the social structure and population at that time; modern day labs continue to use many of these reference values, because it is costly and time consuming to do all of the necessary work to create new reference intervals (Katayev et al., 2010). New data confirms that lab values that have been created by relying on young, healthy, white males as the standard are at best irrelevant for people who are critically ill, and at worst are fatal (Xu et al. 2021)

The Flexner Report, requisition by the newly formed American Medical Association (AMA), a professional group who had formed to represent the sect of regular doctors, recommended a reform of all of the medical schools in the US, which effectively eliminated women and people of color from medical school instruction and licensure until the landmark 1972 Title IV outlawed sexual discrimination in admissions practices. The financial and time cost of the prerequisite 2 years of college was enough to ensure that wealthy white men were the sole proprietors of medical knowledge for generations to come (Dusenbery 2018, 15).

Simone de Beauvoir highlights this specific act of othering women:

‘...social subordination as between the sexes no longer exists and that on the whole, in spite of differences, woman is an equal. As, however, he observes some points of inferiority – the most important being unfitness for the professions – he attributes these to natural causes. When he is in a co-operative and benevolent relation with woman, his theme is the principle of abstract equality, and he does not base his attitude upon such inequality as may exist. But when he is in conflict with her, the situation is reversed: his

theme will be the existing inequality, and he will even take it as justification for denying abstract equality' (1972).

Consequently, the persistence of a male-centric medical system has resulted in a medical bias against women that is both endemic and nearly invisible. Dr. Yut-Lin Wong describes examples of that bias in a report, published by the United Nations in 1998, describing how medical schools in the United States were failing to teach students how to perform breast and pelvic exams, leaving students to learn women's health on "poor patients who are already in pain." She goes on to describe an allegation that some students were only allowed to perform pelvic examinations on patients who were anesthetized for surgery (Nechas and Foley 1994). Such practices simultaneously teach students that illness that can be attributed to being female is not important enough to learn, and that a woman's pain is inconsequential. As a result, doctors, who are primarily white men, become practiced in minimizing illness and pain experienced by women. This can, and should, be understood as failure not of the women being examined, but of the social structures of biomedicine and education.

Localized and/or widespread pain is perhaps the most common symptom of autoimmune disorders (Ahmad and Tagoe, 2014). However, pain not only resists language, it "actively destroys it" (Scarry 1987, 172) It is also nearly impossible to quantify, and has a significant amount of social stigma attached. Many women feel as if they are being checked for mental disorders when they attempt to discuss their pain with health care providers (Biss 2007; Werner and Malterud, 2003). The judgment women feel in response to revealing that they are experiencing pain is one reason why women fail to seek care for acute cardiovascular events in a

timely fashion, resulting in increased mortality. In this instance, crip failure has the possibility to be fatal, unlike a dropped stitch in a shawl.

It is also partially responsible for the delays women experience when seeking an accurate diagnosis for autoimmune disorders (Dusenbery 2018). In a long-form essay, Jamison describes different types of pain women experience: physical pain from injury; emotional pain from loss; pain caused by the rejection of individuals; families or society; the pain of childbirth. What is striking in all of her examples, is that there are not different words to describe the different types of pain. They are all pain, they are all suffering, and they are all invisible (2014). Due to the subjective nature of pain, a health professional questioning someone who has pain is an appropriate step to take before treating that pain. The harm from that questioning happens when women are consistently singled out, and treated in a way that implies they are lying about their pain. A study published in the British Journal of Pain demonstrates that researchers are actively looking for ways to be more objective in their diagnosis and treatment of pain, but absent from the study is any mention of sex or gender (Ung et al. 2015). Extensive research has been conducted by anthropologists into understanding the way women experience pain, and the amount of effort those women must exert to be heard by medical professionals (Werner and Malterud, 2003).

The moment that you realize you don't remember what no pain feels like comes and goes quietly (Huber 2017; Biss, 2007). Like my knitting friends who live with chronic illness that often involves pain, I live with fibromyalgia, arthritis, and three comorbid autoimmune conditions. I could not tell you the last time I did not have pain, a sentiment which is woven through my friendships with knitters who have chronic health conditions. Dr. Arthur Kleinman

has articulated beautifully the need to continuously strive for a clearer understanding of non-conforming health when he says “illness has meaning; and to understand how it obtains meaning is to understand something fundamental about illness, about care, and perhaps about life generally” (2020, preface) .

