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Affecting, emoting, and feeling disability: entanglements at the intersection of disability studies and the sociology of emotions

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Affecting, emoting, and feeling disability: entanglements at the intersection of disability studies and the sociology of emotions

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Editorial: Affecting, emoting, and feeling disability: entanglements at the intersection of disability studies and the sociology of emotions

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Editorial on the Research Topic
Affecting, emoting, and feeling disability: entanglements at the intersection of disability studies and the sociology of emotions

1 Introduction

This Research Topic engages disability as a vital yet underexplored domain within the Sociology of Emotions. It cultivates cross-disciplinary exchanges between the Sociology of Emotions and Disability Studies to deepen our understanding of emotions, feelings, and affect related to disability. Both fields conceptualize their core concerns as socially, culturally, politically, and ecologically situated. In doing so, they challenge dominant understandings that treat these phenomena as natural, ahistorical, or as confined to the realm of the human (Bericat, 2016; Thomas, 2007; Fritsch, 2022).

The emancipatory scholarship within Disability Studies—including subfields such as Mad Studies, Deaf Studies, and Critical Autism Studies—offers a rich repository of emotional and affective knowledge. Often grounded in first-person narratives and lived experiences, this scholarship uncovers affective and emotional dimensions of disability and challenges dominant paradigms within sociological thought. Disability Studies has engaged with questions of ontology, epistemology, performativity, and the more-than-human. Ontological inquiries into the nature of emotions, feelings and affect (Slaby and Mühlhoff, 2019) examine how disability and disabled emotions, feelings, and affect are shaped by experiences of, encounters with, and discourses about disability (Campbell, 2020; Hughes, 2012; Chen, 2012). Epistemological concerns focus on how emotions, feelings, and affect are known and understood (Flam and Kleres, 2015) in relation to disability as an experience, knowledge practice, and social category. Performativity-oriented research asks what emotions, feelings, and affects do (Ahmed, 2014; Wetherell, 2012). It highlights the affective and emotional toll of navigating dis/ableist structures and the multifaceted ways dis/ableism manifests through affective and emotional registers (Burch, 2021). This research embeds emotions, feelings, and affects around disability within broader social, cultural, and political processes by foregrounding their material and relational impacts (Thomas, 2007). Critical approaches to the more-than-human attend to how emotions, feelings, and affects produce, maintain, alter, or dismantle notions of disability. These perspectives have implications for the survival and thriving of disabled people, disability justice, and engagements with the more-than-human (Ray, 2017; Nocella, 2017; Clare, 2017).

2 Contributions to the Research Topic

A major contribution of this Research Topic revolves around the practices and impacts of disrupting affective and emotional expectations of disability. Many of the articles question taken-for-granted feeling rules (Hochschild, (2012) [1983]) and processes of affecting and being affected regarding disability and call attention to feelings and experiences that remain otherwise invisible. Frankel and Stern unpack how unpleasant affective states like anger are cast as alien affects (Ahmed, 2010) in solid-organ transplantation where patients are expected to show gratitude. Lafleur focuses on affective encounters between people and bodily remains on display in a museum. She offers alternatives to the museum's narrative frames by drawing on "the patients' perspective" and her own situatedness. Hiskies discusses how disability disrupts generic modes of responsivity to being affected, theorizing how impairment brings new affordances into the actionable and highlighting the socio-cultural negotiation of the body and the environment. Exploring the subjectification of parents of children with disabilities as "special parents," Tröndle scrutinizes the gendered and ableist aspects of constructing the mother as the one who "suffers" from the situation. Bylund calls attention to the feelings provoked by austerity and the fear, disorientation, and insecurity, experienced by disabled people in the context of cuts to the Swedish welfare state. Finally, Taş questions the assumption that assistance dogs unconditionally love what they do by highlighting the affective labor they perform in interdependent human-animal-relationships.

Many articles in this Research Topic also contribute to the Sociology of Emotions through their adoption of relational approaches to disability and emotion. Karpicz et al. show the emotional labor that disabled archivists must perform to get access and accommodations in their workplace and note the feeling of ease and empowerment arising from collective approaches to access. In a different sort of workplace, Hultman and Hultman explore how it feels to live with personal assistance and perform emotion work at home. Moving into public spaces, Kubenz points to the emotional labor performed by disabled people who need to "walk on eggshells" in their everyday encounters with strangers who question their use of accessible parking spaces. Everyday encounters are also the topic of Ingram's study engaging with the impact that unsolicited advice by non-disabled people has on disabled people. Building on a relational approach, Hauser discusses how self-reflective emotion work embedded in social relationships can be performed in inclusive teacher education as a means to displace ableist practices. Finally, the polyphonic essay by Barden et al. explores whether a mixed-ability team of researchers working on learning disability history may be called an emotional community.

The 12 articles included in this Research Topic approach disability, affect, and emotions from different conceptual and methodological angles. Some of these contributions are theoretical (Taş; Hauser; Hiskes), others engage with diverse qualitative methods, including interviews (Bylund; Ingram; Karpicz et al.; Kubenz; Tröndle), ethnography (Frankel and Stern) or autoethnographic approaches (Barden et al.; Hultman and Hultman; Lafleur). These approaches resonate with Sauerborn and Albrecht's (2024) call for ethnographic, narrative, or autoethnographic methodologies as a way of capturing the observable, narratable, and experienceable aspects of affect. In addition to engaging Disability Studies and the Sociology of Emotions, the articles draw on various research fields, including Human-Animal Studies (Taş), History (Barden et al.), Museum and Curatorial Studies (Lafleur), Welfare State Studies (Bylund; Hultman and Hultman), and Human Geography (Kubenz).

3 Limitations of the Research Topic and publishing venue

What all contributions do have in common is to explore intersections of Disability Studies and the Sociology of Emotions coming from a Disability Studies perspective rather than from an explicitly Sociology of Emotions orientation. While disappointing, this is unsurprising given that one of us is the first author to publish on disability issues within the Sociology of Emotions in *Frontiers* as well as *Emotions and Society* (Wechuli, 2022, 2023). We hope this issue sparks new approaches in the Sociology of Emotions and continued work within Disability Studies.

The contributions are also geographically limited in scope, situated as they are in North America and Europe, largely reflecting our own Disability Studies networks and positionality. While our original call for articles attracted abstract submissions from beyond these regions, many authors ultimately published elsewhere due to the high open access publishing fees charged by *Frontiers* and additional access barriers during the submission and peer review such as issues with the submission platform and AI validation tools that incorrectly rejected articles that we, as guest editors, wished to consider.

As editors, we encountered a range of emotions navigating the *Frontiers* platform, which imposes rigid deadlines and an intense pace of labor we hadn't anticipated when agreeing to guest edit this Research Topic. Our inboxes were flooded with over 900 emails—many automated deadline reminders we couldn't easily adjust or turn off. In the context of unpaid academic labor and other professional obligations—teaching, grading, managing projects, or working additional jobs outside academia—this relentless acceleration caused significant stress, frustration, and anger. These pressures led to the loss of both authors and reviewers who couldn't keep up or who were fed up. Within Disability Studies, "crip time" is often forwarded to challenge normative timelines and enable new temporal orientations (Kafer, 2013). Yet, as Kafer (2021) also notes, living within these alternative temporalities can feel anything but liberatory. For us, this clash between crip time and the platform's rigid demands underscores the need to support publishing systems that can better foster more accessible and care-centered forms of scholarship. This highlights the ongoing importance of Disability Studies and the need to engage with disabled knowledge and experience to transform our social and material worlds—an urgency powerfully reflected in the contributions to this Research Topic.

Author contributions

YW: Writing – original draft, Writing – review & editing. MS: Writing – original draft, Writing – review & editing. KF: Writing – original draft, Writing – review & editing.

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Affects as affordances: disability and the genres of the actionable

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Prominent theorists such as Tobin Siebers, Ato Quayson, and Martha Stoddard Holmes have proposed that disability may not only elicit different affects, such as fear, admiration, or disgust, but have also envisioned different ways in which the relationship between affect and disability is becoming a central concern in considering how disability is ultimately lived through and experienced in social life. This paper supplements the conceptualization of the affect–disability relationship with the conceptual apparatuses of affordances and genre, to offer an account of the actionable. The actionable is proposed as a form of socio-cultural negotiation of the body and the environment out of which opportunities for action—or affordances—arise. Thomas Stoffregen has proposed affordances as being relational-emergent in nature, meaning that affordances refer to the possibilities for action within a particular constellation of elements, while simultaneously not being reducible to the properties of the individual elements. This paper proposes that affect, understood as the bodily capacities to act and be acted upon, may be understood as evoking affordances—opportunities to act or be acted upon. Additionally, the notions of impairment and disability suggest that capacities and the possibilities of action may vary across different bodies. I connect this to the work by Lauren Berlant on genre, who suggests that modes of responsivity to being affected are rooted in generic thinking. Genres act as structuring and historical forms that embed affect in appropriate modes of responsivity within genre conventions. Affordances are subsequently linked to what is deemed a fitting action within a genre. By invoking Berlant's work, this paper proposes that the actionable opportunities afforded by bodies are preemptively inscribed in genre conventions, and that the concept of the actionable enables an analysis of which actions are deemed appropriate within genres. Because impaired and disabled bodies have a variety of capacities, these bodies may therefore also hold the capacity to disrupt generic expectations and therefore further emphasize the normativity of the presupposed appropriateness of actions.

KEYWORDS

disability studies, affect, affordance, actionable, genre

1 Introduction

In literary and cultural studies, monographs such as *Disability Aesthetics* (Siebers, 2010), *Aesthetics Nervousness: Disability and the Crisis of Representation* (Quayson, 2007), and *Fictions of Affliction: Physical Disability in Victorian Culture* (Stoddard Holmes, 2009) have argued that the ways in which affects aroused by and through disability are necessarily subject to both representation and politicization: representation, because disability has been featured in literary writing, feature films, TV shows, and many other cultural artifacts; politicization, because the ways in which disabilities, as well as affective responses to them, are represented, are to be understood as political issues.

In this paper, I suggest that affective responses to disabilities might be understood as affordances. This paper builds on previous work (Hiskes, 2019), wherein I posited the concept of *affective affordances*, which concerns the way in which the appearance of, and interaction with, disabled bodies afford affective responses in relation to other bodies. That paper's primary concern lies with how *reading* for disability concerns the relationship between the form of the bodily impairment and the form of the representation. As affects cannot be represented directly via signs and symbols as Armstrong (2000, p. 124) has argued, the question that paper addresses is how reading for the forms of representations of disability can be generative of affect.

My main concern in the present paper is to delineate how affects may be understood as affordances, which are commonly understood as opportunities for action. I argue that responses to being affected are inscribed within socio-cultural genres, which carry generic conventions as to how a subject *should* act within a specific genre. In other words, that genres have a normative function regarding the appropriateness of actions. However, as not all bodies have the same capacity to act or be affected, I consequently argue that disability holds the potential to disrupt generic conventions of seemingly appropriate actions. The main question this paper explores is consequently how, when a body is affected, it concurrently affords opportunities for action as well as to be acted upon, and how disability often inconveniences the normative generic expectations associated with certain actions. This inconveniencing of disability allows me to theorize what I call the actionable: the socio-cultural negotiation of how a body perceives, is affected by, and acts within an environment, and how we may consequently analyze the appropriateness of actions alongside generic conventions and expectations.

The scholarly literature on the relationship between affect, emotion, and disability remains somewhat limited. Within the existing body of scholarship, several disability theorists have taken an ethico-political approach to the emotion–disability connection. For example, some of Brian Watermeyer's work argues against the nature of the pervasive connection he sees as being made between loss and disability. Watermeyer (2014, p. 101) explains how, due to disability often being valued as a negative characteristic, the connection between disability and loss remains persistent as a projection. Consequently, he suggests that "loss and other painful aspects of our existence" should be reclaimed (Watermeyer, 2009 p. 100). Similarly, Bill Hughes writes on the relationship between disability and disgust that "Disgust in the presence of disability is a form of cowardice in the face of inevitability and a failure to recognize that mortality is not an enemy but simply the price one pays for life" (Hughes, 2012, p. 73). In arguments like those of Watermeyers and Hughes', specific affective states like loss or disgust are decoupled from being central to a conception of disability, as these authors argue that affective states such as loss and disgust are in fact pervasive across abled and disabled bodies alike. By persisting on the reiterative cultural connection of loss and disgust with disability, these authors thereby perceive a risk of the enhancement of ableism.

While I have no qualms with the type of arguments Watermeyer and Hughes make, I want to consider such ethico-political approaches to the affect–disability relationship in light of an argument made by Vehmas and Watson (2016), concerning normativity *within* disability studies itself. They note that "Disability studies has always included a strong normative dimension, founded as it is on a belief that life for disabled people could be better coupled with a desire to identify and challenge what are seen as discriminatory practices and beliefs. All theoretical accounts in the field contain either implicit or explicit normative judgments about the ethical or political issues that affect disabled people's lives" (4). Watson and Vehmas point out how disability studies as a field are intrinsically linked to challenging discriminatory practices toward disability, which consequently leads to it being normative in that it seeks to challenge discriminatory practices and beliefs. Although I agree with Vehmas and Watson's argument, I also want to take it one step further. Rather than only saying the judgment made by disability studies scholars often have normative content, I also argue that the ethico-political approach *itself* is normative in the sense that it gives primacy to the focus on moral judgments in disability studies, often in seeking to combat or undo ableism.

However, as seen in the examples of Watermeyer's and Hughes' work above, such lines of critique tend to forego how disability may or could fundamentally influence a conceptualization of affect and the way it acts upon bodies. In other words, this paper does not seek to supplement the line of ethico-political critiques regarding the connection between certain affective states and disability. Instead, its focus is on the question of how disability may problematize the very notion of affect as what acts upon bodies and causes bodies to act, as disability can effectively question the notion that all bodies are affected the same way or that disabled bodies possess the ability to respond similarly to various affects as non-disabled bodies do.

The motivation for linking the triad of disability–affect–affordance to the notion of genre, is that, as mentioned above, genres carry a set of conventions as to how a subject *should* act, which therefore imbues genre with a normative function. In their book *Cruel Optimism* (Berlant, 2011), Lauren Berlant explores how different kinds of "adjustments to the present" or "the activity of being historical" (20) are grounded in how such activity finds its genre (like narrative, or a soliloquy, or a situation). Ultimately, however, Berlant's interest, as well as my own, lies in how such adjustments to the present and the activity of being historical are manifested in "explicitly active habits, styles, and modes of responsivity" (20). I argue that affects are not themselves a mode of responsivity, as for a body to be affected by another body, event or object simply means that it is acted upon. Rather, to be affected requires a mode of responsivity or an adjustment to the present.

This negotiation between the way in which a body is affected may translate into an appropriate mode of responsivity is what I designate as *the actionable*. The actionable concerns how opportunities for action, or affordances, may emerge when a body is affected and is required to respond or adjust in some way, which, following the study by Berlant, is seen as necessarily socio-historical. This is consequently linked to the notion of genre as delineated by Berlant, which involves the way in which certain modes of responsivity are deemed to be in line with genre conventions, and thereby considered appropriate. However, as disability problematizes preconceptions concerning what may count as a valid or appropriate action, the actionable in relation to disability can never be understood as a simple *given*. This is why I designate the actionable to be a socio-cultural negotiation, as, though all bodies can and will be affected, not all bodies may have the same modes of responsivity available to them. This negotiation between how a body may translate its being affected into a mode of responsivity can thus allow one to gain and develop further understanding concerning what preconditions are posed on a body to be understood as being 'able to act' in a given generic context. Adjacently, and of equal importance, is the fact that there are also many different modes of *in*action that disabled bodies afford and that inactions may disrupt genre conventions. Consequently, affordances are not to be understood here to contain any moral content, such as the notion that a mode of action would be preemptively more desirable than a mode of inaction.

In what follows, I sequentially unpack and delineate the three key terms of this paper—affordance, affect, and genre—and how they relate to disability and to each other. As mentioned in the previous paragraphs, what is ultimately at stake in this paper is examining how disability may inconvenience generic expectations as to how bodies *should* act in relation to how we conceptualize how bodies *can* act. What I have called the actionable thus involves the examination of how and when a body does not act in line with the expectations of a specific genre, which thus, in turn, allows one to query what this means for how we conceptualize ability/disability within that generic context.

2 Affordance theory and disability

The term *affordance* was originally coined by social psychologist Gibson (2014), who employed the term to show how affordances constitute a relationship of possibilities for action between two or more elements. As an example, Gibson offers that supportability exists when an extended surface is rigid enough to support the weight of a specific animal (119). In other words, affordances arise out of the meeting of these elements (in this case animal and surface) and the affordances that emerge are particular to that relationship. This conceptualization of affordance is therefore relational-emergent in nature in that it does not define affordances as properties *of* objects, but as relationships that emerge due to the *meeting* of objects (and their accompanying properties). In this conception, I follow Thomas Stoffregen (2003), who has delineated affordances as being relational-emergent in this way (Stoffregen, 2000a, 2000b). This conception of affordance as relational-emergent is distinct from the conception of affordance as was posed by Turvey (1992), who ultimately posits, in Stoffregen's words, that an affordance "is not a property at the level of the animal–environment system; Turvey was explicit in defining affordances as properties of the environment only" (2003, p. 122). This distinction matters because in Stoffregen's conceptualization it is not only the properties of the environment that may afford certain opportunities for action, but rather that "the animal–environment system has properties that differ qualitatively from properties of the animal and of the environment; that is, the animal–environment system has emergent properties that do not inhere in properties of the animal or of the environment, considered separately" (Stoffregen, 2003, p. 123).

In Stoffregen's conceptualization, the *emergent* properties of an animal–environment system (which we may relate to a disability–environment system as well) cannot be reduced to an enumeration of the properties perceived as belonging to the elements themselves. Rather, they are understood as novel properties that emerge as a result of this meeting. This conceptualization is to a degree adjacent to the social model of disability. That model posits that disability arises out of an interaction between a person with an impairment and an environment (both social and material) that disables them (Shakespeare, 2017). Understood through the lens of affordances, the social model might then be understood as a way to consider how environments might offer 'inaffordances', i.e., limitations of action. However, if one compares this model to Stoffregen's definition of affordances, this definition will not hold conceptually, as the properties of the impaired body and the properties of the environment do not account for all the affordances produced by the 'impairment–environment' system. Thus, even if an environment may foreclose certain opportunities for action, there may also arise different affordances out of this system. As an example, one might consider how stairs are commonly associated to be walked on, but they might also be crawled on—even if this might not be deemed to be normatively appropriate.

Affordances, according to Gibson (2014, p. 127), are morally neutral in the sense that whatever is considered a positive or negative affordance is always related to the way in which they are perceived by an observer. My contention in this paper is that affects related to, or evoked by, disabled bodies are then also to be considered neutral in the sense that Gibson delineated it. In relation to the social model, the way in which disabilities are generated through the meeting between an impaired body and environment, thereby manifesting perceived blockages of action, may then be perceived to be a kind of negative affordance or inaffordance.

Whereas the social model seeks to importantly stress that impaired bodies become disabled *because* of the way an environment is organized and structured, affordance theory assigns the possibilities of action that emerge to the body–environment system as a whole, which allows for the emphasis on the unicity of affordances that arise out of that system. In her book *Activist Affordances: How Disabled People Improvise More Habitable Worlds* (Dokumacı, 2023), anthropologist Arseli Dokumacı offers an impressive study of the different kinds of affordances that arise out of the often creative ways people with disabilities use their environment. As an example, Dokumacı describes how an elderly man with rheumatoid polyarthritis, Henri, uses the stability of a small dinner table to lean on that table and securely place his coffee mug flat on the table without spilling (4). In effect, it is the quality of the stability of the table that Henri perceives that allows him to figure out a way to place the mug on the table due to his impaired mobility. Such a use of the dinner table—not only using it to place objects on but also to lean one's body on it for support—is thus a good example of how properties are *emergent* due to the meeting of a particular body and object out of which such opportunities for action may arise, that might not even be perceived as viable or relevant actions by other bodies.

Dokumacı also notes that affordance theory "does not have any way of accounting for actions and behaviors that take place yet correspond to affordances whose possible behaviors or actions require enormous amounts of *effort*, *endurance*, and *ingenuity* to be realized by impaired humans" (51). The emphasis on effort and endurance in the quote suggests that affordances as perceived by people with disabilities are affectively charged. As with Henri's example, actions cost something of the body and affect them in turn. Interestingly, the relationship between affect and disability is not further delineated in Dokumacı's study, and it is this relationship to which I now turn.

3 Disability studies and the ethico-political approach to affect

As delineated in the introduction of this paper, the scholarly literature that specifically engages with the relationship between affect theory and disability studies are primarily focused on the ways in which certain affective states are repeatedly connected to disability. As mentioned, several articles engage with affects such as loss (Watermeyer, 2009; Watermeyer, 2014) or disgust (Reeve, 2018). An overview article (Goodley et al., 2018) explores how concepts introduced by different affect theorists, including Sara Ahmed (2007, 2010, 2014) and the aforementioned Lauren Berlant (2007) may be relevant in theorizing the relationship between affect theory and disability studies. The article by Goodley et al. therefore seeks to transpose concepts introduced by Ahmed (the feminist killjoy) and Berlant (the notion of 'slow death') to disability (by introducing the notion of the 'crip killjoy', for example).

The aforementioned Quayson (2007) posits that "Contradictory emotions arise precisely because the disabled are continually located within multiple and contradictory frames of significance within which they, on the one hand, are materially disadvantaged, and on the other, have to cope with the culturally regulated gaze of the normate" (18). According to Quayson, this leads to what he calls aesthetic nervousness, which means that the way in which people with disabilities are interpreted in literary texts is coextensive with the way they are interpreted out of that context (19). Although Quayson does not link his study to affordance theory, the fact that his study links the practice of interpretation to the question of affect (namely that the interpretation of disability is evocative of nervousness) one can posit as affordance in that disabilities *evoke* a mode of action (interpretation) that becomes affectively linked to contradictory emotions. Similarly, Tobin Siebers (2010) has posited that the increase in the representation of disability in modern art needs to be embraced and that "disability enlarges our vision of human variation and difference, and puts forward perspectives that test presuppositions dear to the history of aesthetics" (3).

What these examples have in common is what I have called the ethico-political approach to the affect–disability relationship. Provocatively, the connections made between disability and affect by the theorists above all carry a moral aspect. For Quayson, nervousness is evoked through the activity of interpretation, but this is an ethical query. For Siebers, the increase in disability in modern art is something that should be celebrated as bodily variation. For Goodley et al., the crip killjoy is a figure that is disadvantaged in a society that privileges self-sufficiency. While these connections are all well-argued for, the fact that they immediately link the disability–affect relationship to one with ethics and politics inadvertently bypasses how affects evoked by and through disability may be understood to deepen how we conceptualize both disability *and* affect.

What these authors share is a primary interest in the ways in which disabled bodies affect and are perceived by other bodies, and what certain problematic aspects to that may be in how these affects operate socio-culturally. However, these theories bypass the question of how disability itself may inform a theory of affect, for what body is presumed not only to affect, but also to be affected? As was shown above in my brief exposition of affordance theory, affordances are necessarily matters of perception—that a body, being affected in its environment, comes to recognize opportunities for action that are characteristic to the specific combination of *that* body in *that* environment (as was illustrated with the example of Henri and the table). However, this raises the question about what, if any, the presumptions are about the body that perceives those opportunities for action.

As much work done in disability studies critiques and counters pre-established normative (and often ableist) frameworks, they may unwittingly also set a normative expectation to the way in which affect relates to disability, i.e., that some affective responses might be considered to be more desirable than others. Furthermore, the very question of affective desirability neglects the fact that affect cannot be preemptively responded to or altered into a seemingly more desired response. As I argued above, modes of responsivity are themselves responses *to* affect. Thus, while I do not argue to curtail scholarly discussion concerning the ethical dimensions of affective responses (such as nervousness or the celebration of bodily diversity), this should be separated from the question of whether affective responses themselves can be preemptively (i.e., normatively) deemed to be desirable, to which I answer in the negative, as further explained below.

Through establishing a link between affect and ethics and politics, questions of the affordances of the affects that disability evokes remain largely overlooked. One could link Quayson's argument that the evocation of nervousness through the interpretation of disability is an affordance of affect. However, Quayson immediately reframes this matter as one that concerns ethics. As I argue that disability may offer insights into how affect itself is conceptualized, I now analyze some definitions of affect in order to propose how theories of disability may influence that conceptualization.

4 Between capacities and affordances: impairment's relation with affect

In *The Ascent of Affect* (Leys, 2017), Ruth Leys traces the different ways in which emotion and affect have been conceptualized across the social sciences and humanities. Referring to the writings of Massumi (2015, 2021), one approach is to define affect as non- or pre-personal forces (distinguishing it from emotional states), which Leys summarizes as "formless, unstructured nonsignifying forces or 'intensity'" (313). Gregg and Seigworth (2010), who are coming from a materialist perspective, are in line with this definition and define affect as follows:

> Affect arises in the midst of inbetweenness: in the capacities to act and be acted upon. Affect is an impingement or extrusion of a momentary or sometimes more sustained state of relation as well as the passage (and the duration of passage) of forces or intensities. That is, affect is found in those intensities that pass body to body (human, nonhuman, part-body, and otherwise), in those resonances that circulate about, between, and sometimes stick to bodies and worlds, and in the very passages or variations between these intensities and resonances themselves. Affect, at its most anthropomorphic, is the name we give to those forces—visceral forces beneath, alongside, or generally other than conscious knowing, vital forces insisting beyond emotion—that can serve to drive us toward movement, toward thought and extension, that can likewise suspend us (as if in neutral) across a barely registering accretion of force-relations, or that can even leave us overwhelmed by the world's apparent intractability (1).

The definition by Gregg and Seigworth opens by linking affect directly to action. This is because, as the second sentence explains, affect already *acts* upon bodies—it passes from body to body. The second half of the quote again emphasizes action, but this time to explain that affect can *drive* a body toward movement, i.e., action, which, importantly, they signify as 'a barely registering accretion of force-relations', meaning that, even if affect can work upon a body, the ability of that body to register the force that acts upon it is not a pre-emptive given, allowing the affected individual to be left overwhelmed. This quote thus offers crucial insight into the different elements that constitute affect: it acts upon bodies; it establishes relationships between different bodies (human or otherwise) through its acting; it can set bodies in motion through being affected; it is not necessarily registered which kind of forces are acting upon the body; i.e., affect may resist processes of identification and registration that can be reductive in nature. Affect can therefore be 'other than conscious knowing'.

Given the emphasis Seigworth and Gregg put on affect to act upon bodies, this allows me to further elucidate the relationship between affect and affordance. For both Gibson and Stoffregen, affordances are opportunities for action that arise out of the combination of two elements (e.g., a body and an environment), in which that constellation affords specific modes of opportunity for action to arise. Thus, a body that is affected to act within a given environment may then be understood to respond *to* being affected, which is a mode of responsivity in the way that Berlant uses this term, in other words, an adjustment to the present.

As was argued by disability theorists in the treatment of disability theory above, they consistently maintain the need for the recognition of variance and diversity between bodies, which should then also be applied for how bodies can react differently to being affected—in other words, produce different modes of responsivity. This argument is relevant to the way in which we may consider the way affect operates, specifically the bodily 'capacities to act and act upon'. Here, I want to create a connection between this statement and the cultural model of disability. As sociologist Anne Waldschmidt (2017) observes, the distinction made between impairment and disability allows us to question in what ways impairment itself, referring to the material and physical reality of the body, is mediated through discourse, as disability is socio-culturally constructed through a meeting between an impaired person and a (disabling) environment. Elsewhere, Waldschmidt (2018, p. 75) explains what one of the lines of thinking a cultural model of disability may offer is that "this model understands impairment, disability, and normality as categories generated by academic knowledge, mass media, and everyday discourses. In short, they are "empty signifiers," which as a concept implies that the signifier (the word) and the signified (the content a word evokes) have a contingent relation and terms do not simply denote reality but constitute the "things" they talk about". This emphasis on the discursive generation of not just disability, but also bodily impairment and normality, reifies the notion that expectations concerning the way in which bodily capacities should be translated or signified into 'appropriate' or 'normal' modes of action, are themselves artifacts of culture. Or, as the philosopher Wendell (1996, p. 34) has put it "the distinction between the biological reality of disability and the social construction of a disability cannot be made sharply". Importantly then, the cultural model allows one to give an account of bodily and lived experience of impairment *in relation* to the social and cultural forces that shape disability (Snyder and Mitchell, 2006).

Thomas (2012, p. 211) has argued in favor of what she calls a materialist ontology of impairment and impairment effects, the latter referring to the way in which impairments influence one's embodied functioning in the social world, recognizing that both impairments and their effects are socially and culturally constructed. However, Thomas (2014, p. 14) also holds on to the notion that, while recognizing that impairment itself is socio-culturally constructed, "we should not give the bio-medics exclusive rights over the concept of impairment, not perform the poststructuralist 'vanishing act' involved in treating *real bodily* vari*ations from the average* as entirely linguistically or culturally constructed differences. What is required, I suggest, is a theoretical framework that recognizes *the social dimension of the biological* and the irreducibly *biological dimensions of the social*". While the present paper does not offer an entire comprehensive framework that Thomas calls for, it does offer a perspective on what I see as the *inherent entanglement* of the social and the biological as a starting point of analysis for the way in which bodily capacities can come to culturally signify as impairments and disabilities, through the (normative) operations and conventions associated with different cultural genres.

Given the cultural understanding and construction of both disability *and* impairment, I argue that the affective capacity to act and to be acted upon, in relation to disability, cannot be thought separately from impairment in the sense that the notion of impairment suggests bodily diversity *in* these capacities referred to. In other words, disability may complicate the definition offered by Gregg and Seigworth by pointing out that such capacities can themselves never be a given but are a variable across bodies. Additionally, how a body in turn *responds* to it being affected, that is, to have a mode of responsivity to affect, is equally variable and may be implicated by impairment. This argument both recognizes the 'biological reality' of impairment that Thomas refers to, given the recognition of the diversity of capacity across bodies, yet simultaneously asserts that it is not possible to conceive of 'impairment' *without* a socio-cultural context, like genre, in which bodily capacity becomes appraised as impairments in the first place.

What I want to suggest is that the definition of affect as put forth by Gregg and Seigworth offers up many questions that pertain to disability, or formulated more strongly, *should* not be thought of without considering disability. For just as the capacities to act and be acted upon vary between bodies, and may even vary within different bodily states in one body, so too is the question of the 'registering' affect in 'conscious knowing' not preemptively the same question to all bodies. What I call *the actionable* involves the way in which affordances, conceived of as opportunities for action, necessarily involve the fact that the kinds of opportunities that are perceived as 'available' are a negotiation between the capacity for a body to be affected (which varies among bodies), and the way into which this may translate into a mode of responsivity, which is necessarily influenced by the socio-cultural forces referred to by Waldschmidt and Thomas. Consequently, opportunities for action and modes of responsivity are also not free from normative expectations. To elucidate how a body that is affected may determine a suitable mode of responsivity, I turn to the notion of genre, as it can delineate how modes of responsivity, which, following Waldschmidt, are discursively produced through cultural means, get embedded within conventions appropriate to that genre.

5 Organized inevitably: thinking of actions in genres

Above, I briefly mentioned how Berlant is interested in the way the activity of being historical relates to how such activity finds its genre. Genre is commonly thought of as involving acts of classification, particularly in relation to literature, film, music, and other art. However, major early theorists of the genre, such as Fowler (1982), already argued that thinking about the genre as a classificatory scheme is limited. Instead, genre can act as a communication system in the sense that once genres are identified they tend to offer a set of expectations and conventions to their audiences (1982, p. 256). Consequently, when one is being confronted with the fact that genre conventions are *not* met, one may point to what one presupposed the convention to be (rather than that what it necessarily is). Berlant's thinking on genre has been described as a way to give "an account of the relation between affect and the aesthetic" (Cefai, 2023, p. 269). This implies that what Berlant refers to as 'the activity of being historical' involves the way in which particular social conduct (which Berlant sees as necessarily cultural-historical) finds its own specific esthetic forms to mediate the appropriate social conduct. Duschinsky and Wilson (2015) have delineated Berlant's concept of genre as follows:

> For Berlant, a "genre" is an emotionally invested, patterned set of expectations about how to act and how to interpret, which organises a relationship between the acting and interpreting subject, their feelings and impressions, their struggles and their historical present. Genres also organise conventions about what might be hoped for, explicitly or secretly, and the bargains that can be made with life. Genres serve as mooring, or placeholders, for intensities within streaming experience. Their conventions give a place and pacing to—and thereby partially hollow out—the discrepancies and the possibilities which occur within the constitution of a particular form of feeling subject (179).

As this quote shows, genre encompasses a myriad of aspects concerning the way in which a subject adjusts to living in their historical present. The 'emotionally invested, patterned set of expectations about how to act and interpret' suggests not only that there is a normativity associated with how to act but also that genre implicitly lays a connection between affect and behavioral pattern. In other words, the conventions associated with a genre carry their own affective charge *toward* the expected actions involved. To illustrate this, Berlant (2011, p. 5) offers the example of the situation as a genre which organizes subjects in a particular way: "A situation is a state of things in which something that will perhaps matter is unfolding amid the usual activity of life. It is a state of animated and animating suspension that forces itself on consciousness, that produces a sense of the emergence of something in the present that may become an event". In a situation, there is a given state of affairs that makes up for one's everyday life. However, as one recognizes that one is in 'a situation' (e.g., a failed relationship and a loss of direction of one's career), what comes to matter is the sense of the emergence of an event that radically alters the situation *qua* situation, i.e., that radically upends this state of affairs.

Genre consequently organizes affect in a way that is not only associated with that genre's conventions, but rather, affect is also imbued with the set of *expectations* one carries within the boundaries of a genre, or as mentioned in the quote above "what might be hoped for" (or, just as well, dreaded). Not only does genre therefore organize an affective relationship regarding the way one *should* act or interpret within the confines of a genre (thereby espousing normativity), it also affectively organizes one's horizon of expectation, originally coined by literary scholar Jauss (1982) to defer to a common set of expectations and anticipations.

Elsewhere, Berlant (2001, p. 46) writes that "For genre to exist as a norm it has first to circulate as a form, which has no ontology, but which is generated by repetitions that subjects learn to read as organized inevitably". Genre, then, establishes a connection *of* social form (that is, a set of habits and actions deemed appropriate to and expected from that genre's conventions), but it also carries with it a sense of inevitability, through which genre is imbued with its normative power. In other words, this suggests that not only is genre loaded with expectations through the way subjects read the genres they live through but also it is affectively charged as being predetermined from the outset.

Given this notion of genre as producing a repetitive and reiterative social form of how to act in a given context, I now want to link back to the notion of affordance as shown above. In the example taken from Dokumaci's study, Henri uses the dinner table in a way that breaks with conventional use; he leans on it to balance himself. In genres that may be commonly associated with the use of dinner tables—the chit-chat, the family dinner, the meeting—their respective affordances do not necessarily endorse the use of tables as objects to secure one's stability. In fact, they may advise against it. Such non-normative use of the dinner table is a way in which disability disrupts the normative expectations associated with the coffee table and its conventional usages. Simultaneously, this affordance of the usage of the coffee table arises in part because Henri's mobility is impaired: "he has a very limited range of motion in his wrists, which affects their flexion and extension, Henri described with almost mathematical precision how he puts a full mug on the table without spillage" (2). As such, in the constellation between Henri, his coffee mug, and the coffee table, a beyond-normative affordance of the coffee table can emerge.

If we bring Berlant's work on genre in relation to the work on affordance, a provocative query can now be offered: how does the relational-emergent notion of affordance relate to Berlant's conceptualization of genre as providing normative expectations in relation to how we may conceive of the actionable? As Berlant's argument is that modes of responsivity to being affected are determined by the expectations set by a genre that a subject finds itself in, affordances, as opportunities for action, are relational-emergent *in relation* to genre. In other words, the convention that certain actions would be appropriate to particular genre conventions is something that disability is able to be disrupt and challenge precisely when new affordances arise due to the novelty of how impaired bodies can interact with their environment. Consequently, I argue that disability is crucial in conceptualizing the move from being affected to a mode of responsivity and action, precisely because disability is disjunctive to *both* the capacity to be affected *and* the ability to act.

I can now delineate further why I have called the actionable a matter of socio-cultural negotiation. Affordances arise as properties of the body–environment system as a whole, where a body perceives opportunities to act because it is affected by that environment. This in turn offers a space of negotiation on how to act within that space.

Since opportunities for action, as Berlant's work argues, are inscribed within generic conventions. The negotiation of how to act is not necessarily a process of conscious decision-making, as modes of responsivity appropriate to a genre are not explicated. However, as the example of Henri shows, beyond-normative usage of one's environment can make us aware of what such genre conventions actually are. Leaning on a dinner table for support may actually be dismissed by others as inappropriate or potentially dangerous use, whereas sitting down for a chit-chat at the same table would not raise any questions.

In their later work, Berlant states in the context of the affective force of inconvenience that "what's in front of you is not all that's acting on or in you" (Berlant, 2022, p. 3). In other words, Berlant reminds us that direct perception of one's environment does not entail the entirety of the ways in which an environment affects the body. However, as I argue, being affected does offer the opportunity to attune the subject to the negotiation concerning how one's capacities to act and be acted upon may translate into modes of responsivity suitable to the genre one is living through. This attunement may also involve the possibility of the 'inaffordance', a foreclosure of action that is relational-emergent to the specifics of that genre. If genre conventions can prescribe appropriateness in relation to actions, this may also allow one to question that appropriateness through the inaffordances that arise.

6 Discussion

This paper has explored the intricate relationships between affordance, affect, genre, and disability, arguing for a nuanced understanding of how these concepts interrelate. By examining the relational-emergent nature of affordances, this paper highlights how opportunities for action arise not from the properties of the environment or the body, but that properties are emergent from the meeting between the two as a system. Affect, understood as the capacities of bodies to act and be acted upon, plays a crucial role in this dynamic, influencing how affordances are perceived and can be enacted by impaired and disabled bodies.