Most of October, all of November, and part of December have come and gone. Everyone is busy with injury, illness, travel, art exhibitions, and countless other things. Working on this project has stalled for almost everyone. This passage of time has me thinking about burdens, balances, and benefits. I know this project has some amount of burden, such as the time required to knit, and often it requires uninterrupted time. Watching everyone, and talking with them about illness, it seems like so many of us who are just tired of being sick or in pain all of the time, start to see medical care as a burden. Not just because of the gaslighting, though that is a big one, but just the banality of it all. The same tests, with the same answers. The economy of hope exists for normies³: test results that are fine are a good thing, and screening procedures offer a promise of a long healthy life. But once you get shuffled into the chronic, or disabled camp, you become a burden to those meant to treat you- and that part of the relationship becomes reciprocal: health providers seemingly become the barrier to feeling better with every dismissal.

Jacqueline: Also I can't seem to get through to her office. I've called literally 10 times with no luck. I've even called the physicians exchange who then called her office but when I call they don't pick up

Rita: Ugh. Sometimes I hate the way we have to interact with specialists here [Hawaii].

Jacqueline: Also I can't seem to get through to her office. I've called literally 10 times with no luck. I've even called the physicians exchange who then called her office but when I call they don't pick up.

³ Slang for a normal person. In this context normal refers to someone with normative health.

Jacqueline: yeah it's weird. it's like pushing a rock up a hill. I can see why people forgo treatment. not just the expense but just the challenge to get in.

Rita: so much this

However, these burdens are balanced by the benefits of knitting, and of sharing time, thoughts, and stories with each other. This next conversation took place over the course of about two weeks, from mid-November through the beginning of December, 2022. The relationships that have developed over the course of the first half of the KAL are evident, as participants share information and encouragement across a wide range of topics, in a seamless way.

11/14/2022 Michelle: To all in this hui, I'd like to invite you to a short talk I'll (nervously) be giving tonight! It's a 6:30pm event in person at Honolulu's Marks Garage gallery, but is also being offered via ZOOM. I don't yet have the link, but if there's interest, I'll share here when I find it. The new work I'll be discussing is ~80% fiber with bonus pressed plants and underwater drawings as field work. 🌺🌺👍

Jess : Cool! What time is that EST?

Michelle : Just got the link -
https://hawaii.zoom.us/join/9tJlqdeqorj8sG9TFva9hh_LzK81B7b14VIDc

Rita: @Jess that talk is 11:30pm for you

Michelle : Yup - we're quite a ways away!

Rita: Michelle, your talk was wonderful!

Michelle : Thanks Rita! I went a good deal longer than the moderators wanted, even though I was trying to scale it back on the fly — yikes! Just glad I didn't spontaneously combust (a phenomenon which always seems likely during a public speaking engagement).

Michelle : I cut out a number of points I had hoped to make but meh, next time.

Rita: I hope everyone had a great day yesterday

and find good yarn deals today
(i got a neighborhood fiber co mystery bag!)

Jess : Check my buddy Jessie at Yarn Over New York

Jess : That's what I was using for my shawl 😍

11/25/2022 Jess : I'm just hacking up my lungs. I got the flu from the kids
Fevers gone but I'm still out of it

Rita: Oh goodness! You all have had a rough fall!

Michelle : Aw shucks — hope you're better soon Jessica

Jess : More like rough summer to fall 😞 but it's everywhere. Even my friend in Canada
is going through it with her kiddo

Darn school

Jess : Daycare etc

Jess : 15 things going around doctors are saying

Rita: I had dinner with a nicu/pediatric doc last night and he we have avoided most of
what is happening on the continent. but that just means that we will get hit with it all later

Jess : Well I hope not, but the pediatric hospitals are seeing so many, even adults
getting RSV it's crazy town!

Rita: yeah- my mother in law got a nasty case of rsv last winter

Jess : Yucky!

12/2/2022 Rita: Thinking about all of you, I know there's travel coming up, and also some
happening currently, and I hope all of you who were feeling lousy have started to feel a
little better.

Jess : Thanks Rita!

Way better than I was but things still hectic here until next week! Good vibes, prayers,
w.e. That we are done with the illnesses and health stuff for a long while! 🙏🍀
How are you doing?