Genres, as socio-historical constructs, embed normative expectations about appropriate actions and modes of responsivity. Lauren Berlant's work on genre illuminates how these expectations shape and are shaped by affective responses, structuring the ways bodies are perceived and how they are expected to act. This paper has posited that disabled bodies, by their very nature, challenge and disrupt these normative expectations.

The actionable, as proposed in this paper, represents the socio-cultural negotiation of how bodies perceive, are affected by, and act within their environments and can consequently comply with or resist generic conventions. This concept is pivotal in understanding how the socio-cultural mediation of impairment, as has been argued by proponents of the cultural model of disability, may take place. I argue that recognizing these dynamics is essential for the possibility of a more comprehensive socio-cultural analysis of the relationship between disability and action to take place and what is perceived and/or sensed as being *valid* actions.

As this paper has sought to argue that disability may complicate and enrich the relationship between affect and affordance, the question that I would like to close with is the question that may arise whether disability offers its particular own modes of responsivity, or whether the argument could even be made that disability may produce its own genres. Certainly, disability is a staple trope in what is called 'genre fiction'—which refers to demarcated literary genres such as horror, fantasy, and romance. In her book *Disability, Literature, Genre: Representation and Affect in Contemporary Fiction*, Cheyne (2019) examines the relationship between these different genre fiction and disability. She concludes that, while genre *can* resist or even adjust ableist representations of disability, it can also reproduce or encourage disabling attitudes (166).

One way in which Berlant (2018) delineates the complication of how genre pervades normativity in both its affective horizon of expectation and those habits and behaviors it deems appropriate to generic conventions is through the concept of so-called *genre flailing*:

> Genre flailing is a mode of crisis management that arises after an object, or object world, becomes disturbed in a way that intrudes on one's confidence about how to move in it. We genre flail so that we do not fall through the cracks of heightened affective noise into despair, suicide, or psychosis. We improvise like crazy, where "like crazy" is a little too non-metaphorical (2018, p. 157).

For Berlant, genre flailing happens due to the instability and uncertainty of how to move in one's disturbed object world. In other words, genre flailing occurs at the moment when a subject is confronted with an event where the normative conventions associated with that genre do not work, and there arises a need for continuous recalibration to that object world (the type of activity Berlant refers to as crisis management). This quote establishes a link between disruptive and erratic behavior and how such behaviors may discombobulate genre conventions. It is not my intention here to argue that people with disabilities may be considered experts in crisis management due to the often unstable object worlds that they venture and live in. As I have shown with my delineation of the actionable, this involves a theory of how the possibility of action may arise in an environment but might also cause friction with the appropriateness of action. Genre flailing, then, can be understood as both intruding on one's confidence in navigating their object world while simultaneously undermining the nature of generic convention.

The cultural model of disability makes a distinction between impairment and disability, where the claim is that impairment, too, is socially and culturally mediated. A theory of the actionable, or how opportunities to act may even arise, I believe is important in further understanding how such processes of mediation can operate culturally. Genre flailing, which Berlant describes as 'a little too non-metaphorical', thus points to the nature of the body that is perceived as acting outside of generic conventions, as disabled bodies are often perceived as doing. This importantly links the category of action to that of culture; i.e., it suggests that the non-metaphorical nature of flailing that Berlant refers to may also point to bodies that are perceived as acting 'out of control' in specific generic contexts.

When bodies do not function in a way that is in line with generic conventions, Berlant points out that falling 'through the cracks of heightened affective noise' leads subjects into bodily states where the issue of control over the body is exactly the issue that comes to be at stake. The terms Berlant gravitates toward to describe subjects overwhelmed by such affective noise—despair, psychotic, crazy—all refer to states in which impairment becomes an inconvenience not only with regard to not fitting in with genre expectations but rather disrupts the presupposed affordances associated with that genre, i.e., the set of opportunities for action as defined by a genre's horizon of expectation. Consequently, when impairment becomes inscribed as a disability within a genre, the notion of 'capacities to act and be acted upon' is always present to simultaneously hold the capacity to disrupt that genre, but also, incidentally, to attune people to what the genre's conventions were—it may attune subjects to those very conventions. Berlant wrote that inconveniences make you aware of the fact that 'what's in front of you is not all that's acting on or in you'. Impairments, then, can consequently heighten us to the cultural conventions of genres we live through.

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Rethinking love, independence, and speciesism in assistance dog discourse

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This paper challenges the prevailing belief that assistance dogs inherently love their roles, arguing that the notion of "unconditional love" in discourses on assistance dog perpetuates a human-centric perspective and reinforces speciesism. It emphasizes the importance of recognizing the affective experiences of these working animals and of acknowledging the interdependence between people with disabilities and assistance dogs. The paper has four main objectives: (1) critiquing the concept of unconditional love attributed to assistance dogs, (2) recognizing the physical and affective labor of assistance dogs, (3) highlighting the importance of interdependence over independence, and (4) exploring the intersections of ableism and speciesism in the context of assistance dogs. By examining the role of love as a narrative-framing device, the paper aims to reveal how anthropocentric viewpoints often obscure the exploitation of assistance dogs. Incorporating insights from human-animal studies and disability studies, the paper seeks to enrich sociological research on emotions and power structures, advocating for a shift toward valuing the labor and wellbeing of assistance dogs. This approach challenges the liberal ideology of independence and promotes a more inclusive understanding of interspecies relationships, ultimately enhancing the sociological study of emotions, and intersections between sociology, disability studies, and human-animal studies.

KEYWORDS

assistance dogs, love, affective labor, independence, interdependence, speciesism

1 Introduction

Assistance dogs provide support for people with disabilities by performing various tasks. They are often purpose-bred by accredited organizations to ensure that they possess the ideal temperament and physical traits tailored to their human companions' needs (Bolak, 2024). There is a wide range of assistance dogs available, each trained to meet the specific needs of people with disabilities (Bremhorst et al., 2018). Examples include "guide dogs" helping blind people, and "hearing dogs" providing support for deaf people. All other assistance dogs are categorized as "service dogs" (Assistance Dogs International, 2024). Among them are "mobility assistance dogs" for people with balance issues, "medical alert" or "seizure dogs" for detecting hormonal changes in humans and alerting them, "psychiatric assistance dogs" for helping people deal with depression, anxiety, or stress disorders, and "autism assistance dogs" primarily helping children on the autism spectrum (Assistance Dogs International, 2024; Gross, 2006). Their job requires "real-time predictive or responsive responses, and round-the-clock involvement in serving someone's needs" (Coulter, 2016, p. 59). Most assistance dogs begin their journey in accredited schools, where they are placed with volunteer foster families, known as puppy-raisers, to undergo basic obedience training focused on positive reinforcement rather than punitive methods like shock collars (Assistance Dogs International, 2024). Once the dogs—mostly Golden Retrievers and Labrador Retrievers—reach approximately one and a half years of age, they receive public conduct and distraction training at specialized assistance dog schools, which distinguishes them from most companion animals or emotional support dogs (Walther et al., 2017).

The physical and affective care work that assistance dogs perform is rooted in selective breeding of the most obedient dogs coupled with hundreds of hours of work and advance training (Price, 2017). Most assistance dogs start their lives in confined spaces, where they are conditioned to follow specific norms and commands from puppyhood. Behavioral conditioning often relies on food, and dogs showing fear or anxiety typically do not qualify as effective assistance animals (Tomkins et al., 2011). This paper challenges the common assumption that assistance dogs enjoy their roles and feel unconditional love for the humans they assist, calling for a deeper exploration of the implications of these beliefs. Such unquestioned presuppositions often conceal the realities of control, restriction, and the exploitation of canine labor. Instead, the paper argues that the work of assistance dogs should be understood as affective labor, with their wellbeing as a key focus. Scholarly discussions continue about the ethics of employing animals for ongoing service and caregiving roles, with some raising concerns that such practices could infringe upon the animal's wellbeing, social relationships, and autonomy (Coulter, 2016). Given these considerations, one must question whether dogs genuinely enjoy their work or if they lack sufficient agency. That is why focusing on human-canine interaction, critiquing the notion of love, and emphasizing the relational dimension of such interactions can offer valuable insights for sociological research, particularly when applied to contexts such as critiques of anthropocentrism, which have received less attention in studies of love within the Sociology of Emotions.

When it comes to discussions on human-assistance dog interaction, human mental health, welfare, and quality of life comes first (Shintani et al., 2010; Rodriguez et al., 2021). Several studies have found that people who spend time with dogs experience reduced stress, anxiety, and social isolation (Friedmann and Son, 2009). In such human-centric perspectives, canine welfare or health is of secondary importance. This explains the limited amount of research conducted on the welfare of assistance dogs, as well as their behavioral and cognitive abilities (Bremhorst et al., 2018). For instance, existing research on the use of autism assistance dogs is said to be inconsistent, scarce, and human-centric (Harrison and Zane, 2017; Tseng, 2023). While some studies, such as Shintani et al. (2010), suggest that evidence for the positive impact of assistance dogs on human psychosocial health and wellbeing may be methodologically limited, this gap highlights the need to equally prioritize rigorous research into the welfare of assistance dogs themselves. Neglecting to understand and address physical and psychological welfare concerns in dogs poses risks not only to the dogs but also to people with disabilities and their caregivers (Burrows et al., 2008). For instance, autism assistance dogs often wear tether harnesses that prevent children from wandering, which can strain the dog physically and psychologically, compromising the dog's wellbeing. If the dog becomes stressed or injured, this could lead to a breakdown in the caregiving dynamic, ultimately impacting the safety and support for both the child and the caregivers who rely on the dog's assistance. This article emphasizes the significance and political urgency of reflecting on canine affects within the context of assistance dogs. The political urgency stems from the increasing reliance on assistance dogs in public and private sectors, coupled with growing advocacy for animal welfare rights, which demands immediate policy attention to ensure that both the animals and individuals with disabilities receive appropriate protection and care. This perspective underscores the article's argument that the responsibility of caring for assistance dogs and individuals with disabilities is not separate but rather interconnected.

The common assumption prevalent in most assistance dog discourse is that dogs love working for people and provide increased independence for them (Oliver, 2016). Reduced to their functionality and performance, dogs are to find joy and fulfilment in their roles, deriving satisfaction from pleasing their disabled companions. Nevertheless, this particular viewpoint predominantly originates from liberal and anthropocentric perspectives, which reduce "everything to usable equipment or productive labor" and value human lives over nonhuman animals' (Oliver, 2016, p. 247). Although dog trainers and handlers who state that assistance dogs love working and helping people are quite common (Cochrane, 2020), there are also a considerable number of scholars and animal activists who examine the issue through the lens of domination and exploitation (Sorenson, 2014; Taylor, 2017). This paper calls for a critical examination of the assumptions of unconditional love in assistance dog discourses, which play a pivotal role in shaping human-canine relationships. Such assumptions on love can mask systems of oppression, confinement, and exploitation of dogs. By exploring human-assistance dog interactions and reframing canine work as affective labor, this paper seeks to deepen our understanding of love's complexities within interspecies relationships, broadening the concept beyond human-human connections and addressing its implications for assistance dogs.

While assistance dogs may empower individuals with disabilities to navigate daily life (Bennett and Goodall, 2024), it is essential to recognize the reciprocal nature of the relationship. How do the interactions between individuals with disabilities and their assistance dog companions create unique opportunities for connection and affective experiences, which differ from the relationships people have with their non-working dogs? What new affective patterns arise in the interdependent relationship between assistance dogs and people with disabilities, moving beyond human-centered concepts of independence? Exploring these inquiries has the potential to enhance the collaboration between disability studies and critical animal studies, thereby offering fresh perspectives on sociological investigations pertaining to emotions. This examination challenges the predominant anthropocentric beliefs in sociology and highlights the need to prioritize the physical and affective work of dogs (Section 3–4). By examining assumptions about love we can deepen our comprehension of assistance dogs and their caregivers, as this approach unveils the intricate and reciprocal emotional interactions between them (Section 5). One obstacle to such endeavors is the emphasis on independence over interdependence (Section 6). The unacknowledged canine work and affective experiences within a discourse of independence requires a critical perspective on speciesism – discrimination based on species membership, and how it intersects with ableism (Section 7). The relatively unexplored relationship between dogs and individuals with disabilities provides valuable insights for sociology, particularly given the global rise in demand for assistance dogs.

2 Sociology of emotions in more-than human worlds

Sociology maintains a deeply human-centric perspective, which reflects a speciesist bias, prioritizing the interests and welfare of humans over those of other animals, even as it acknowledges humans' animal nature (Arluke, 2002; Nibert, 2003). The term "speciesism," introduced by Ryder (1970, 1971), brought attention to this bias by drawing parallels between human treatment of animals and other forms of discrimination, such as racism and sexism. However, while Ryder's concept of speciesism has sparked important ethical discussions, its sociological application lies in its capacity to critique the human-nonhuman divide that is embedded in institutional structures, everyday practices, and knowledge systems (Matsuoka and Sorenson, 2018).

> "Speciesism does not refer simply to human relationships with other animals, but means socially, politically, economically, and culturally constructed everyday practices and a body of knowledge that supports such relationships. When Richard Ryder coined the term 'speciesism' in 1970, he discussed this as a form of prejudice and discrimination although he acknowledged that cruelties toward other animals are institutionalized" (Matsuoka and Sorenson, 2018, p. 1).

Speciesism reflects broader patterns of oppression and serves as a critical concept for sociological inquiry into social justice, prompting sociologists to reconsider how nonhuman animals are integrated into or excluded from societal structures, thus revealing new layers of inequality and bias. Historically, sociology's human-centered definitions of society have largely excluded animals, even though classical sociologists like Max Weber recognized the potential for sociological study of animals (Weber, 1947; Peggs, 2012) with a few notable exceptions (Beirne, 1995; Nibert, 2013). This human-centered approach ties into the concept of human exceptionalism, the idea that humans' rationality and symbolic capabilities make them fundamentally different from and superior to other animals (Dunlap, 1980).

In recent years, there has been growing recognition that nonhuman animals play a significant role in human society, and that many animals exhibit complex social behaviors, engage in intentional actions, participate in symbolic interactions, and have emotional capabilities (Taylor, 2011; Bekoff, 2007; Irvine, 2023). Especially within the last three decades, animals as sentient beings emerged as political actors with complex emotions, a topic explored in Anthrozoology, also known as Human-Animal Studies (HAS), which integrates perspectives from the social sciences, the humanities, and the natural sciences (Shapiro and DeMello, 2010). HAS researchers urge that nonhuman animals, whose agency has hitherto been ignored or compromised in anthropocentric narratives that uphold human exceptionalism, be viewed as "the latest beneficiaries of a democratizing tendency" in academic research (Ritvo, 2004). Thus, while sociological research primarily centers on humans, nonhuman animals "are so tightly woven into the fabric of society that it is difficult to imagine life without them" (Irvine, 2008, p. 1954). Therefore, it is crucial for sociology to embrace a broader perspective that transcends the conventional focus on humans and acknowledges the significance of nonhuman animals in society.

The relevance of animals in sociological research is further illuminated when considering the sociology of emotions. The field delves into the examination of how emotions are conceived, exhibited, and regulated within different social contexts since the 1970s (Hochschild, 1975; Kemper, 1978; Denzin, 1984). The sociology of emotions aims to explore how individual emotional experiences and expressions influence institutions, social norms, values, and interactions, as well as how these external factors reciprocally affect emotions. The last three decades saw remarkable progress within the field, and "the study of emotions is now one of the forefront areas of sociological inquiry" (Turner and Stets, 2012, p. 284), connecting micro and macro level of social reality. This paper does not aim to provide a comprehensive exploration of different conceptualizations of emotions and their distinctions from sensations, affects, moods, or sentiments. Nevertheless, it is clear that sociological studies on emotions have predominantly disregarded the intricate emotional experiences of animals and the affective dimension of human-animal interactions. Here, the limitations of human exceptionalism become more evident, as animals' emotional lives and their capacity for symbolic interactions align with the core concerns of the sociology of emotions.

The absence of attention toward this subject can be attributed to various factors including methodological and ethical challenges, anthropocentric biases, the objectification of animals, institutionalized speciesism, and the dearth of interdisciplinary collaborations. Despite the recognition that animals possess feelings, sentiments, and emotions akin to humans, there has been a longstanding absence of comprehensive analyses on the human-animal bond and nonhuman emotions within the wider field of sociology. In 1979, Clifton Bryant critiqued sociology's disregard of the "zoological connection" in understanding human behavior (Bryant, 1979, p. 399). Sociologists, he claimed, "have tended not to recognize, to overlook, to ignore, or to neglect (some critics might say deservedly so) the influence of animals, or their import for, our social behavior, our relationships with other humans, and the directions which our social enterprise often takes" (p. 399). He further suggested that the study of human emotions—so central to understanding social interactions—remains incomplete without considering how animals shape these emotional and social dynamics. Despite this call for attention lasting over four decades, and animals playing a significant role in social development, the interactions between humans and nonhuman animals, along with the complex social meanings they embody, have often been overlooked or marginalized in sociological research. Building on this critical gap, the following section examines the affective labor of assistance dogs, offering an opportunity to reconsider the idealized concept of unconditional love, which can obscure recognition of dogs' physical and emotional work.

3 Affective labor and assistance dogs

Following Spinoza's notion of affect, which involves the ability to both influence and be influenced simultaneously, this paper utilizes "affect" as a means to discuss pre-linguistic bodily sensations, moving past the customary terms of emotions, feelings, or sensations (Spinoza, 1994). Based on the examination of emotions, feelings, and sensations, affect theory delves into the complex interaction between bodily experiences and cognitive processes, shaping human perceptions, interactions, and expressions. This theoretical framework has undergone significant development, sparking discussions that demonstrate its intricacy and implications for comprehending the human condition (Stewart, 2007; Ahmed, 2004). While emotions are often regarded as being linguistic, affect theory considers pre-linguistic, non-verbal stimulations, feelings, and sensations, which can enhance sociological investigations on emotions and animals. This discussion has broadened its focus beyond human beings, leading to a notable exploration of animal affects (Bekoff, 2000). According to Donovan Schaefer, the affective perspective provides "a window onto the way that bodies operate prior to and in excess of language" (2017, p. 18). Affect theory is about:

> "What makes bodies move, think, act and desire. In other words, affect theory is a theory of power, but a theory that sidesteps what I label the 'linguistic fallacy'. The linguistic fallacy is a hidden presupposition sitting close to the heart of many projects in the humanities. It essentially says that in order to make things happen in the human world, a thought must be involved" (Schaefer, 2017, p. 19).

As a theory of power that transcends reason and thought, affect theory enhances our understanding of power dynamics in human-nonhuman interactions. It emphasizes the role of nonverbal communication and embodied experiences, particularly relevant to the interactions between assistance dogs and their handlers. The embodiment of affective experiences in dogs, as demonstrated by their ability to interpret emotional cues through body language challenges conventional models of affections that prioritize reason and verbal communication. This shift in focus encourages a more inclusive outlook on affective experiences and contributes to a deeper understanding of the various ways in which affect is expressed *within* and *across* species. Additionally, this critique of reason and emphasis on nonverbal communication resonates with disability studies, which also challenge normative standards of communication and cognition (Kafer, 2013).