Rita: I'm so glad to hear things are better, at least for the moment!

I'm alright, I had a bilateral medial nerve branch block done yesterday, and I didn't take any sedative or pain medicine, so I'm pretty tender today. (However, there were a few hours yesterday that were marvelously pain-free!)

CHAPTER FOUR: CAST-ON and KNIT (THE BODY ON CRIP TIME)

It is a surprise to find how, starting from the simplest of beginnings, a surface of such complexity can emerge (Ingold 2022).

Instructions: Your Time

Using A, CO 3 sts. K 7 rows.

If you have ever knit a shawl, you've already got some sense of what operating on cripple time feels like even if you do not know it. For those of you who have not knit a shawl or experienced cripple time, I'll walk you through it now. To begin you cast-on three stitches, very simply that means to make three loops on a knitting needle. It's a *very* quick process. Then you knit that row seven times, which is still very straightforward. However, things go sideways, quite literally, very quickly. The knitted fabric is turned on its side and you are instructed to pick up and knit seven stitches (those are the seven rows you just made), turn again and pick up another three. In two easy and one complicated steps, three stitches have become eleven. From here, you begin knitting in sections, and they go fast at first, making it easy to feel accomplished. Every seven rows a new section is added, and each section creates more stitches. By the end those eleven stitches you started with have become 1200 stitches, which can take thirty minutes or three weeks to complete a single row.

What starts as a profound feeling of accomplishment can quickly feel overwhelming and even insurmountable. When considering how people with disabilities operate in a world that understands able-bodiedness as a universal starting point, it becomes readily apparent that the flow of time becomes necessarily shifted, and there is no single variable alone that is the cause.

Jacqueline: i feel like “abled” people really have no idea how hard it can be. and that some days are much better than others

it’s so hard to know what works and what doesn’t because everyday can be different

In this chapter my aim is to highlight the similarities and differences between what I call *normie* (or what Margaret Price called *normate* time), and crip time. Regarding crip time, Kafer asks:

How might our understandings of queer futurity shift when read through the experiences of disabled people, or when interpreted as part of a critique of compulsory able-bodiedness or able-mindedness? What does it do to queer time to place it alongside crip time, or queer futurity alongside crip futurity? Can we crip queer time? (2013, 27)

Throughout this thesis, I have engaged with feminist, queer, and crip theories, because one alone is insufficient to appropriately address the wants, and needs of people with chronic illness, pain, and/or disability. In an essay on the intersections of queer and crip, Carrie Sandahl examines the pejorative terms cripple and queer, describing them as “fluid, and ever-changing”, which is precisely the nature of our knitting project (2003, 27). Progress, and the need for shifting definitions become the hallmark of knitting shawls on crip time. As we progressed through this KAL, what started out as a neatly organized timeline quickly fell apart, as I realized, four weeks into the project, that pre-paid postage labels expire after 28 days. All of the time I

spent purchasing postage, printing labels, and ensuring that each participant got the correct number of labels that were addressed to the correct recipient was for naught.

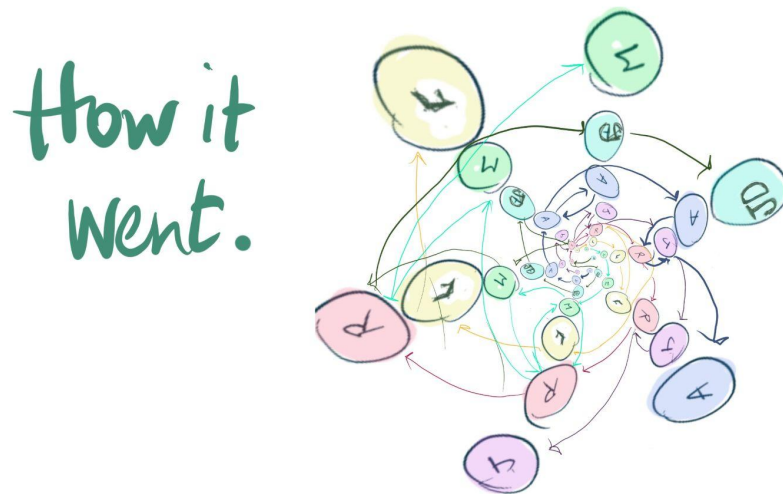
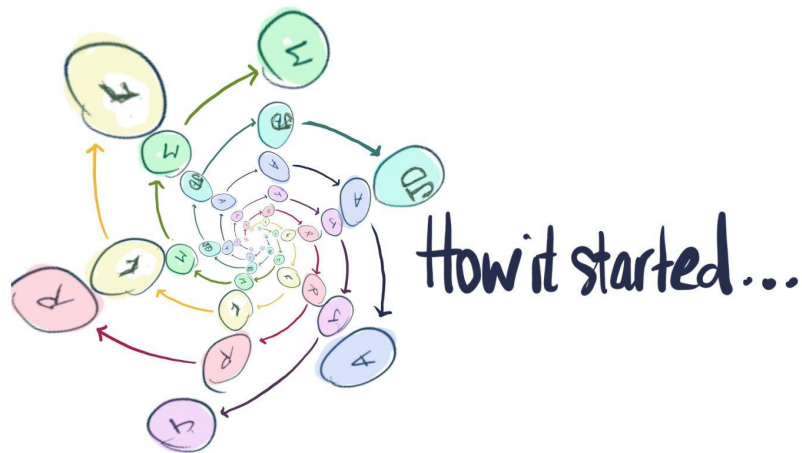


Image 9. The Round-Robin Shawl-Swap Plan

Section 1: Normie Time

Row 1 (RS): K3, yo, k to m, yo, slm, k to last 3 sts, yo, k3. 3 sts increased.

Compulsory able-bodiedness is a concept that describes how bodies are understood to be universally abled and healthy. Normie time, then, becomes the way to talk about how these healthy bodies move through life based on a theory that was explored in the early 2000's by critical disability scholars. Kafer, in particular, models a paper after Adrienne Rich's 1980 paper "Compulsory Heterosexuality and Lesbian Experience" in which heterosexuality has acquired a mantle of universality. She follows a similar trajectory as Robert McRuer, who, in the same time period, describes how universal able-bodiedness is maintained through two primary mechanisms: physical force, verbal and non-verbal messaging (2003, 79-80). The experience of normie time while residing in a body that insists on immune dysregulation means that whole days can be lost trying to navigate the hedge maze of biomedical peripherals: insurance denials, prior authorizations gone awry, pharmacies that run out of meds, pharmacists who refuse to fill prescriptions, and planning around the side effects of those meds. Normie time, with its rigid linearity, simply does not account for the number of deviations that happen routinely and unpredictably at once.

Jess : My measured productivity has decreased for several reasons. My health is def one of those factors. When I say measured productivity, I mean more testing, designing, sample making, or commissions