The relationship between an assistance dog and a person with a disability operates through mutual affect, with each affecting and being affected by the other. This intricate emotional connection transcends mere functionality. Haraway (2008, p. 38), in discussing human-canine relationships, differentiates between companion animals and working animals based on "an economy of affection" and functionality, respectively. She suggests that affection poses a potential risk for animals, contrasting with the perceived safety of ethically bred working dogs. However, this oversimplification of the relationship between affect and functionality fails to capture the complex and meaningful bonds that form between assistance dogs and individuals with disabilities. Criticizing Haraway's distinction between "pets" and working dogs based on skills and "an economy of affection," Avigdor Edminster argues that separating affection from other economies is not feasible:

> "While assistance dogs are clearly not solely dependent on 'an economy of affection' in the same way as a 'pet' might be, the various ways that the relationships between assistance dogs and clients are explained makes any clear distinction between 'economies of affection' and skillful work an uncertain proposition" (2011, p. 138)

The critique offered by Edminster challenges Haraway's clear-cut distinction between pets and working dogs by emphasizing that it is impossible to fully separate affective bonds from functionality in the context of assistance dogs. In addition to their physical labor, assistance dogs also invest their affective wellbeing in their work by navigating complex social situations, processing sensory information, meeting the emotional needs of their handlers, and carrying out repetitive tasks. Assistance dogs are trained to carry out unique tasks that are beyond the capabilities of both humans and other animals (Arnold, 2011; Oliver, 2016). For instance, they have the ability to detect physiological changes in the human body and alert their handlers in a timely manner (Reeve et al., 2021). While guide dogs rely on visual cues to assist their handlers, medical-alert dogs rely on their keen sense of smell to perform effectively, establishing a crucial bond with their human partners (Reeve et al., 2021). These working dogs are not only highly skilled in their tasks but also deeply attuned to the emotional and nonverbal signals of their handlers, and can detect subtle changes in facial expressions, body language, hormone levels, and vocal tones (Mialet, 2020). While working, these dogs are not allowed to socialize with other humans or animals. This empathic understanding and affective responsiveness enable assistance dogs to provide comfort and enhance affect regulation among individuals with disabilities (Rodriguez et al., 2021). Their mere presence, companionship, and the release of oxytocin during interactions can lead to positive effects on mood, stress levels, and overall emotional health (Marshall-Pescini et al., 2019). Assistance dogs not only facilitate social interactions but also help in breaking down barriers, fostering social engagement, and reducing feelings of isolation for individuals with disabilities (McManus et al., 2021). This social dimension can influence affective experiences and contribute to a sense of belonging and identity for people with disabilities. However, the affective labor and wellbeing of these working dogs is overlooked in welfare discussions, which reflects "wider human exceptionalism" (Blattner et al., 2020, p. 5).

The concept of "emotional labor" introduced by Hochschild (1975, 2008) was groundbreaking in how it illuminated the invisible emotional management often required in certain gendered service and care professions. Hochschild distinguished "emotional labor," specific to paid work, from "emotion work," which refers to similar emotional management in unpaid context. Hochschild (1975, 2008) highlighted how individuals, especially women in traditionally "feminine" occupations like nursing, teaching, and service, manage their emotions as part of their professional obligations. This process involves not only the regulation of their own feelings but also the active facilitation of the emotional experiences of others, making emotional management an essential, though often underacknowledged, component of their work.

Although Hochschild initially focused on human experiences in gendered and commercial labor, this framework can also apply to assistance dogs. Kendra Coulter, use the term "emotion work" to describe how these dogs not only perform physical tasks but also manage their emotional states and help their human companions regulate their emotions. As Coulter notes, these working animals "are asked and expected to be in particular places and positions, to behave in specific ways, and to subvert their feelings or desires in order to meet the needs of people; that takes and is work, and provides yet another example of animals' emotion work" (2016, p. 76). Additionally, they need to learn to ignore other animals while working to focus on their tasks diligently and act professionally by controlling their emotions.

The concept of emotional labor, as defined by Hochschild, remains widely used for analyzing interpersonal dynamics involving emotional regulation. Hardt and Negri, however, broadened this to "affective labor," encompassing a wider range of relational activities beyond emotional regulation.

While emotional labor primarily focuses on the management of emotions in paid work contexts, affective labor "produces or manipulates affects," which are prepersonal (Hardt and Negri, 2004, p. 108). This paper prefers the term "affective labor," as it is better suited to address human-animal relations and nonhuman animal perspectives. The affective labor of assistance dogs exemplifies the intricate and expansive emotional regulation, display, and management that are central to the sociology of emotions, highlighting its complexity beyond the more limited concept of emotional labor. However, their affective care work seldom receives social recognition and it is a topic still underexamined (Coulter, 2016). As Coulter writes, "the study of multispecies work still comprises a very small proportion of the total collection of research in the sociology of work" (2016, p. 22).

This gap in recognition highlights the need for a multispecies perspective that critically examines the relationships between humans and nonhuman animals. Cary Wolfe, a prominent figure in animal studies and posthumanism, delves into the realm of affect theory to illuminate the complexities of these human-animal interactions (2010). By focusing on the affective intensities that surface during human-animal interactions, Wolfe highlights the nuanced emotions and sensations that transcend conventional modes of communication and cognition. Wolfe's work invites a rethinking of anthropocentrism and opens up possibilities for more inclusive understandings of affect. Opposing "the fantasies of disembodiment and autonomy" (Wolfe, 2013, p. xv), Wolfe's posthumanist discussion enables a more complex understanding of affective investments of humans and the taken-for-granted ways of experience. Wolfe's examination of posthumanism prompts a critical reassessment of anthropocentrism by acknowledging the intricate affective connections that blur the boundaries between different species. Speaking of disability and service dogs, Wolfe writes:

> "…instead of seeing nonhuman animal as merely a prop or tool for allowing the disabled to be mainstreamed into liberal society and its values, would not we do better to imagine this example as an irreducibly different and unique form of subjectivity– neither *Homo sapiens* nor *Canis familiaris*, neither "disabled" nor "normal," but something else altogether, a shared trans-species being-in-the-world constituted by complex relations of trust, respect, dependence, and communication (as anyone who has ever trained—or relied on—a service dog would be the first to tell you)?" (Wolfe, 2013, p. 140–141).

Wolfe's critique of the dualism between humans and animals aligns with the transformative nature of the affective labor performed by assistance dogs. The affective bond between an assistance dog and a person with a disability disrupts traditional distinctions between human and non-human experiences. This bond creates an opportunity to consider "interspecies solidarity," which emphasizes respect, reciprocity, and the enhancement of working animals' lives by acknowledging both their physical and affective labor (Coulter, 2020).

Building on the idea of attunement, Hélène Mialet provides further insights by focusing on diabetic alert dogs, describing them as loving, nonjudgmental "living prostheses" (Mialet, 2020, p. 2), capable of accessing "certain information about human individuality that humans themselves ignore" (2020, p. 3). For Mialet, dogs' sense of smell and sensations make them ultimate ethnographers, reacting to miniscule changes in the body that are imperceptible to humans themselves. It is their affective capacity, responsiveness and acute sense of smell that make the dogs living prostheses (2020, p. 2). In addition to training, the establishment of a strong attunement and bond between the canine and their human companion is imperative for the success of this partnership. Mialet writes, "The trainer attunes to the dog, the dog attunes to the trainer; the dog attunes to the individual, the individual to the dog: all are ethnographers of each other, all inhabit each other worlds, all exchange properties" (2020, p. 7). While Mialet emphasizes attunement and the bond between dogs and their human counterparts, her portrayal may unintentionally promote an instrumentalist perspective that overlooks dogs' affective labor and unique abilities, reducing them to mere extensions of the human body. This approach can undermine the dog's agency and autonomy by suggesting they are solely functional in nature. It is important to acknowledge that while these dogs serve as empathetic companions, attuned to the emotional needs of their human partners, they also possess their own needs, desires, and capacities that extend beyond their utility to humans.

While Mialet highlights the importance of attunement, her framing of dogs as "prostheses" contrasts with other perspectives that emphasize their agency. For example, Vinciane Despret's concept of "embodied empathy" offers a more reciprocal view of the human-dog relationship (2013).

This view contrasts with the idea of a "prosthesis," recognizing the dog as an active participant who co-creates meaning and emotional bonds with their human counterpart, rather than merely responding to signals. Despret highlights the:

> "feeling/seeing/thinking bodies that undo and redo each other, reciprocally though not symmetrically, as partial perspectives that attune themselves to each other… Empathy is not experiencing with one's own body what the other experiences, but rather creating the possibilities of an embodied communication" (Despret, 2013, p. 51).

Highlighting the inseparability of affection and utility in the co-dependent relationships between assistance dogs and their human partners, this paper draws on Wolfe's critiques of the species divide and liberal humanism to introduce fresh perspectives into the conversation surrounding assistance dogs. Liberal humanism often prioritizes human agency and rationality, which can marginalize nonhuman experiences and reinforce hierarchies between species. By highlighting the often-underestimated affective labor of assistance dogs, this investigation prompts a re-evaluation of these conventional hierarchies and dualisms in human-animal interactions. As Charlotte Blattner et al. (2020) observe, animal "labor has been a site of intense instrumentalization, exploitation, and degradation" (p. 4), yet they also emphasize animal agency "as a site of interspecies justice" (p. 6). Embracing the intricate affective interactions between humans and assistance dogs signifies a step toward a more comprehensive and empathetic understanding of affective encounters that transcend species boundaries. By combining affect theory's emphasis on bodily interactions with the sociology of emotions' focus on emotional management, we can gain a more nuanced understanding of the profound emotional and affective bonds formed between assistance dogs and their human companions. A crucial aspect of this endeavor involves exploring the concept of unconditional love attributed to dogs, which can obscure the physical and affective labor that assistance dogs perform—an issue that will be further explored in the following section.

4 Do assistance dogs love working for humans?

In the discourse surrounding assistance dogs, it is commonplace to assert that they love helping people. Organizations like Can Do Canines promote this idea, depicting assistance dogs as fulfilled by their work and enjoying intricate bonds with handlers (Assistance Dogs FAQs, 2024). Similarly, another organization named "Paws as Loving Support" underscores assumptions of unconditional love through their services. Moreover, financial donors to such assistance dog organizations often express sentiments affirming the deep bond between these animals and their human counterparts. One donor notes that an assistance dog's capacity surpasses human limitations, that they never get bored and love their human companions unconditionally (Then Along Came Liberty, 2024). Rather than scientific rigor, anecdotal narratives about a vague notion of love determine the bond between a dog and a handler. If we accept that "the experience and expression of hardwired emotions is the product of learning" (Turner and Stets, 2012, p. 285), then reflecting on what love *does* rather than what love *is* within assistance dog literature, can contribute to improving canine welfare and critical work on the sociology of emotions. Rethinking "love" in assistance dog literature is essential for advancing human-canine interaction, as emotions are integral to forming and questioning social structures (Turner and Stets, 2012).

Despret (2013) argues that animals are active participants in their relationships with humans, and underscores the importance of adopting a more humble and curious stance when engaging with animals' emotional lives. If "understanding an emotion means understanding the situation and social relation that produces it" (Bericat, 2016, p. 495), we must expand our perspective to acknowledge the full spectrum of affective states dogs may endure. What if assistance dogs are merely tolerating their job because they were not given any other chance since their birth into incarcerated spaces? As it is difficult, if not impossible, to fully understand what a dog needs, likes or wants, accounting for the best interests of all those involved in assistance dog partnerships necessitates a re-evaluation of love. Denying complex emotions to animals because it is difficult to study them directly does not eliminate the fact that animals experience a variety of emotions (Bekoff, 2000).

> "Many emotions are wired into the body systems responsible for emotions, but their activation, expression, and use are highly constrained by the emotion culture of a society and the structure of those situations that call for individuals to experience and express particular emotions." (Turner and Stets, 2012, p. 286).

It is outside the purview of this article to delve into the question of whether love can be classified as an emotion or simply a social bond. Nonetheless, "there is a conspicuous lack of serious reflection on the topic of love in the classical sociological tradition" (Rusu, 2017, p. 4). One of the reasons for that lack of involvement is that love is regarded as a private, psychological phenomenon. It is elusive and difficult to measure (Rusu, 2017). However, as Jackson (1993) puts it, "far from being just a personal, private phenomenon, love is very much a part of our public culture" (p. 202). Love, according to Jackson, is intertwined with the social and cultural setting in which individuals perceive it. It is a key element of the emotional background of social interactions, shaped by cultural, societal, and personal influences. Love is "characterized by its capacity to unite two individuals who are free to decide whether they want to be with each other in a shared sphere of intimacy" (Seebach, 2017, p. 54). In sociological examinations of this nature, the focal point of analysis lies in the evaluation and criticism of romantic, monogamous love and marriage. One notable instance is the emphasis on gender disparities, as highlighted by De Beauvoir (1972) when she stated "the word love has by no means the same meaning for both sexes" (p. 652). Building upon de Beauvoir's perspective, the paper raises the question of whether the concept of love holds the same significance for both humans and dogs. Swen Seebach posits that "love can be criticized as a form of concealed discrimination and oppression" (2017, p. 62). Therefore, exploring the notion of unconditional love within the context of assistance dogs can offer a more nuanced analysis of the unequal power dynamics that love may serve to conceal.

In her work, Rudy (2011) writes that "emotional connection with real animals, connections based on love and shared lives, need to be included in the discourse of animal advocacy in order to maintain and model a better world for them" (2011, xii). Rudy explores the role of emotions in animal advocacy, arguing that love for animals can be "politicized" and used as the foundation for a broad animal ethic. She posits that "who we love is always a question of politics" (p. 25). Nevertheless, this article posits that an unexamined concept of love and affection can detrimentally affect the lives of assistance dogs. As Coulter writes, "the word love is a very political and significant metaphor and mobilizing force in animal communities and workplaces with many meanings and interpretations" (2016, p. 82). Therefore, when love is assumed without question, it may manifest as shallow, insincere, or even detrimental, neglecting to prioritize the genuine needs and welfare of the animals in question. Love can be "not really about caring for another," but "a very self-centered emotion," operating in a culture which values individualism and paternalism (Jackson, 1993, p. 210). Marran (2011) labels this form of assumed love directed toward and received from animals as "domesticating animal love" (p. 42). Domesticating love sees animals as things "onto which anthropomorphizing notions can be projected and through which social standards are maintained" (2011, p. 43). Examining the relationship between humans and animals through the lens of love could significantly enhance sociological investigations, given that this bond encompasses "many faces, some of which include moral elements, and some of which are fraught with moral dangers" (Gheaus, 2012, p. 589). The unchallenged assumptions such as "most companion animals love us nonjudgmentally" or "animal love lacks the control human beings have over their love and its expression" (Gheaus, 2012, p. 589) upholds oppressive social standards and anthropocentrism.

Martin Heidegger's concept of "enframing" (*Gestell* in German) is a pivotal lens through which we can examine the ways in which love operates as an emotion glossing over power relations in human-assistance dog interactions. Enframing refers to a way of perceiving the world that reduces it to a resource to be controlled and optimized for human purposes (Heidegger, 1977, p. 12, 24). In the context of human-animal relationships, this lens can illuminate how assistance dogs are framed as tools to enhance human experiences and capabilities, particularly for individuals with disabilities. When applied to the use of assistance dogs, enframing suggests that these animals are seen as assistive technologies—resources designed to help individuals with disabilities navigate their environment more effectively. Heidegger's concept of enframing is useful for understanding how assistance dogs might be viewed through a utilitarian lens. However, these dogs also resist this reductionist view by forming deep emotional connections with their handlers, offering companionship and care that go beyond their functional roles. This challenges the conventional view of enframing by introducing a more holistic way of understanding human-animal relationships—one that acknowledges the agency and affective contributions of the dogs themselves.

Viewing love as an enframing concept helps reveal how framing assistance dogs as merely "loving their work" risks neglecting their agency, individual needs, and complex affective experiences. The discourse of dog's love for their work presents work for people as a core priority for dogs (Eisen, 2020). This concealment through "unconditional love" can lead to the invisibilization of the dogs' complex affective landscapes and perpetuates anthropomorphism and human exceptionalism. This enframing through love might inadvertently simplify the relationship between assistance dogs and humans, reducing it to one of mere obedience and the fulfilment of human desires. As Seebach writes, "the danger of love and of the discourse of love rests in the projected possibility of creating a (homogeneous) one out of two, and to present such a (homogeneous) unity as something desirable" (2017, p. 63). In such unity, the affective experiences of assistance dogs, which go beyond utility and efficiency, can often be hidden from view. This notion aligns with Turner and Stets (2012), who assert that "whereas emotions operate to sustain or change social structural arrangements, it is equally true that social structures constrain the nature of emotional arousal" (p. 293). This perspective suggests that our understanding of love as expressed by assistance dogs may be shaped by conditioning and training, framed by human needs and expectations. Thus, the perceived emotional connection may reflect not only the genuine bond between humans and assistance dogs but also the influence of societal structures that dictate how such emotions are expressed and understood. Reflecting on the importance of sociological analyses on love to understand the society better, Seebach writes that "as a modern phenomenon," love "had its role to play in the shaping of our current society, not just transporting inequalities of the past into the future, but reshaping the future by redefining the past" (2017, p. 75). Following this line of argument, we can say that love operates as a strong force within human-canine bond, which can cover over histories of selective breeding, reproductive control, practices of conditioning, intra-species isolation, coercion, and behavioral modification and training techniques, which are crucial to produce assistance dogs.

Assistance dogs are trained to perform specific tasks, and their behavior is modified with rewards or reinforcement (Audrestch et al., 2015). However, it is important to recognize that not all dogs successfully complete this training. Studies indicate that training failure rates can range from 50 to 70%, depending on various factors such as temperament, behavior, and health issues (Duffy and Serpell, 2012). As a result, many dogs are rehomed as pets rather than serving as assistance animals. If a dog fails to succeed in training, does this indicate a lack of desire or affection for the tasks, or does it reflect a mismatch between the dog's natural temperament and the specific demands placed upon them? Framing assistance dogs as creatures that love their work may obscure the complexities of their emotional experiences and the coercive aspects of their training. The conditioning that assistance dogs undergo can create difficulties in distinguishing between genuine affection and learned responses.

Despite the impact of training on the expression of love in assistance dogs, some believe that it does not diminish the authenticity of the bond they form with their human partners (D'Souza et al., 2020). That is why it is crucial to adopt a more critical perspective on love within the context of the assistance dog-human relationship. This paper argues that love is a crucial factor in shaping human-assistance dog relationships, a dimension deserving closer examination. As closely intertwined with human social life, dogs provide a unique lens for investigating how emotions structure interspecies bonds, offering valuable contributions to sociological research on emotions. However, assumptions about canine love—such as the notion that dogs naturally love working for humans—risk obscuring the underlying systems of confinement and exploitation embedded in canine labor. Therefore, rather than focusing solely on dogs' desire to please, it is important to examine the relationship through the lens of mutual respect, care, and affective reciprocity and an intersectional exploration of power. This perspective brings us to the concept of interdependence, framing human-assistance dog relationships as grounded in mutual care rather than in one-sided or purely functional interactions.

5 From independence to interdependence

Michalko (1999) reflections on his interactions with his guide dog, Smokie, offer an early exploration of interdependence in human-assistance dog partnerships. Unlike medical narratives that frame disability as mere impairment, Michalko regards blindness not as a deficiency but as an authentic way of being, enriched by his connection with Smokie. Where blindness is often perceived as a loss or limitation, Michalko reframes it as a unique mode of existence. His bond with Smokie enables him to reinterpret blindness, not as an inability, but as an experience shaped by emotional connection and trust (1999). This bond, emphasizing touch over the more distanced utility of a white cane, redefines blindness as something beyond a physiological difference and speaks to the deeper, affective dimensions of interdependence (Michalko, 1999).

Michalko's challenge to ableist narratives that label blindness as a lack also resonates with Eva F. Kittay's emphasis on dependency as an essential aspect of human life. Kittay underscores the importance of dependency in human life, and argues that "we cannot acknowledge our interdependency without first recognizing our dependency" (Kittay, 2015, p. 55). While dependency is inherent in human life, it has been historically associated with women, children, and individuals with disabilities, often leading to the infantilization and stigmatization, prompting individuals to pursue independence, which, according to Kittay, is a myth (Kittay, 2015). This stigma surrounding dependency negatively affects both disabled and nondisabled individuals' sense of self-worth (Kittay, 2015, p. 58). Kittay writes,

> "A consideration of dependency forces the question: can one still protect the benefits to be gained by disabled people's demands for independence without re-stigmatizing those who do not benefit? Can we accept the inevitability of dependence without denying the negative effects of an *imposed* dependency on the lives of many disabled people? And can we accept reliance on dependency workers without subordinating their interests to those of the disabled person? (Kittay, 2015, p. 57).

This paper aligns with Kittay's inquiries, considering assistance dogs as "dependency workers" whose labor often go unacknowledged within independence-focused discourses. Yet, as highlighted by Oliver (2016), Kittay's feminist ethics of dependence is limited to interdependence between humans, overlooking the nuanced dynamics between humans and assistance dogs. While the narrative of unconditional love attributed to dogs can gloss over inequalities and obscure the labor and exploitation inherent in these relationships, emphasizing interdependence instead highlights the significant physical and affective labor performed by assistance dogs.

Unlike dependence, interdependence allows for the recognition of assistance dogs as active participants whose presence shapes their human partner's lived experiences. Through physical tasks and affective attunement, assistance dogs play a crucial, skillful role, reshaping human experience beyond companionship. This understanding resonates with Sunaura Taylor's framing of dependency "as an integral part of our world and relationships," rather than negative or unnatural (Taylor, 2017, p. 210). For Taylor, all individuals live along "a spectrum of dependency" (2017, p. 210), which stands in opposition to liberal, ableist beliefs linking self-reliance with value. Recognizing interdependence fosters mutual respect, addressing the "dog's existence as a separate being" with agency (Edminster, 2011, p. 133). Put differently, the narrative of independence reinforces a hierarchical dynamic that overlooks canine agency and the relational autonomy that exists between humans and dogs. Moving away from *independence* toward *interdependence* involves recognizing the shared dependency and vulnerability inherent in this relationship, where both humans and dogs contribute to each other's wellbeing and development.

Wolfe's emphasis on "a shared trans-species being-in-the-world" together with Kittay's analysis of "dependency workers" and Taylor's relational dependency challenge the notion of human independence which ignores the mutual co-dependency between assistance dogs and humans. Although dogs may not rely on humans for basic survival in the wild, their evolutionary history and selective breeding have fostered a deep interdependence with humans. This approach contrasts with human-centered notions of independence, which position animals as mere functional tools. Emphasizing interdependence highlights that dogs require care and respect just as much as their human companions. By recognizing this mutual dependency, the labor of assistance dogs challenges species bias, promoting a view of dogs as co-participants rather than instrumental aides. Thus, a shift toward interspecies interdependence not only contests speciesism but also advocates for respect for the affective states and wellbeing of assistance dogs. This perspective requires reconsidering speciesism and compulsory able-bodiedness, fostering a more inclusive attitude toward canine wellbeing. The subsequent section will delve into addressing and opposing speciesism as a means to restore a sense of interdependence.

6 Intersections of ableism and speciesism in the case of assistance dogs

The relationship between ableism and speciesism is essential for understanding the complexities of human-animal interactions, especially concerning assistance dogs (Taylor, 2017). These dogs enhance the autonomy and quality of life for individuals with disabilities (Rodriguez et al., 2021), by performing specific tasks while also offering companionship and emotional support, creating a bond that transcends utilitarian views. This dynamic challenges the traditional framing of assistance dogs solely as resources and calls for a nuanced understanding that recognizes their agency and emotional investment. Acknowledging both dogs' physical and affective labor reframes the human-animal relationship as one of partnership, rather than utility, thereby contesting speciesism. However, prevailing speciesist attitudes often overshadow their contributions, fostering the idea that animals exist solely for human use, and neglecting their emotions wellbeing. Deeply ingrained in Western thought, speciesism perpetuates hierarchies that devalue nonhuman animals while simultaneously impacting individuals with disabilities. Exploring how these intersections shape perceptions and treatment of both individuals with disabilities and nonhuman animals provides valuable insights into the ethical implications of their relationships.

The emphasis on reclaiming humanity in disability studies and challenging hegemonic ideas of humanity in animal studies has presented difficulties in fostering coalitional politics between these two fields (Taylor, 2017). These tensions are further complicated by debates surrounding Peter Singer's speciesism framework, which has been critiqued for its ableist underpinnings (Taylor, 2017). While my work engages with the critical examination of speciesism, I reject Singer's utilitarian approach, which disregards the lived experiences of people with disabilities and perpetuates ableist comparisons between disabled individuals and animals by prioritizing reasoning and cognitive capacities (Singer, 1975). Instead, I advocate for a framework that recognizes the shared vulnerabilities and interdependencies between humans and nonhuman animals. Such a perspective aligns with Taylor's argument that the oppression of animals and individuals with disabilities is deeply interconnected, suggesting that their paths toward liberation are intertwined (2017, p. xv). Taylor, writes:

> "disability liberation cannot happen when our environments, the species who share those environments with us, and individual animals who live their lives entangled with ours continue to be seen through ableist and anthropocentric lenses that view them as things we humans can own and control–as discardable, fungible, and killable" (2017, p. 202).

Incorporating nonhumans into intersectional theory is essential for a comprehensive understanding of oppression. As Jackson (2020) emphasizes, this distinction is not solely rooted in biological differences;

it is also deeply influenced by race and gender, contributing to processes of dehumanization and animalization. This racialized and gendered perspective intertwines with the concept of animality, weaving a complex web of abject humanity and racial hierarchies. Furthermore, as Taylor argues, "ableism is intimately entangled with speciesism" (2017, p. 57), highlighting the interconnectedness of these oppressive systems. This entanglement calls for a re-evaluation of how we treat both assistance dogs and individuals with disabilities. By recognizing the overlapping nature of these oppressions, we can advocate for a more inclusive approach that respects the rights and welfare of all beings involved.

The endeavor to restore humanity by individuals with disabilities who have endured historical dehumanization must not come at the cost of perpetuating animal oppression and speciesism. Practices such as selective breeding, favoring obedient traits, and applying standardized measurements to train assistance dogs can contribute to ableism by promoting conformity to normative standards that align with ableist expectations of utility and obedience. As many thinkers argue, "the oppression of [nonhuman animals] and speciesism overlap with other forms of oppression, such as racism, sexism, heterosexism, and so on" (Grauerholz et al., 2020, p. 131). The insufficiently theorized aspect of the assistance dog phenomenon presents a distinctive chance to advance intersectional analyses in sociological studies, particularly in the realms of disability, animality, and speciesism. Failing to address these interconnections "leaves wide gaps in our sociological understanding and theories of human society" (Grauerholz et al., 2020, p. 121).

The evolving field of Critical Animal Studies (CAS) encourages methodological and theoretical experimentation and calls attention to the interconnected systems of oppression that affect both humans and nonhuman animals (Matsuoka and Sorenson, 2018). Researchers were able to trace racial and social class interactions between people and animals in the context of European colonialism, for example, by concentrating on the history of dog breeding practices (Worboys et al., 2018; Wallen, 2017). Dogs in particular had a specific part in separating the ruling class from the general populace as well as the "civilized" from the "uncivilized." In line with the affordances of a CAS perspective, there is a growing body of literature pertaining to the intersections of animality with race (Wallen, 2017; Scott, 2007), gender and sexuality (Sorenson, 2014; Stanescu, 2012), class (Worboys et al., 2018), colonialism (Montford and Taylor, 2020), biopower (Wolfe, 2013), and disability (Edminster, 2011; Taylor, 2017). Works that examine and challenge speciesism shed light on the interconnected origins of oppression and offer a thorough examination of its intersections with various social constructs. As Taylor asks, "if animal and disability oppression are entangled, might not that mean their paths of liberation are entangled as well?" (2017, p. xv). In this context, interdependence refers to a framework highlighting the mutual reliance and active contributions of humans and animals, moving the narrative away from the dog's labor as a matter of mere obedience or affection. Hence, the examination of animals from a sociological perspective, the exploration of animals' affective encounters, human-animal interactions, and the human and animal divide can offer significant insights into the complex intersections of disability, affect, speciesism, and animal welfare.

7 Discussion and conclusion

Integrating human-animal interactions and animal affect into current affect research and sociology of emotions broadens the scope of investigation beyond human experiences and contributes to a more nuanced and complex understanding of power relations. This expansion allows researchers to examine affective processes and expressions that might transcend species boundaries. Therefore, the utilization of sociological methods and concepts to investigate animals would contribute to a deeper comprehension of society, social interaction, the interconnected nature of oppression, and power relations (Stuart et al., 2013, p. 218). This intersectional perspective not only enriches sociological inquiry but also informs practices that promote equity and justice for both humans and nonhuman animals.

Acknowledging the affective labor of assistance dogs challenges anthropocentrism and fosters a more inclusive understanding of emotional engagement in human-animal relationships.

Drawing from Haraway (2008) insights on emotional labor, which "link feeling … to the issue of social justice" (p. 50), we can begin to unravel the preconceived hierarchy in human-animal interactions by recognizing the affective depth of dogs' labor. Hochschild's framework opens new avenues for examining animal labor, urging us to question our assumptions about assistance dogs' unconditional love for their work. By linking this love to broader issues of power dynamics, abuse, and interdependence, we can better understand the full range of emotions these dogs may experience and what they "themselves seem to value most" (Eisen, 2020, p. 152). This perspective not only enhances their wellbeing but also encourages us to ensure that they are thriving in their roles rather than merely tolerating them.

Assistance dogs' emotions, like excitement or stress, are often evident in subtle behaviors, making it vital to observe behavioral and physiological cues to better understand animal affect (Tomkins et al., 2011). By paying attention to behavioral cues, physiological responses, and cognitive assessments, a more comprehensive understanding of animal affect can be achieved. Research into animal affect should foster interdisciplinary collaboration across psychology, veterinary science, and animal behavior. Regular assessments by qualified trainers and veterinarians can help ensure that these dogs are emotionally healthy and capable of effectively assisting individuals. This revised perspective encompasses a more inclusive and empathetic comprehension of the affective experiences that bridge the species divide and challenge human exceptionalism. If emotions are social phenomena and dogs are part of our social life experiencing complex emotions themselves and with us, then sociology should integrate animals and human-animal interactions into its critical research. Researchers can develop a more intricate and thorough comprehension of the interconnected origins of oppression and power abuses by examining the impacts of nonhuman animals and their interactions with humans.

The intricate interdependence between an assistance dog and persons with disability necessitates a contemplation of care and a curiosity toward our interaction with dogs and addressing their welfare needs. Emphasizing assistance dogs solely as means of promoting human independence fosters a human-centric, speciesist view that overlooks canine experiences, values, and affect (Wadiwel, 2020; Oliver, 2016). Instead of perpetuating romanticized and misleading narratives of love and independence, it is essential to question assumptions, challenge potential abuses of power, and acknowledge the interdependence between humans and dogs. Embracing a deeper comprehension of love and emphasizing interdependence can cultivate relationships that are characterized by respect, communication, and dependency, thereby improving the welfare of both individuals with disabilities and assistance dogs.

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The author declares that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Raising aluminum foil fists: how to speak about anger in transplant medicine

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Dominant narratives of solid-organ transplantation foreground vocabularies of gratitude. Solid-organ transplantation is often celebrated in biomedicine for its high-tech innovation and specialization. But transplantation also includes the organizations that oversee the distribution of donated organs to potential recipients who disproportionately outnumber available organs. Wait-listing for transplant weighs urgency and fitness for transplant against availability, as individuals must simultaneously demonstrate that their conditions are severe enough to warrant transplantation while also showing they are well enough to withstand the transplant procedure that is meant to return the individual from critical illness to able-bodied health. This article considers how promises of cure make affective demands on transplant recipients. Dominant transplantation narratives and metaphors frame transplantation as “rebirth” and the “gift of life.” But this framework constrains transplant recipients’ affective and emotional repertoires, positioning gratitude as the primary—if not only—acceptable feeling for performing that the “gift of life” was deserved. Such narrowly sanctioned possibilities for expression elide the affective complexities of transplant recipients’ experiences and foreclose opportunities for expressing anger and frustration. This paper unpacks the politics of verbalizing anger among solid-organ transplant recipients at an urban North American hospital. Using arts-based sensory ethnographic interviews with 27 participants, this paper draws on affect theory to understand how transplant recipients critique and protest curative imaginaries while also upholding them. Theorizations from Critical Disability Studies provide generative ways to question negative feelings and more fully understand recipients’ experiences.

KEYWORDS

affect, curative imaginaries, transplant, cruel optimism, crip negativity, anger

Introduction

Anger rarely surfaces in public discourses of solid-organ (heart, kidney, lung, liver, and pancreas) transplantation. Solid-organ transplantation constitutes a highly technical medical arena that intervenes in terminal conditions to extend the lives of transplant recipients. Discourses around transplantation are suffused with positive affective registers that coalesce around hope and gratitude: hope for a return to health and gratitude for the donor’s decision, for the donor’s kin who upheld the donor’s wishes, and for the biomedical practitioners and technologies that make transplantation possible. Transplants are deeply valued by recipients, their loved ones and donor families, for how they extend the lives of recipients—and, through recipients, the lives of donors. However, depictions of solid-organ transplantation as a “miracle” or the “gift of life,” leave little if any space for expressions of affective intensities related to experiences of pre- and post-transplant complications, rejection, and the debilitating effects of the immunosuppressant medications necessary to preventing rejection. Such affective regimes simultaneously foreclose and stigmatize expressions of so-called negative affect.

The promises of transplant medicine to return recipients to a state of health comprise the curative imaginaries in the field. Curative imaginaries situate medical interventions as fixes intended to erase pathology and disability (Clare, 2017; Kafer, 2013). In solid-organ transplantation, the curative imaginaries of biomedicine often fail to account for the complexities of living with transplantation: curative imaginaries depict solid-organ transplantation as a cure to organ failure, creating a neatly bifurcated temporal frame of before and after transplantation (Berkhout et al., 2024). A growing body of social science and humanities literature highlights the ways in which curative imaginaries of biomedicine, with their insistence on medical intervention as fixes that erase pathology and disability (and associate disability with pathology), fail to account for the complexities of living *with* transplantation (Heinemann, 2020; Sharp, 2014). This literature reveals more circular temporalities informed by routine and urgent hospital visits (Heinemann, 2020, 2024), multiple hauntings (McCormack, 2021), and celebrations of technological advancement that fail to take into consideration recipients' often painful embodied experiences (Sharp, 2014). We contribute to this body of literature by asking, What affective demands do curative imaginaries make on solid-organ transplant recipients? And what do expressions of anger reveal about the stakes and politics of transplant medicine's affective registers? These questions have important implications for grappling with the politics of disability as they reveal the pull of curative imaginaries, the desire to protest those imaginaries' affective expectations, and the harms that those imaginaries can produce.

Centering affect directs attention to the intensities and reactions that move through and between bodies—that are atmospheric (Massumi, 2002) and swirling (Stewart, 2007). The term affect has acquired multiple and sometimes conflicting usages and definitions. We draw on Sara Ahmed's and Lauren Berlant's writing on affect as pre-personal feelings that can structure relations, namely Ahmed (2010)'s affect alien and Berlant's cruel optimism (Berlant, 2011). Each concept calls attention to the promises of happy objects and the affective dimensions of the reproduction of social economic structures. We show that curative imaginaries embody relations of cruel optimism (Berlant, 2011), attachments to unrealizable promises, while angry affects in transplant milieus constitute *alien affects*, the dispositions of killjoys (Ahmed, 2010) who do not participate in reproducing affective ecosystems that characterize solid-organ transplantation. Understanding the affective demands that curative imaginaries make on transplant recipients is essential to unmasking the affective expectations of a so-called good life. We turn to examinations of tragedy, pain, and grief in Critical Disability Studies to deconstruct and reconsider how so-called negative experience is produced and conceptualized—to imagine, instead, anger as affirming of life (Abrams and Adkins, 2020).

This article considers how transplant recipients in a small qualitative study express anger and how they reflect on it. Understanding anger in the context of solid-organ transplantation is essential to identifying the ways in which curative imaginaries make affective demands on transplant recipients. That is, anger is instrumental to apprehending unspoken regimes of affective politics in transplant medicine. We found that expressions of anger were verbal and material, emerging during an arts-based sensory ethnographic interview process. Participants were invited to create foil casts of their hands and forearms that spoke to their transplant experiences. When anger surfaced, it often did so as a clenched fist. The gesture of the clenched fist has been associated with labor, feminist, and civil rights movements across the globe since the early 20th century. We understand participants' fists, evocative of anger, as critiques of the compulsory and sanctioned affects of transplant medicine. These clenched fists highlight the failures of curative imaginaries to create space for so-called negative affects. But participants' foil casts did not celebrate negative affect. They are evidence of wrestling with the cruelty (Berlant, 2011) of curative imaginaries in transplant medicine and the politics of rejecting them. As a result, participants in this study did not *crip* their experience, that is, they did not subvert "mainstream representations or practices to reveal able-bodied assumptions and exclusionary effects" (Sandahl, 2003, p. 37). We argue that these foil fists gesture simultaneously toward resisting and reinforcing the affective demands of curative imaginaries, revealing both their pull and their stakes. Participants engage in the work of trying to make space for anger and other alien affects, but they do so while still reproducing the affective regimes that they protest. The result is a story about how participants materially create space to speak about anger in transplant medicine.