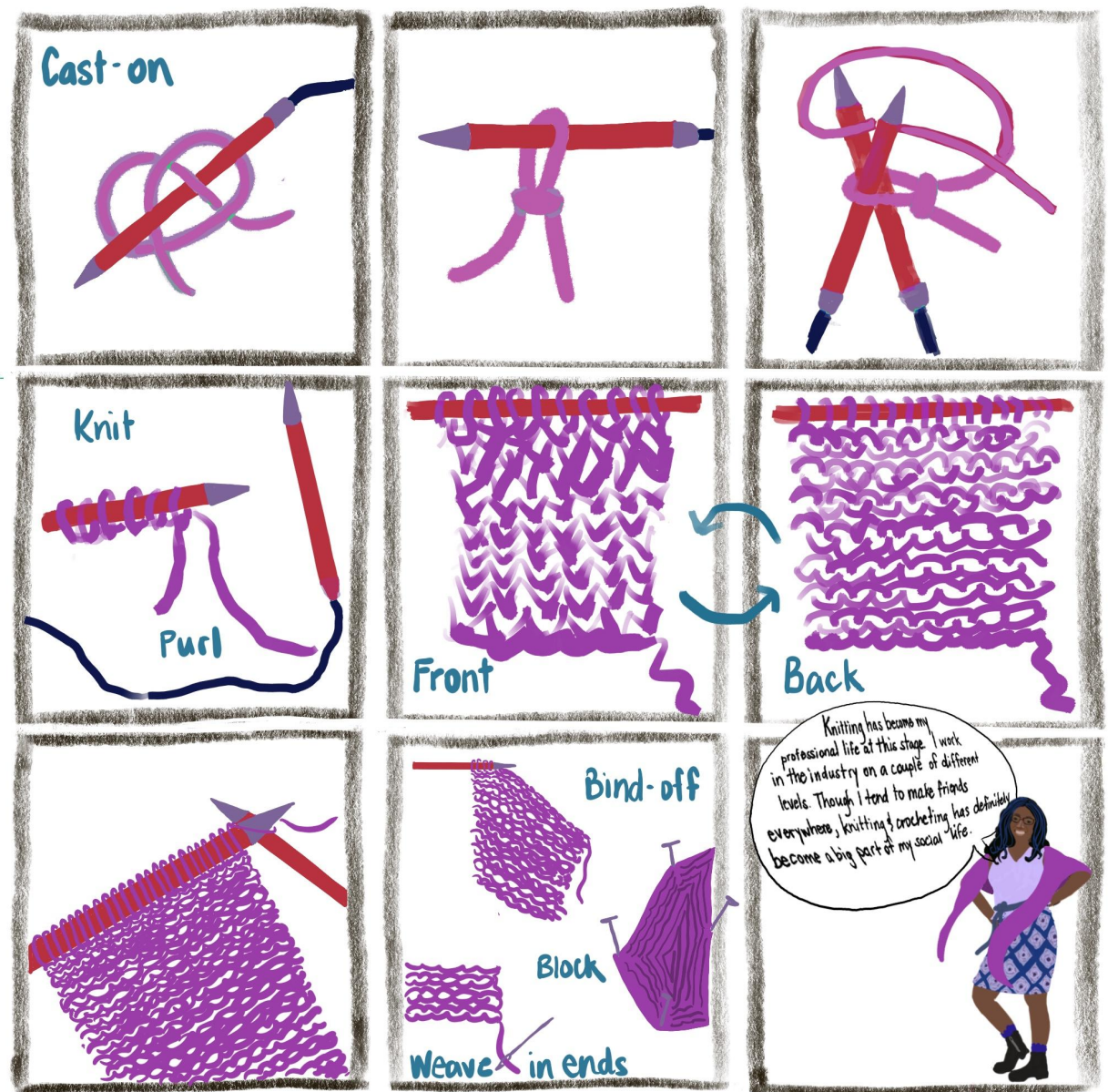


Image 10. Jess Teaches Knitting. The text reads: Knitting has become my professional life at this stage. I work in the industry on a couple of different levels. Though I tend to make friends everywhere, knitting and crocheting has definitely become a big part of my social life.

Section 2: Productivity and Success

Row 1 (RS): K3, yo, k1, yo, pm, k to m, yo, slm, k to last 3

sts, yo, k3. 4 sts increased.

Consider the ideas of productivity and neoliberalism, from an anthropological standpoint. James Ferguson examines neoliberal capitalism, and finds that all avenues of thought consistently lead to the inevitable conclusion that “the rich are benefiting and the poor are getting screwed” (2009, 166) The poor here are deemed powerless, and can be read as any person in need of social support or intervention. It is not a stretch to say that in order to acquire or maintain any measure of power compulsory able-bodiedness is necessary. Ferguson goes on to note that the entire domain of society is predicated on the “figure of the wage-earning man”, which excludes the majority of nearly any population. Those who require social interventions include the elderly, children, procreating women, and the disabled. As a group made up of procreating aged women, some with children, some with elderly family to care for, and all with some measure of disability, it is a good idea to be specific about how such monolithic terms like *neoliberalism*, *productivity*, and *progress* are used, challenged, and bent in order to repurpose them into techniques “put to work in the service of political projects” that might change crip futurities in such a way that crip bodies no longer need to bend to normate time in order to have some measure of social power (Ferguson 2010, 183; Kafer 2013).

One aspect of progress and productivity that came up numerous times in our conversations was laziness, or being idle. Because fatigue is a hallmark of autoimmune disease, most people who are disabled, especially those with varying levels of energy and no outward signs of disability, are accused of being lazy. These accusations can come from employers, from family, and from health providers who have been stymied in their mandate to cure incurable

chronic disease. We saw earlier how Amy was called lazy and drug seeking as she attempted to have status migrainosus identified and addressed.