The structure of this article retraces the ways in which anger surfaced and materialized in the arts-based sensory ethnographic interviews from which the data emerged. As a result it does not follow the familiar format of background, methods, results, discussion, and conclusion. Elaborated in the Methods section, these interviews asked participants to recall sensory experiences of transplantation and invited each to make an aluminum foil sculpture that they then transformed. We structured the article in a way that reflects the research process in order to better contextualize our data—that is, participants' stories and foil sculptures—within the epistemological and ontological frameworks from which they emerged (Barad, 2007). Configuring our research in this way draws inspiration from feminist anthropology and science and technology studies (STS) literatures that understand knowledge production as profoundly situated (Haraway, 1988; Abu-Lughod, 1991). Feminist approaches to knowledge production often foreground personal stories (verbal and arts-based) and demonstrate how individual experience is entangled in, and informed by, historical and sociopolitical processes (Hartman, 2008; Sharpe, 2016). Centering personal stories importantly counters tendencies toward abstraction and the harmful erasures that abstraction engenders. This work of situating participants' contributions becomes even more important for social science and humanities research in biomedical arenas. Biomedicine's narrow epistemic frame (Squier, 2007) of what forms of information are salient—alongside the tendencies to value abstraction (Kleinman, 1997) and objectification (Jain, 2013) in biomedicine—makes working with contextualized stories rather than objectified datapoints central to how we conduct and communicate this particular research. Our aim is not to produce generalizable assertions about anger in relation to transplant medicine, but to ask what kinds of affective politics anger can reveal. We demonstrate these connections between individual experience and affective relations by interweaving participants' stories with scholarly discussions in affect theory and Critical Disability Studies. In this way, participants feature in the article not as datapoints or research subjects but as theorists of their own experiences.

We first provide a discussion of our methods, the larger project out of which this research emerged, and the contributions of a small-scale qualitative study. The following section elaborates the contexts in which recipients' foil casts materialized, connecting the casts to recipients' transplant experiences and public imagery of fists as symbols of protest and solidarity. We then examine the affective obligations of curative imaginaries. These obligations reveal how the imaginaries become normalized and hegemonic. The last section draws on Critical Disability Studies literature on tragedy (Abrams and Adkins, 2020), pain (Lau, 2020; Patsavas, 2014), and grief (Crosby, 2019) to problematize the association of so-called negativity with negation. With this reframing, we examine the implications of how participants transformed their casts and intervened in the anger associated with the casts' clenched fists. While participants did not outright reject curative imaginaries, they wrestled with how to make space for anger. Clenched foil fists, then, become calls to recognize the limits of curative imaginaries and the experiences they obscure.

Methods

The research presented in this article is part of a larger project titled Frictions of Futurity and Cure in Transplant Medicine ("Frictions"). The Frictions research team is an interdisciplinary group of researchers and mental health practitioners, including psychiatrists, Critical Disability Studies scholars, medical anthropologists, an art therapist, artists, and medical students. In-person and participant-facing research began in August of 2022 at a large urban North American transplant center. The Frictions project draws on feminist STS, medical anthropology, and queer and crip theory to generate ways of knowing transplant experiences differently. Transplant medicine is often hailed as the height of biomedical achievement. While metaphors of transplantation as offering "miracles," "the gift of life," and second chances circulate widely in the field, the team sought to understand health and illness in transplantation afresh by examining and complicating transplant medicine's curative imaginaries: What experiences get obscured amid these celebrations? What imaginations and materializations of living, thriving, and grieving unfold when the norms and expectations of transplant medicine are questioned rather than taken for granted? What futures emerge in their wake (Sharpe, 2016)? Research methods include participant observation in transplant—focused clinical liaison psychiatry rounds, a pre-hab and rehab clinic for lung transplant patients, and an outpatient liver transplant clinic; standard and arts-based interviews with transplant recipients; discourse analysis of transplant manuals provided to transplant patients; and sensory ethnographic methods, including sound walks through the hallways and wings where participants in the study were being treated. The Frictions project also supported research creation projects, such as rewriting a liver transplant manual in poetic form, and artist residencies that prioritized artists with lived experience of transplantation and wait-listing. In addition, the Frictions team developed digital stories and art workshops, and hosted public salons, and pop-up art installations. Through these different streams that each engage unique ways of knowing (e.g., through art, discourse, and embodied experiences), the Frictions project sought to illuminate intertwined logics of cure and futurity and their unintended consequences for transplant recipients, those wait-listed, and their families.

Research participants were recruited through multiple streams: recruitment posters were hung in the waiting areas and elevator lobbies where transplant patients would be likely to see them; the transplant medicine clinical liaison psychiatry team shared information about the research with individuals referred to transplant psychiatry, and only those who expressed interest were approached. We shared information about the study with transplant support groups via their newsletters, and participants also circulated the recruitment posters for the study through their own transplant networks. At the time of writing, 27 transplant recipients were interviewed from across solid-organ transplant clinics: three heart recipients, six kidney recipients, sixteen liver recipients, and two lung recipients. The majority of participants identified as women (16), and the remaining identified as men (11). Two individuals identified as queer or gay and one as asexual. Twenty-three participants identified as white North American, two as Middle Eastern, two as Latin American, one as South Asian, and one as Southeast Asian. Two participants were under 40 (one early 20s, the other mid 30s), two participants were in their 40s, and the remaining participants were over 50. Two participants had multiple kidney transplants, and one was waiting for her second kidney transplant.

The research presented in this article focuses on the results from the second interview in a three-interview protocol. Each interview was developed to elicit different forms of engagement and evidence about transplant experiences. The first was a conventional semi-structured interview that asked participants to recount their transplant experiences with a focus on the psychosocial supports that were most meaningful. The second interview brought together sensory and arts-based research methods. This approach was designed to elicit participants' embodied transplant experiences in a trauma-informed way (see Frankel et al., 2024 for further discussion). The third was also a conventional semi-structured interview that focused on the transplant information manuals that were distributed to patients. This third interview queried participants about these manuals, their experiences of the tone and content of the manuals, and how they used them and what they wished to find in them.

The data presented in this article comes from the second, arts-based sensory ethnographic interview. Here, we invited participants to (1) scribble on a piece of paper with whatever mark-making materials were available, then reflect verbally on what they saw; (2) recall aloud their sensory experiences of transplantation; and (3) embody a gesture that spoke to their transplant experience, and based on this gesture, create an aluminum foil cast of their hand and forearm. Once recipients created the cast, they were invited to transform it—paint it, re-shape it, embellish it with further marks, words, or materials—until the cast felt complete (Frankel et al., 2024). The arts-based component was designed to work with art supplies as well as any mark-making materials (e.g., pens and pencils) participants already had available. Interviews were conducted online and in person according to participant preference. Participants' varying levels of comfort for meeting in person, in addition to travel considerations—many participants lived more than two hours away—necessitated online interviews.

This article focuses specifically on expressions of anger that surfaced in arts-based interviews. Although participants shared numerous knotted, complicated, and ambivalent sensory and affective responses in this interview—joy, resolve, dissatisfaction, broken-heartedness, confusion, gratitude, frustration, to name only a few—we specifically engage with anger here. Anger not only interrupts and challenges the taken-for-granted discourses of gratitude and hope that circulate in transplant medicine's milieus, but also holds a mirror back to those expectations. Understanding anger and what makes anger speakable is instrumental to revealing the affective expectations and demands of curative imaginaries in transplant medicine. Seven participants (25.93 percent of participants at the time of writing) explicitly named anger as part of their experience. When participants expressed anger, it tended to be accompanied by the gesture of a fist. Six participants (seven including the wife of one participant who accompanied her husband to the interviews and participated in the mark-making activities) constructed clenched fists as their gesture, which then became the center of their artwork. Fists were thus the most common symbolic response. Participants' verbal comments often expressed complaints about how cold their recovery room was, the incessant beeping of machines, and announcements over the intercom that interrupted much-desired sleep. Others still spoke about how surprised they were at the extremes of pain they experienced post-surgery, with one saying that if asked within the first two weeks of his lung transplant if he would do it again, he would give a resounding "No!"

This article focuses on three of the participants who named anger as part of their transplant experience and one who described the gesture of the fist as symbolic of strength. We decided to center on these four participants for two reasons: to more closely engage with the multiple textures of their stories and experiences, and because these participants vividly connected their foil fists with protest and unfulfilled promises of curative imaginaries. This small-scale study thereby does not offer a generalizable account of solid-organ transplant experiences, or of why and when anger emerges in these contexts. Instead, we take a feminist ethnographic approach that understands personal stories as political (Abu-Lughod, 1993). We examine how participants both hold onto desires for curative imaginaries to be realized, while simultaneously protesting the hegemony of positive affect in transplant medicine. As a result, this research holds a mirror to the cruel optimism (Berlant, 2011) of curative imaginaries and asks how so-called negative affects might be imagined otherwise.

Aluminum foil fists

When anger surfaced in interviews, it often materialized in the foil casts as clenched fists. Lisa[1] propped her phone up on her kitchen table so that the camera showed her pressing aluminum foil around her clenched fist. She looked down and then into the camera at us, and exclaimed, "You know what? As I'm doing this, I'm angry! I'm angry! I'm angry and I have a fist and I'm angry." Lisa's anger took her by surprise. A middle-aged white woman, her reflection on her sensory experiences of transplantation revealed anxiety-laden hallucinations and slips in and out of consciousness—in which she could hear those around her but could not move or speak. Lisa had received a liver transplant six years before the interview. She punctuated her memories with explanations that all the feelings and intensities associated with transplantation were just as strong now as they were at the time. Her liver disease led to encephalopathy, a condition in which toxins that the liver would otherwise have filtered from the blood caused hallucinations. At night, the clock hands would slow to a halt, inducing panic that she would forever remain with liver failure. On multiple occasions, she saw doctors entering the hospital room to say that a donor liver had been found, that the liver was a match and was hers, only for her husband to have to later explain that those experiences were hallucinations. She said she could not trust what she saw, only what she heard. Although her husband's voice often offered comfort and reassurance, while in one of these in-between states, she also heard him ask her best friend if he ought to start making funeral arrangements. Lisa remembers screaming silently from inside her body.

While Lisa's anger surprised her, Julia, another participant, was already aware of her frustration. Julia, a woman of color in her mid 30s, received her first kidney transplant as a teenager in the early 2000s. In 2016, her doctor told her abruptly that her kidney "was done" and left the room. She made the painful return to dialysis, and in 2022 received her second kidney transplant. In our first interview, her frustrations coalesced around failures of care, the discrimination she faced at work for needing to accommodate dialysis and its intensely tiring effects on her body, doctors with whom she had to plead to get a letter for her work, financial stress, and receiving incomplete information since 2016 about psychosocial supports. She explained that she relied on the coping strategies learned in the children's hospital during her first transplant—the importance of soothing touch, whether petting a dog or holding onto a soft blanket. The comparative lack of attention to her psychic distress as an adult surprised her. But she didn't label these feelings of anger until the second interview, when she looked up from her aluminum foil cast saying, "It was anger, the fist."

Christina and Anna created their aluminum fists without hesitation. Christina, a white middle-aged woman with one child, began participation in the research roughly eight months following her kidney transplant. Christina experienced numerous complications before and after her kidney transplant. She spent nearly ten years on the waitlist. After six months on the kidney-pancreas waitlist, she received "the call" but the donor organs were not a match. Three years later, in 2017, she had a stroke and had to be removed from the list. Once she returned to dialysis, she developed heart troubles that again temporarily removed her from the waitlist. In 2022, she received a kidney-only transplant. Nine days later, she went into rejection. She noticed the telltale fever and her husband immediately drove her the two-plus hours to the transplant hospital, where the medical team was able to halt rejection and save the kidney. In the time between the transplant

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[1] All names are pseudonyms to protect the identities of research participants.

operation and our first interview nearly eight months later, she had fallen and broken her ankle. The break became more complicated due to co-morbidities and necessitated a fiberglass cast that, while not a complication of transplantation, prolonged the isolation and distress that her wait-listing inaugurated. The ankle injury, she explained, stopped her from enjoying the transplant, for which she had waited so long. She added that although she worries over her new kidney every day, it is the ankle injury "that has really caused me a lot of emotion, and a lot of being upset and angry and pissed off."

Anna, however, did not identify her fist with anger but with strength and power. We met Anna in her hospital bed, and with her permission replaced the notebooks and devices on the bedside table with foil, markers, yarn, and pipe cleaners. Soft-spoken throughout the interview, she made a foil fist immediately. Anna, a middle-aged white woman, had a liver transplant only weeks before our first interview. She was working as a healthcare practitioner and at first attributed early signs of liver cirrhosis to the fatigue of working in a hospital as the COVID-19 pandemic gripped the globe. Upon being waitlisted, the transplant program encouraged her to seek out a living liver donor. They suggested that she post her story to a social media group where someone seeking to donate a kidney or part of their liver might find potential recipients. A woman in the same medical field found her, and they were a match. But the donor liver was too big, and Anna's gall bladder had to be removed to make room. She also suffered painful fluid buildup in her abdomen (ascites) that would seep through the stitches from the transplant surgery. While still in the hospital, she noticed that her right foot was not responding to her; imaging revealed a fracture in her spine. Her aluminum foil fist stood for everything she had weathered and survived: on the foil, she wrote a pound sign (#), medical shorthand for a fracture; the words "pain," "tears," and "IV" in pink; and in green "fluid buildup," "feeling weak," and "being ignored." The fist bore all that she had endured by virtue of moving through it.

The gesture of the clenched fist carries multiple connotations. It is the beginning of a punch, a hand clenched in rage, and a protest. The clenched fist is a widely recognized gesture of protest and solidarity. One of its earlier appearances occurred in 1917 as a symbol of labor strikes for the Industrial Workers of the World. In 1972, Ms. Magazine published a photo of Dorothy Pitman Hughes and Gloria Steinem with fists raised. Indeed, the clenched fist of the Black Lives Matter movement "root[s] this contemporary moment in the Black Power movement of the late 1960s and 1970s" (Leverette, 2021, p. 4). Ahmed (2017) connects the raised fist to feminist willfulness, "re-signifying the hands of feminism as protesting hands" in contrast to the hand engaged in domestic work (p. 85). The foil exercise's prompt to create a cast of one's forearm and hand invites a necessary consideration of gestures as traces of affect and communication. Gestures "reveal the inscription of social and cultural laws, transforming our individual movements" into accounts of collective experience (Rodriquez, 2012, p. 6). Lisa, Julia, and Christina's casts connect their anger to protest, while Anna's foil cast testifies to all she endured but had not bargained for as part of her transplant. These entanglements of anger, protest, and endurance raise the questions: What is the object of anger? What is being protested, and how? Understanding the affective demands of transplant medicine is essential to grasping the salience of these foil fists. It is these affective demands that make anger difficult to speak, and shape how anger and protest, once surfaced, are circumscribed and dampened.

Affective obligations of curative imaginaries

Anger runs against the grain of transplant medicine's dominant affective registers of gratitude and hope. Gratitude functions as a normative and obligatory response to transplantation for recipients. Transplant recipients, donors, donor families, and medical professionals often refer to transplantation as the "gift of life," making this gift a key metaphor in and outside hospital spaces. References to transplantation as the "gift of life" also adorn clinic walls. In the waiting room of one clinic hangs a quilt whose panels bear notes from transplant recipients, donors, and donor families, offering their thanks, especially to donors and higher powers (Figure 1). Gifts, however, require reciprocation and obligation (Mauss, 2005[1954]), thereby making certain demands on recipients. For Berkhout et al. (2022), these obligations manifest in medical teams' expectations that patients who are wait-listed for transplantation must commit to "full code" status—to being revived via cardiopulmonary resuscitation (CPR), intubation, defibrillation, and medication administration in the event of a medication emergency like cardiac or respiratory arrest. That is, transplant candidates are expected to reject the option to have do-not-resuscitate orders, in order to demonstrate their commitment to the life that transplantation offers, no matter its terms. The affective registers of this commitment to life coalesce around what Shildrick (2015) refers to as the "rhetoric of hope" that "leaves little room for any exploration or understanding of negative affects and emotions that recipients may experience" (p. 21). Heinemann (2020), in her ethnographic work on experiences of solid-organ transplantation in the rural Midwestern United States, similarly describes the hegemonically positive discourse associated with transplantation as a genre unto itself, one that covers over the "more complicated" and "lived" realities of transplantation (p. 1). These emphases on positivity find further connection to transplant technologies (Berkhout et al., 2024). In what Sharp (2014) names "transplant imaginaries," mainstream praise for the technological advancements that make transplantation and xenotransplantation possible fails to acknowledge the "physical and psychic suffering endured by patients" (p. 3).

Talking about transplantation in registers of hope and gratitude is not only socially sanctioned but obligatory. The salience of gratitude appears in an exchange across several issues of the *American Journal of Transplantation*. Poole et al. (2011) published a small qualitative study that questioned the efficacy of the practice of having transplant recipients author thank-you notes to donor families. Their findings at a Canadian transplant center revealed that recipients struggled to write anonymous thank-you notes to "real people" (any personal or identifying information is redacted by a third party to ensure that the recipient and donor families are kept anonymous) and felt significant distress when

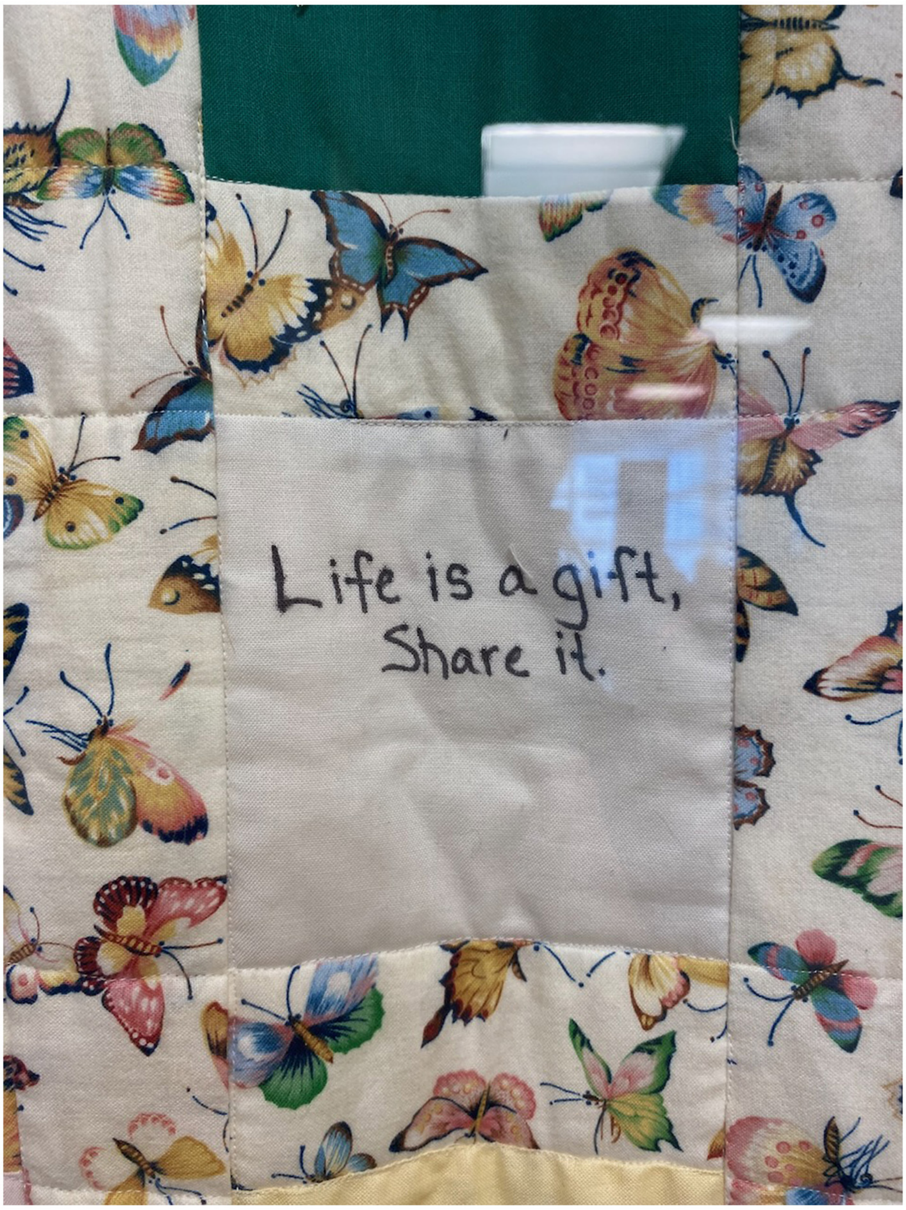

FIGURE 1
A close up of a quilt that hangs in the waiting room of an outpatient transplant clinic. Donors, recipients, and families have written on squares of fabric in permanent marker. The squares are stitched together with panels with a butterfly pattern. The panel depicted reads, “Life is a gift, share it.” Photo taken by Alexandra Vieux Frankel.

notes from donor families were not reciprocated. Poole et al. (2011) conclude that reducing thank-you notes to a technical exercise that limits expression via anonymization is “associated with profound degrees of embodied distress” (p. 621). A letter to the editor, authored by two hepatologists, protesting, stressed that writing thank-you letters was a necessary and cathartic process that relieved rather than induced distress (Selves and Burroughs, 2011). Poole et al. and Selves and Burroughs write from multiple intersections of difference—among them, the former conducting qualitative, multimodal research in Canada, while the latter work in the United Kingdom as practitioners. These different contexts are necessarily also embedded in different power structures, expectations, opportunities, norms, and pressures for narrative (and because Poole et al.’s work is multimodal, also embedded in visual cues). Where and how they collide, however, is most salient here, as they crash in a dispute over the sanctity of gratitude in transplant medicine.

Author and two-time heart transplant recipient Amy Silverstein references similar expectations of gratitude in her *New York Times* guest essay, which was published shortly before her death in 2023. She writes: “Only in transplantation are patients expected to see their disease state as a ‘miracle.’ Only in transplant is there pressure to accept what you’ve been given and not dare express a wish, let alone a demand, for a healthier, longer life” (Silverstein, 2023). The op-ed focuses on stagnation in the development of better immunosuppressive medications for transplant recipients.

Required to prevent a transplant recipient's immune system from rejecting the transplanted organ, immunosuppressants also increase vulnerability to bacteria and viruses, increase cancer risk, and can cause kidney damage. Pressure "to see their disease state as a miracle" references the affective demands that curative imaginaries make in transplant medicine.

Anger emerges as a break from affective expectations—as an alien affect (Ahmed, 2010) in solid-organ transplant medicine. Ahmed (2010) develops the concept of "affect aliens" in her discussion of "happy objects" and how the institution of the family "sustains its place as a 'happy object' by identifying those who do not reproduce its line as the cause of unhappiness" (p. 30). Although Ahmed writes in terms of "affect aliens"—those subjects who refuse to reproduce happy objects—here we draw attention to how affects themselves are made to be alien. "Happy objects" refer to objects of desire. Berlant (2011) discusses happy objects in terms of objects of desire that constitute a "cluster of promises" (p. 23). Happy objects are not necessarily discrete or physical. The happy object, therefore, is not the donor organ itself but the socially associated fantasies of curative imaginaries that are a compact of medical models of cure. That is, the promises of curative imaginaries constitute happy objects, and this affective alignment manifests in normative expressions of hope and gratitude. The vocabularies of desire and promise that Ahmed and Berlant employ are thus especially apt in solid-organ transplantation where curative imaginaries promise a return to health and consequently the erasure of illness and disability (Kafer, 2013; Clare, 2017). While alignment with happy objects yields happy affects, alien affects move in a different direction and thereby contest the sanctity of the happy object. In Ahmed's analysis, queer figures emerge as affect aliens who do not reproduce the imagined norms of the nuclear family. This refusal constitutes a "queer art of failure," the celebratory failure to be pressured and disciplined into embodying heteronormativity (Halberstam, 2011). Those who express alien affects reject these relations and consequently risk alienation from their objects of desire.

But alignment with the promises of curative imaginaries does not necessarily lead to their realization. Curative imaginaries in transplant medicine can unfold in what Berlant describes as "scenarios of cruel optimism." Cruel optimism refers to the ways in which attachment to objects of desire also produces distance from those desired outcomes. We may contrast "scenarios of cruel optimism" with "ordinary notions of repair and flourishing" to reveal how our attachment to unrealizable forms of healing can produce harm (Berlant, 2011, p. 49). The tighter one clings to those vaunted scenarios and promises, the more disheartening and painful the outcomes become. Eli Clare describes the yearning for cure as a "connection to loss." Clare (2017) writes, "What we remember about our body-minds in the past seduces us. We wish. We mourn. We make deals. We desire to return to the days before immobilizing exhaustion or impending death, to the nights 30 years ago when we spun across the dance floor" (p. 57). This form of yearning turns to the past to imagine a future (Clare, 2017), neglecting the ways in which thriving, adapting, and learning unfold in the present.

Project participants often expressed being pulled in multiple directions by grief and yearning. Lisa explained that although her transplant surgery took place more than six years before the interview, she still sometimes feels as though it had happened yesterday—with her fear and anxiety still raw. Anna similarly expressed that her transplant experience unfolded in ways that were wrought with grief. An ultrasound conducted after her surgery brought her to tears. It took three hours for the technician and later the doctor to determine whether blood was indeed moving through the newly transplanted liver. Although she was not explicitly told the reason for the lengthy ultrasound, her experience in healthcare allowed her to piece together what was going on: blood was not moving through the liver and the graft might be lost. Although the ultrasound ultimately found blood flowing and she was discharged from the hospital weeks later, her grief lingered.

In an atmosphere that insists on gratitude and hope as transplant's natural corollaries, how do we understand alien affects such as anger? On the one hand, we may associate so-called negative feelings with complications—that is, so-called negative affects emerge only when curative imaginaries remain unfulfilled. But this narrative acquiesces to the terms of curative imaginaries by reproducing an equivalency between health and "positive" affect. On the other hand, to reject curative imaginaries can risk refusing all medical interventions—interventions that are desired, that have pull, and that can be lifesaving. Yet, as Clare (2017) writes, "the promise of cure can also devalue our present-day selves. It can lead us to dismiss the lessons we've learned, knowledge we've gained, and scars acquired" (p. 61). That is, cure can engender multiple forms of erasure, including of one's own experience.

Affirming "negative" affect

Normative affective registers sustain transplant medicine's curative imaginaries and fail to make space for negativity—for the recognition of worry, pain, and grief. The social model of disability has been particularly attuned to refuting medical narratives that equate disability with tragedy. The social model shifts attention from individual bodies to the ways in which disability is produced through built environments, providing a necessary correction to medical models that pathologize disability and cast it as needing cure or eradication (Clare, 2017; Siebers, 2008). As a response to the "history of debilitating classifications" endured by bodies with disabilities (Snyder and Mitchell, 2001, p. 374), the social model and its rejection of tragedy results, however, in a lack of attention to lived experience, to phenomenologies of disability. In refusing to engage with tragedy and felt experience, the social model of disability, like the medical model, implicitly likens tragedy to negation and deficiency (Abrams and Adkins, 2020).

Critical Disability Studies' grapplings with negativity can radically redefine tragedy itself. Abrams and Adkins (2020) articulate tragedy as a matter that affirms life rather than negates it. This redefinition of tragedy creates space for dwelling with bodymind pain without reproducing curative imaginaries' harmful associations of disability with tragedy. Abrams and Adkins develop their understanding through an analysis of a Canadian clinic working with families whose children have been diagnosed with Duchenne Muscular Dystrophy. Their term "tragic affirmation" draws on Nietzsche's writing, based in a philosophy of life that relies on neither pessimistic approaches to tragedy nor optimistic ones that avoid discussion of tragedy altogether. Instead, tragedy features as a part of life—not an interruption of it. Abrams and Adkins expand tragic affirmation through their engagement with Spinoza (1994; E4P18S) and Sharp (2011): they build on Spinoza's understanding that bodies cannot be apprehended a priori but must be addressed in context; and on Sharp's attunement to the ways in which power and agency extend beyond human bodies to more-than-human assemblages. As a result, tragic affirmation works against abstract equations that both identify tragedy with disability and "obscure the actual affective relations at work" (Abrams and Adkins, 2020, p. 12).

Tragic affirmation prompts a reconsideration of "negativity" itself. Rather than an attitude that eradicates, removes, or lessens one's vitality, so-called negative affect and experience can instead give rise to sources of life-giving connection. This rearticulation of tragedy builds on reckonings with pain and grief in Critical Disability Studies (although not necessarily in direct conversation) that do the work of articulating the affective relations, atmospheres, and flows entangled with disability. Bodymind pain, while *painful*, is also a source of knowledge and community (Patsavas, 2014; Lau, 2020), and can thereby mitigate the objectifications of ongoing medicalization (Jain, 2013). Patsavas (2014) locates this kind of knowledge in cripistemologies of pain, where cripistemology, a combination of the terms crip and epistemology, refers to "a process of knowledge production that situates pain within discursive systems of power and privilege" (p. 205). Cripistemologies of pain push against the individualization of pain and instead foreground pain as "shared and shareable" (2014, 215). Crosby (2019), similarly, calls for greater attention to experiences of grief in Critical Disability Studies, not as a negation of disability joy, but as part of a refusal to partake in expected narratives "of healing and renewal that end in suffering redeemed" (p. 619). Smilges (2023) describes such feelings in terms of "crip negativity," which calls attention to "the many bad feelings that disabled, debilitated, and otherwise non-normatively embodyminded people encounter with some regularity: pain, guilt, shame, embarrassment, exhaustion, fear, and anger" (p. 9), while simultaneously critiquing pushes to look toward the future. Indeed, Crosby (2019) draws on Benjamin (1968)'s figure, the Angel of History, who looks backwards at crisis and devastation as a way of moving into the future.[2] The Angel of History complicates narratives of historical progress, and thereby the belief in cure and technological fixes that propose futures devoid of disability (Kafer, 2013).

These works underscore multiple ways of making room for tragedy, whether in the form of pain or grief. They highlight how tragedy can be rendered as a source of knowledge, a source of connection, and as a way of protesting curative imaginaries, while simultaneously pushing back against the false equivalency between disability and tragedy as negations of life. Such reformulations prompt new observations on the ways in which research participants in this project literally and figuratively handled their anger. That is, research participants engaged in work that embodies the theories we discuss: experimenting with how to make space for anger and how to articulate those experiences and feelings that—while not uncommon—find little expression in "rhetorics of hope" (Shildrick, 2015) and yet may lead to generative connections.

Yet, the space that these participants made for negative affect were carefully partitioned. Lisa, shortly after declaring that she was angry and had made a fist, asked, "Can I break the cast?" Her own forearm had gotten hot in the process of molding the foil around it and her closed fist. After removing the foil from her arm and placing the cast on a blank sheet of paper, she traced the cast's outline in blue and pink, and shaded blue the place on the page that corresponded to where she felt heat (Figure 2). To her, blue was colder and associated with water that she, as a lifelong swimmer, found comforting. She colored the page to change her body's state. She then tore up pieces of pink tissue paper and carefully placed each piece on the fist that she had ripped from the cast forearm. "I only wanted it [my anger] in a spot. I don't want it spilling out anywhere. It has to stay like this pink, it has to stay here…it [the tissue] was softening it, it [the anger] was making it so harsh." Lisa used the mark-making materials available to ameliorate the anger and heat that she felt—and, more importantly, to isolate the anger and keep it from contaminating the rest of the cast and her transplant experience.

Julia similarly used color to intervene in the anger that her clenched fist cast materialized. She placed the foil fist on the left edge of a poster-size sheet of white paper and used tempera paint to cover the entire sheet and foil sculpture. Her forearm was painted black. The color stopped abruptly at her wrist where she started using long green brush strokes. Below her forearm were swirls of blue. And above it, long strokes of yellow and orange with a large block of green to the right (Figure 3). She explained, "I felt like my soul was being drained away." She continued, "that [is a] fist of anger, and it's like often sometimes that black cloud that can sit over you sometimes with the illness." This black cloud as a dark space was doubly significant, as she developed a fear of the dark during the hospital stay for her first kidney transplant, a fear that she connects to the uncertainties of falling in and out of comas. The vibrant green, blue, yellow and orange created boundaries around the fist.

Participants used the materials to fence off the angry affects that emerged in the foil exercise. Lisa softened her anger with pink tissue paper. Julia flattened her fist and painted it green. In each of these instances, the materialization of anger was acted upon to ensure that it did not spread. Christina ripped the foil cast in two at the wrist. She crushed one half of the foil into a ball and the other half she carefully flattened, working to smooth it against the table. The crumpled fist, she said, was where she was, and the smoothness where she wanted to be.

In each of these instances, the clenched fist, as anger, was not desirable and it contrasted with desired affects expressed in the softness of pink tissue paper, vibrant colors, and smooth and open qualities. Such contrasts enabled participants to create material fences around their anger. Participants' boundary-making practices—the need to soften and materially contain and separate anger—suggest that they can be rendered as sources of pollution or contamination. Treating anger in this way positions it as *matter out of place*, as something that falls outside established cultural orders and poses a threat to them (Douglas, 2003[1966]; Lugones, 1994)—in this case, a threat to dominant transplant imaginaries and their affective regimes. Boundary-making practices

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[2] For a discussion of the present in crisis imaginaries, see Wong-Mersereau (2023).

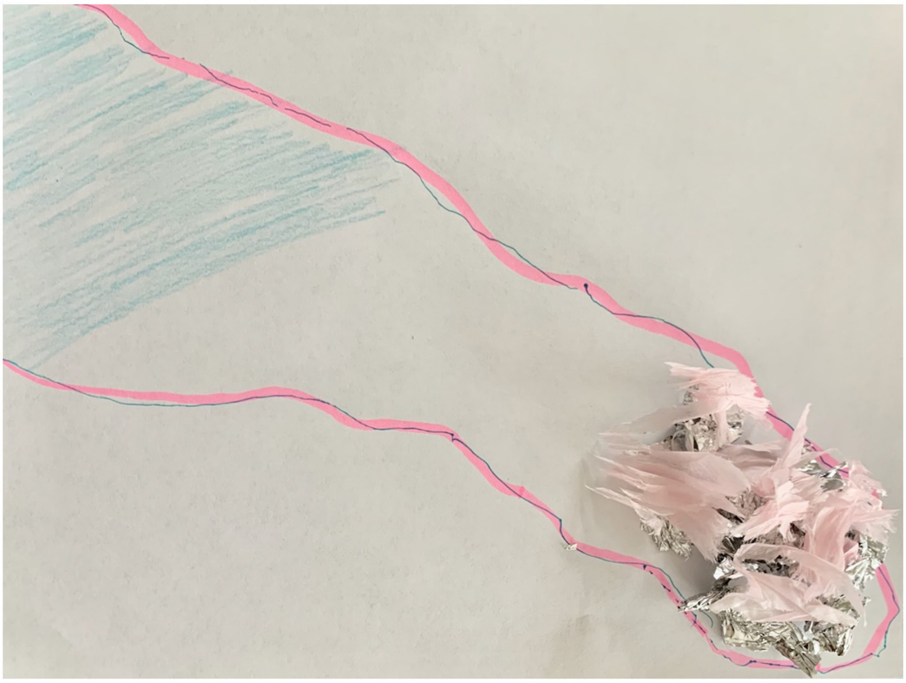

FIGURE 2
An outline of the participant's forearm and hand drawn in blue pen and pink highlighter. In one corner, near the elbow, the participant filled in the outline with a light blue pencil. At the other end, in the outline of the fist, sits a pile of torn up foil (from the cast) and small pieces of pink tissue paper on top. Photo by participant.

FIGURE 3
The participant painted the forearm in black, flattened the fist, and surrounded it with bright blue, green, yellow, and orange. These colors spill off of the foil and onto the large sheet of paper beneath it. Photo by Alexandra Vieux Frankel.

do the important work of creating space for anger in transplant's hegemonically positive affective economies. In so doing they also reaffirm how curative imaginaries position angry affects outside of socially sanctioned affective ecosystems in solid-organ transplantation. Separating matter out of place preserves the purity of social order. That is, the act of cordoning off anger and illness reinforces problematic associations of cure with joy. Participants' transformed clenched fists embody alien affects while simultaneously reproducing the very affective expectations that they protest. Here, curative imaginaries of transplantation are preserved at the same time that they are critiqued. As a result, anger is rendered separate from hope and gratitude.

Participants' initial clenched fists embody gestures of protest. But they also reveal an attachment to objects of desire. The clenched fist "is not merely a symbol of defiance" but also something that, like happy objects, "links subjects to their objects of desire" (Longford, 2020, p. 287). Fists can signal an orientation toward the future, connecting to the hope and gratitude that curative imaginaries sanction. And while a health-giving attitude, hope and gratitude can also become a source of harm when the attitude stigmatizes, erases, and fails to make room for anger and other so-called negative affects. In looking forward with hope, the fist can also signal relations of cruel optimism. Christina's meditations on her transplant experience, after making her foil cast, illustrate the challenges of navigating this charged affective terrain: "My kidney is doing great. I'm thankful for that. That was the main goal." But she immediately follows it with, "It's this [broken ankle] that has really caused me a lot of emotion, and a lot of being upset and angry and pissed off." Just as in the foil exercises, anger is distanced from the transplant itself. But her anger around transplantation becomes stickier, more complicated, as she adds, "I worry about my kidney every single day. I'm assuming that's normal, but I haven't had a bit yet where I haven't been able to not worry about it, because as soon as I went into rejection it's been crap." Christina works to hold gratitude alongside the "crap": the complications and isolation she endured. Here, she wrestles with how to refuse the affective impositions of transplant medicine's curative imaginaries, while also minimizing (if not eliminating) her alienation from the promises of curative imaginaries. Her broken ankle and graft rejection are named as sources of negative affect—of alien, angry affects. Alternately emphasizing one over the other, we hear her struggle with her loyalty to affective regimes and expectations of curative imaginaries.

The stakes of preserving positive affects are high. Institutions associated with transplantation, whether hospitals, professional associations, or recipient-donor networks, rely on the reproduction of positive affects. Positive affective atmospheres communicate the importance of solid-organ transplantation as a life-saving intervention which purports to eradicate illness. Within solid-organ transplant circles, many worry that expressions of unwelcome outcomes might diminish donor pools and enthusiasm—and thereby undermine the very structures that make transplantation possible (Bartlett, 2023). Participants in our study regularly noted their volunteer work to increase voluntary donation and raise awareness of organ donation, whether through the hospital itself, various organ-specific organizations, or other transplant networks. They are actively engaged in the labor of ensuring that access to transplantation, as imagined through increased donor pools, continues. In this context, finding ways to fence off anger means that participants can express anger—can make room for tragedy, grief, and pain—while still enacting affective regimes that support the enterprise of transplantation.