Jess: Knitting keeps my hands busy. I have the need to do something productive while idle. If it's also art that's a plus too. Knitting relaxes me.

Jacqueline: my biggest challenge when it comes to knitting is my never ending to do list and issue with being productive. both of which are i'm sure self imposed. that's why i like knitting that i can do when doing something else like watching tv or visiting cause then i can do both

Michelle: Unfortunately I do a lot of stitching while sitting in my car (during public EV charging sessions). While I appreciate the quiet time to be productive, my sore back doesn't agree. (Ok — I'll admit I also crochet while stuck in traffic...but preferably while my passenger is asleep and doesn't see what I'm doing...)

Amy : I haven't gotten much done, but.. I think that's kind of the nature of this as well? I can mail whenever, I'll work a bit more on it this weekend

Once again, understanding how bodies respond to pain, back in pain and how that determines how you knit and what the knitting feels like-- the phenomenology of it all. how sometimes knitting relieves pain, sometimes it has to be put to the side in a brain fog. how your pain refuses to be docile, demands your fullest attention.

Flora: I think especially in the last 3 years I've struggle with disability and idleness. Though I suppose it's not really idleness it's more like idle feeling rest. The energy limitations of fibro are for sure the most frustrating symptoms. There's always more that I want to do than what I have capacity for And I've gone from one extreme to another. Over scheduled and over committed to literal disability. At the peak of grad school I think I made 8 garments or more. In 2021 I made myself 2 things. I think last year the number is the same And we're 3/4 through 2023 and ive made maybe 2 things ? In grad school I was working part time the entire time. So I would guess the hours i spent a week between school and work is about 50-60

But I don't think there has ever been a time when that hasn't been my schedule pre-fibro (fibromyalgia)

Rita: How many hours a week do you work for Adrian (Tam)?

Flora: Mmmmmm depends during session solidly 35-40

Rita: Has he ever expressed his frustration with the limitations that come with fibro and endo?

Flora: Only once

When I was having the flare In july and mt car broke down

I messes up a lot of things on our calendar

Otherwise I'm able to do this job in even in a somewhat dominated capacity

I'd say up to like 60% capacity. Lower than that I should take sick days

Interim I work a lot less. More like 30hrs max

Flora

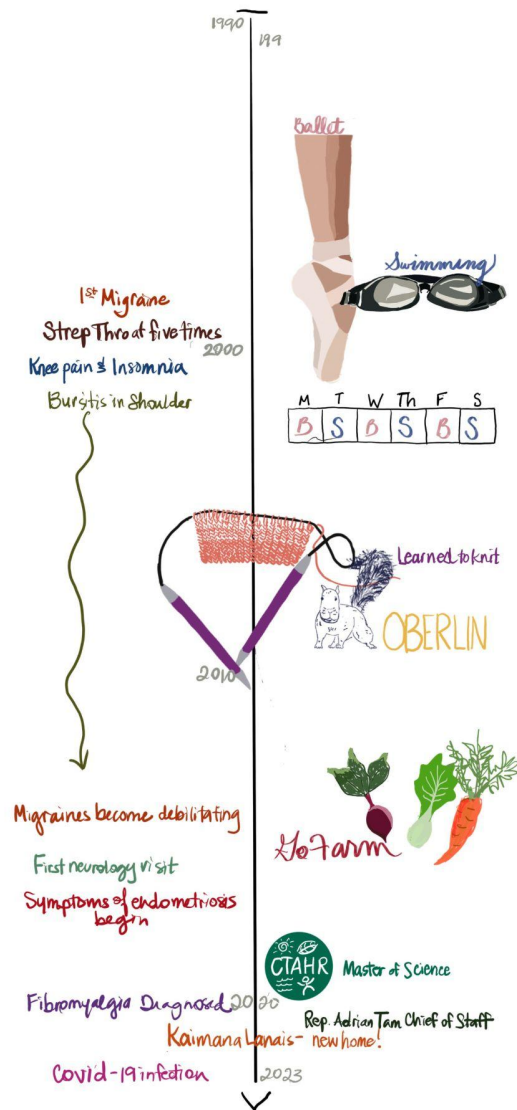


Image 12. Flora's Story

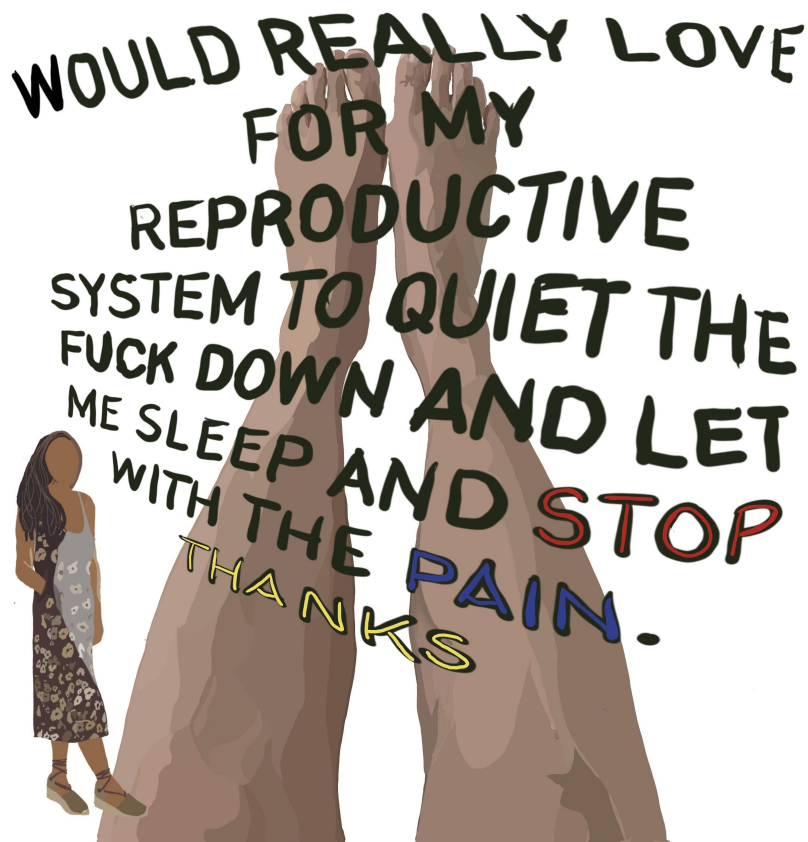


Image 11. Flora's Request

Just as we noted in Chapter 3, the language surrounding chronic illness creates a shift in the meaning of progress. This shift, in turn, makes it clear how progress, in certain contexts, results in grief, which is one aspect of crip time. About halfway through the project Amy lost a

beloved pet. Her shift into grief time (Samuels and Freeman, 2021) becomes evident, her participation in conversations slows, but does not ever stop entirely.

Amy : I wrote it out on my notes app when I couldn't sleep a while ago, so I hope it is coherent! I'll share it here because that's easiest and I'm low effort at the moment - my cat just died and things are rough.

:... She was 16 and had kidney failure - we were able to manage it for a few years but it progressed very quickly the past few weeks. I just tried to give her as many good moments as I could

Section 3: Crip Time

Row 1 (RS): K3, yo, k1, yo, pm, *k to m, yo, slm; repeat from * until you slip the final stitch marker, k to last 3 sts, yo, k3.

Being productive on crip time is an interesting concept, because it must allow for brain fog, swollen hands, insomnia, and sometimes toddlers who require invasive diagnostic imaging. Consider Jess, who is in the midst of this project, as well as caring for three young kids (one a newborn), and working at a yarn store. When her son requires an endoscopy, she voices concerns:

Rita: Everyone back to feeling okay at your place?

Jess : I didn't mail it yet... this week Coming though

Jess : Yeah we are feeling okay thank you, though allergies are starting and I'm sure we'll get saddled with back to school colds 😞

Jess : Just as long as there's no COVID or hospitalizations I'll be happy

Jess : My son also needs an upper endoscopy

Rita: I've had an endoscopy and an EGD, feel free to pick my brain.

Jess : So have I but he's 2 and never been in drf anesthesia

Rita: ahh, gotcha

Jess : Under*

Rita: Well, I'll be here offering support however I can from the sidelines.

Jess : Thank you! 🥰💜

Even though Jess did not need imaging herself (though a fall one month later would mean she needed an MRI) she was struggling with the weight of the ongoing health issues of her child, which only intensifies her own experiences of operating on crip time. Endoscopies are an invasive procedure where a camera is inserted into a person's mouth, and threaded down their throat and into the stomach. It can be a useful diagnostic tool to visualize polyps, lesions, erosive patterns, and ulcerations. Twilight sedation, a type of anesthesia that is not as profound as general anesthesia, is used during the procedure- and this was the source of Jess's concern. The drugs used for twilight anesthesia are generally a combination of a benzodiazepine, a narcotic pain medicine, and a drug called propofol. This combination relaxes a person, reduces any discomfort the body experiences (bodies have a physiologic response to pain that occurs even if the patient is not conscious), and creates a short-term amnesia. These drugs, like most drugs, are used on people in drug trials to determine safety, and then dosing guidelines. However, until very recently the drug trials used to determine safety and efficacy were only done on young men, much like the process of determining standard reference values and metrics that was discussed earlier in Chapter 3. Through the course of the project, this type of information has been discussed, and the knowledge that medication that was tested only on young men haunts her. This crip time is also worry time, and like all crip time, moments flow around worry, anxiety, and even the grief a mother feels when their child is suffering, in a different way.

Throughout this project each participant experiences circumstances that make it necessary to adjust the way they perceive their own notions of productivity and success. In these instances where normate time shifts into crip time, success is no longer completing an entire section of the shawl, it's simply remembering where the shawl is, or finding the energy to add

one or two stitches. Nobody on this project scoffed when one of us needed to slow down to accommodate illness- for every one of us got sick with COVID-19 during the course of this project. We also had instances of RSV, asthma attacks, migraines, and autoimmune flares that caused swollen joints and aching muscles. “Crip time is time travel” (Samuels 2017), full of stops, starts, dropped stitches, and lost shawls, making crip productivity and crip success different from their normie counterparts, but no less satisfying and no less useful.

CHAPTER FIVE: SHAWL BORDER and BIND-OFF

Border

Row 1 (RS): K3, yo, *k to m, yo, slm; repeat from * until

you slip the final stitch marker, k to last 3 sts, yo, k3.

Chronic illness does not end. All six of us will continue to live on crip time in a normie time world, long after every shawl has been completed. In Chapter 2 we discussed what difference is made when where we gather, and the ground that we gather on changes. For each of us, the ground will perpetually shift, and change because our bodies insist on dysregulation, excess, and failure. However, crip time isn’t just grief time and broken time, crip time is also communion time, encouragement time, and success time. When our gathering ground changes, we simply bend time and circumstances to meet our ever changing needs, encouraging one another the entire way.

Jacqueline: ... even though i wasn't very engaged it was nice to know there is a group of awesome women out there that struggle with autoimmune but are living fruitful productive lives

I-cord BO and Blocking

*K2, k2tog tbl, sl3 sts onto left needle; repeat from * until all sts are bound off. Break yarn and pull it through the 3 I-cord sts.

Weave in ends and wet block the finished shawl to smooth the fabric. You can pin the wingspan edge of the wet shawl onto a rug, mattress, or blocking mat and then pin each increase point outward to exaggerate the fun shape.

I am knitting when I should probably be writing. All writing comes with a deadline, and this project is no different, and much like making the shawls, my words come in ebbs and flows, crip words on crip time. But my delay is not typical procrastination, because I am spending time binding off Amy's shawl before mailing it to her, and moving on to Flora's shawl. With each segment completed, my anticipation gains momentum. These shawls, who look like siblings or cousins, hold the energy of all six knitters. Ensuring that they are properly finished was never the goal, but is becoming increasingly important to me as I near the end of this project. With each row of i-cord I am adding gratitude, relief, and joy. I am even looking forward to weaving in ends, because I know that relieving Amy of that burden will make her happy. Earlier this year she told us

Amy: I have a lot of stuff that is complete, except for weaving in the ends. I'm allergic to finishing

and reiterated that sentiment again a few days ago.

So this ebb in my writing in order to finish a shawl has taken on an unexpected significance for me, as if binding-off will bind us all together, even after the shawls are done and this thesis is published. Dr. Michele Feder-Nadoff understood that our stitches do move together to make up a life world, with all of its turmoil and pauses, as well as its affirmations, supports, and encouragements that all tumble in together. The importance of the movement of stitches, fabric, and stories, can be found in a simple utterance from Michelle after a tragic event ‘thanks for your support, fiber friends’(2022).

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