Conclusions

How anger is talked about in transplant medicine is inextricably tied to how cure and disability are discussed and imagined. Curative imaginaries in solid-organ transplantation make affective demands on recipients. These imaginaries are wrought with references to transplantation as a "gift of life," a "miracle," and a "pinnacle of hope." Indeed, while transplantation can be a life-saving intervention for many, the affective ecosystem of its imaginaries inhibits acknowledgment of anger and grief, compounding these feelings with shame and embarrassment. As a result, expressions associated with these states come to represent alien affects, those affects that are not aligned with their objects of desire—in this case, promises of cure (Ahmed, 2010). Further, attachments to curative imaginaries can result in scenarios of cruel optimism (Berlant, 2011), where the tighter one clings to promises of a return to health, the greater the distance between onself and the realization of that promise of health. Silverstein (2023) references such relations when she describes organ transplantation as one of the few situations in which individuals are expected to "see their disease state as a miracle."

It is significant that participants who expressed these alien affects most often did so through the gesture of a clenched fist. Participants started the foil exercise after verbally reflecting on their sensory and embodied transplant experiences, at which time they were invited to choose a gesture that spoke to their experiences and then form an aluminum foil cast around this hand and forearm gesture. Clenched fists emerged again and again. The fists are notable for their associations with protest and solidarity. These aluminum fists embodied demands for recognition of the pain and grief that were part of their transplant experiences but not reflected in the dominant public discourses. As a result, when anger emerged, it first emerged non-verbally, as a fist. But the fists were not all-out rejections of curative imaginaries. Using the foil and other materials present, participants intervened in their anger. They cordoned it off, creating borders around it that would prevent it from seeping into the rest of their foil sculptures. This practice of boundary-making mirrored the interview transcripts, as participants often expressed anger with the caveat that they were grateful for their transplants despite being angry. Boundary-making, thereby, became a way to express alien affects while simultaneously participating in the reproduction of transplant's affective ecosystems.

Neither participants' verbal nor material expressions of anger necessarily embodied tragic affirmation, although their maneuvering to make space for anger does similar work in theorizing how to make anger speakable. Tragic affirmation offers a way to grapple with pain and grief by asserting tragedy as part of life, rather than a negation of it. Indeed, the concept challenges the notion of negativity as negating, showing instead that the negative can also be creative, generative, and cumulative. This is a crip move, a subversive appropriation of tragedy that is turned against the narratives and attitudes that cast disability as tragic and needing eradication or cure (Hamraie and Fritsch, 2019). Tragic affirmation enables anger and other alien affects of transplantation to be understood as life-affirming. *Casting* tragedy as part of life provides important opportunities to explore anger, grief, and pain, while simultaneously acknowledging the harm that curative imaginaries produce. In this way, tragic affirmation invites an exploration of radical ambivalence, the sticky and messy affects involved in seeking medical intervention, while still maintaining a critical eye on curative ideologies, their promises and implications.

Data availability statement

The datasets presented in this article are not readily available because this research generated ethnographic data that includes confidential and highly contextual information. Requests to access the datasets should be directed to frankela@yorku.ca.

Ethics statement

The studies involving humans were approved by University Health Network-Toronto General Hospital. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

AVF: Conceptualization, Formal analysis, Methodology, Writing – original draft, Writing – review & editing. E-MS: Conceptualization, Formal analysis, Methodology, Supervision, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Present(ed) bodies, absent agency: "patients' perspectives" at the Museum Vrolik of the body and medicine

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Medical exhibits are complex spaces, especially when displaying human remains. This research focuses on Amsterdam's Museum Vrolik, a prominent museum of the body and medicine in the Netherlands with an important role in the conservation and exhibition of the material heritage of Dutch medicine of the 18th and 19th centuries. I am interested in the affective encounters that are at play in such a setting between us—the living—and the remains on display: How the agency and subject-hood of those who lived and live with ill health, medicalization and disability are effectively present and absent in the context of affective influences in the Museum Vrolik. I deploy the concept of "patients' perspectives" as a conceptual tool for looking at those who have been impacted by medicine's medicalizing gaze and handling. Their presence/absence is investigated by using embodied inquiry to attend to the affective encounter between the audience and the bodily remains on display, as felt through the embodied experiencing of visiting the exhibit and mediated by the cultural, physical and institutional context and curation of the Vrolik itself. To analyze the resulting data, I take the museum as a site of storytelling with its curatorial techniques and texts acting as narratological frames and "orientation devices". The most central pattern emerged as a dissonance between the affective orientation I bring into the space due to my own situated-ness and the orientations prompted by the museum's frames. The remains on display have been decontextualized from their original home as a part of someone, and transformed into "specimens". At the same time, my lived experience and identity as a person with chronic illness brought an impulse/intensity towards identification and closeness to the "specimens", grasping for a sense of their agency, voices, perspectives, personhood. To move forwards from here, persons with disabilities, illness, bodily differences, impairment and injury need to be included and recognized in their capacity as knowers, as having vital embodied knowledge via their lived experience, as narrators and subjects in the stories that are told.

KEYWORDS

affect, embodiment, medical museums, illness, disability, narratives, critical health humanities

1 Introduction

Medical exhibits are complex spaces, especially when displaying human remains. This research focuses on Amsterdam's Museum Vrolik, a prominent museum of the body and medicine in the Netherlands with an important role in the conservation and exhibition of the material heritage of Dutch medicine of the 18th and 19th centuries. Originally based on the anatomical collection of physicians Gerard (1775–1859) and Willem (1801–1863) Vrolik, it is now located on university hospital premises. While it still fulfills some of its original function as a site for medical education, over time it has become self-aware of its role as preserver of material heritage and seeks to respond to a broader public interest in the history of medicine. It has also begun engaging with issues surrounding the collection and display of human remains—particularly by investigating the colonial past of some of the collection. With the Vrolik's main display still consisting mainly of historical (largely human) specimens, it highlights some of the key tensions inherent in medical museums: Navigating a collection with problematic origins, seeking to stay relevant as a site for research and education, while also trying to welcome broader audiences and responding to contemporary debates on health and heritage (Arnold, 2004).

As a researcher, audience member and chronically ill person, I am interested in the affective encounters that are at play in such a setting between us—the living—and the remains on display. Following Porter's (1985) epistemic critique of medical historiography overlooking the "patient's view", my research focuses on *how the agency and subject-hood of those who lived and live with ill health, medicalization and disability are effectively present and absent in the context of affective influences in the Museum Vrolik*. I do this by examining how our encounters in the Vrolik move us and are mediated, giving us an "orientation" (Ahmed, 2006) towards seeing through certain eyes by "foregrounding" and evoking empathy and identification with certain perspectives rather than others. This research builds on a phenomenological interest of prioritizing lived embodied and sensory experiencing, as well as a concern with the "liveliness of matter" (Truman, 2019, p. 2) as centered in feminist new materialisms. To fundamentally incorporate the understanding of knowledge as corporeal and situated, embodied experiencing becomes a source of data in the act of empirical research. This led to using the method of embodied inquiry (Brown and Leigh, 2021) allowing me to draw on my own embodied and sensorial experiencing in the museum as data for analyzing its affective, emotive, visceral and empathetic entanglements. This meant exploring how I am "placed" and encouraged or discouraged to place myself in relation to the objects/specimens/bodies in the exhibit via the mediating practices of collecting, preparation, curation, presentation and narration in the museum context. These mediating practices and the affective data generated through embodied inquiry are further interpreted as stories. Analyzing the data with narratological tools allows me to untangle the museal encounter as a co-authored experience between the audience, the curators, the displayed remains themselves and the historical anatomists. This enables me to search for "patients' perspectives" by examining the mediating "frames" that "orient" us towards particular "perspectives", or "points of view", thereby making sense of my affective responses.

This research can be situated in the field of medical and health humanities which emphasizes the agency, subject-hood and essential role of those experiencing illness, disease, disability, impairment and medical treatment. The humanities have also been credited with impacting the practice of modern anatomy towards a more humanist approach (Štrkalj, 2014). Moreover, academic and scholarly sidelining of these experiences has also been increasingly addressed and counterbalanced in the practice of medical historiography (Stolberg, 2011), disability studies, activist history, mad studies, "crip theory", critical health humanities, and innovative projects in the history of medicine, illness and disability (Davies et al., 2021). One approach involves the collection and display of innovative source material, such as recordings of psychotherapeutic sessions, private personal effects, journals and autobiographical material of ill or disabled persons of the past (Birdsall et al., 2015; Davies et al., 2021; Scarfone, 2020). However, many such archival projects prioritize not only the gathering and writing of history *about* the ill and disabled, but actively collaborate on such research and writing *with* them, as seen in projects such as DisPLACE (2022), After the Asylum (2019) and History in Practice (Davies, 2014). Furthermore, many scholars are engaging with topics of health, illness, disability, healing, medicine and history with the insight of their own lived experiences (Brown and Leigh, 2020; Toombs, 1992). This larger shift is also taking place in the case of museum exhibitions, such as "Bedlam: The Asylum and Beyond" (Harris, 2017) which incorporated ill persons' narratives as well as their artwork and reflections; "Misbehaving Bodies: Jo Spence and Oreet Ashery" in which the artists contemplated their own experiences of care and illness (Vasey, 2020); and "Medicine and Treatment" which included the sharing of personal experiences and stories of being on the receiving end of medical treatment (Bond et al., 2021). These examples illustrate the shift away from an exclusively medicine- and doctor-centric view, towards centering those who were and are experiencing illness, disability, and practices of healing and medical treatment. Throughout this research, these strategies and approaches served as reference points and helped broaden my perspective for what is possible and achievable in the context of a "medical museum".

The Museum Vrolik itself has already been concerned for some time with many of the issues raised in this paper, is engaging in research on several of them and seeks to change the exhibit in the near future to actively include more marginalized perspectives. Here, I hope that my critique can serve to highlight affective and empathetic responses in addition to cognitive engagement. To acknowledge specimens as not merely transparent vehicles for (anatomical) knowledge renders them more resistant to classification and objectification, freeing them from exclusively scientific frames. At the same time, persons with disabilities, illness, bodily differences, impairment would also need to be included and recognized in their capacity as knowers, as having vital embodied knowledge and epistemic authority, and thus be an explicit part of such a transformation process. This article is thus a starting point for working with the Vrolik to develop new (narratological) framings and curatorial practices with the potential of dismantling common hierarchies embedded in the production of knowledge, and contributing to making the experiences of historically "othered" groups more present.

2 The Museum Vrolik case study: from cabinets of curiosities to museums of medicine

The chosen case study—the Vrolik—is situated in a broader history of medical museums in Europe. Its practices, both historical and contemporary, are in conversation with others in the Netherlands and beyond. The origins of contemporary European medical museums can be traced back to the Renaissance and early Modernity, when "medical men" began to accumulate their own collections of "curiosities" and "materia medica" in their workplaces and homes (Arnold, 2004, p. 146). These were sites of research and experimentation, and over time, the collected materials became an integral part of medical education and training, which gave birth to many medical collections attached to medical educational institutions. Such collections were not merely "neutral" sites of education and research, but were entangled in evolving cultural and sociopolitical histories. They emerged at a time when the body was seen as uncharted territory, awaiting exploration and discovery via scientific inquiry and dissection (Sawday, 1995). To be delineated, named, and categorized: "Like the Columbian explorers, these early discoverers dotted their names, like place-names on a map, over the terrain which they encountered" (Sawday, 1995, p. 23): the Fallopian tubes, the Eustachian tube, the pouch of Douglas. Thus, the body in pieces, embellished by the craftsmanship of dissection and preparations of conservation and display, found itself behind glass or on pedestals as trophies or treasures, along with botanical, mineral or other natural matter. "The quantity and diversity of specimens assembled inside these "cabinets of curiosities" became a symbol of status for their owners" (Davidson, 2021, p. 79), demonstrating one's culture, wealth, travels, and access in the emerging and burgeoning fields of natural history and natural philosophy. In many cases the human remains and objects that were gathered, studied and used formed part of European imperial and colonial projects. In the case of human remains these often acted as material evidence supporting theories of racial difference and reinforcing racist and ableist ideals. This was also the case for Museum Vrolik, where about 8% of the human remains came from the colonial context (de Rooy, 2023).

Museum Vrolik is based on the collections of the anatomists and physicians, father and son, Gerard (1775–1859) and Willem (1801–1863) Vrolik (de Rooy and Van den Bogaard, 2009). As scientists, collectors and preservers, the Vroliks kept their original collection at their home in Amsterdam. After Willem's death, it was bought and then donated to what is now the University of Amsterdam, and since the 1980's it can be found as part of the Academic Medical Centre, which includes the university hospital affiliated with Amsterdam university. Until the 1950's, while being used as a medical laboratory, many successive anatomists of the university contributed to the collection (de Rooy and Van den Bogaard, 2009). Currently the museum "takes care of about 25,000 objects. The permanent exhibition comprises over 2,000 of these objects" (Visit the Museum, 2024). Over the course of the 1990s, the teratological specimens were cataloged (Oostra, 2009) and a series of articles was published in the "American Journal of Medical Genetics" reevaluating the specimens with congenital anomalies from a contemporary genetic and medical perspective (Moorman, 2009), reinstating the collection's contemporary research value. Presenting itself as a "historical museum of the human body", the Vrolik prides itself mainly on its human (and to some extent its other animal) anatomical preparations, consisting of "wax models, plaster models, anatomical preparations in liquid, dried anatomical preparations injected with wax and dried skeletons and skulls" (About the Museum, 2024). Although not found on display, the museum also contains in its archive: glass slides and photographic negatives, antique medical objects, tools and instruments of Amsterdam hospitals and the medical faculty, as well as materials of dentistry and botany (Collections, 2024). As with other collections, a lot of the animal specimens had been split from the original collection. Many of these are now back on display at the Vrolik as a loan from Naturalis Biodiversity Center in Leiden to better represent the collection's historical makeup.

In 2012 the Vrolik reopened after a major restructuring of its permanent exhibit, with the intention of making the exhibit more accessible and engaging to a wider audience than the medical and scientific researchers and students that had been its main audience (de Rooy and Moorman, 2011). At the time of my visits over the spring and summer of 2022, the museum was still in process of creating its identification guides, which name and explain all the specimens and objects on display, following its declared intention for accessibility to a broader lay audience. The Vrolik's main display still consists almost exclusively of historical specimens, making it both a typical medical collection that is engaged with current debates and yet choosing different modes of engagement from other institutions of its kind.

3 Theoretical framework

3.1 Patients' perspectives

British historian Porter's (1985) essay, *The Patient's View: Doing Medical History from Below*, is a critique of the conventional, physician-centered historiography of medicine. Porter advocates an alternative, pluralist account of the history of medicine, one that fundamentally includes the "patient's view", with the ultimate goal of broadening the field towards a history of healing, health and illness. His efforts towards building this "history from below" start with outlining the historical misrepresentations involved in the "implicitly endorsed […] view that the history of healing is par excellence the history of doctors" (Porter, 1985, p. 175). The medical encounter is an (at least) two-person affair of the doctor and "patient". Medicine as a field of scientific knowledge and practice owes its existence to patients' health and sickness and to their material bodies for research and treatment. Porter suggests that the medical establishment produces "histories of itself essentially cast in the mold of its own current image" (Porter, 1985, p. 175). This re-frames the telling of history as something beyond the account of what occurred, and highlights the bias involved. This informs my current project by pointing to a gap in institutional knowledge and by encouraging me to actively search for "patients' perspectives" with an attentiveness not only towards what is present (ed), but also towards what is absent. This includes other concerns, beliefs and practices around health than those included in physician-centered histories of medicine. Porter notes the example of how health was a communal concern rather than an individual matter confined to institutionalized or medicalized roles. Furthermore, taking the diversity of experiences, practices and forms of knowledge about health and healing into account can also serve to humanize the establishment of medicine itself as consisting of people, themselves vulnerable to illness, disability or injury, in mind and body.

Despite the theoretical and historical importance of Porter's essay, at times his approach to the "history from below" lacks intersectionality. His claim that "pain has been even-handed enough to visit the rich, educated, and visible scarcely less than the poor" (1985, p. 183) overlooks the immense specificity of the experiences of ill-health based on people's literacy, education, class, and social, ethnic and gender identities. While anyone can fall ill, those who are in precarious socio-economic positions, people of color and people of marginalized identities are disproportionately more likely to experience ill-health, as well as complicated and often negative encounters with medical professionals and difficulty in accessing treatment (Epstein, 2007). Everyone can fall ill, however there are plenty of illnesses that only occur in those who have uteruses and for which medicine still grapples with addressing. Anyone could be or become disabled, but if you have the means and social capital to receive care, assistance and access, then living with disability will look radically different.

A history of medicine/health that does not consider these intersections fails to truly be a history from the actual diversity of "patients' perspectives" and falls into issues similar to those Porter tries to criticize. If we fully consider the implications of gathering overlooked histories, of those who were excluded from the master narratives of medical history, then it must be intersectional. The many histories of the ill, of the disabled, of the neurodiverse, of marginalized genders, sex, ethnicities and socioeconomic classes are not separate nor mutually exclusive, and taking this into account can only enrich our collective understanding, nuance and (situated) knowledge (Haraway, 1988). Taking an intersectional approach that inquires into the dynamics of social power of the past is not about "castigat(ing) the sexism, racism, and other-isms of our forebears" (Bynum, 2008, p. 4) as some medical historians complain. It is about taking a critical eye towards those whose voices were or are idolized in contrast to those whose voices were excluded from the public discourse or production of authoritative knowledge and who's perspectives take dedicated work to bring to light today. It means including an awareness and a questioning of these very dynamics of power and oppression into our historiographical processes. To mark this conceptual shift, I employ the plural "patients' perspectives" over Porter's singular "patient's view".

3.2 A note on language and terminology

The term "patients' perspectives" is not the most applicable when we wish to center the diverse perspectives of those experiencing illness, disability, impairment, injury, etc. Using the word "patient" places ill and disabled people into exclusively medical terms, and medicalizes those who may not be or see themselves as patients. It also overshadows those who are undiagnosed, or struggle to even access the status of "patient". Furthermore, it reinforces the false doctor-patient binary, wherein doctors are not seen as beings who experience health and ill-health within their own bodies, as well as the dichotomy between health and illness/disability, which are not mutually exclusive categories. Moreover, illness and disability can be both overlapping or entirely separate experiences (Wendell, 2001), and one can experience differing health or ill-health on multiple dimensions, be it mental, physical, emotional or social. On an existential level, health, illness, pain, healing and medicine are ubiquitous, universal to the human experience. And yet, when being ill, chronically ill, injured or disabled forms a defining part of one's life, these experiences are immensely specific and fall outside of dominant norms and expectations.

For the purpose of this research, I nonetheless deploy the term "patients' perspectives" as a conceptual tool for looking at those who have been medicalized by virtue of their bodies being handled and treated by medical practitioners, whether in life or only posthumously, and whose remains are the objects of the medical museum in question. It is also worth noting that many of these bodies were not necessarily patients of the doctors or scientists who made use of their remains. These were acquired post-mortem, and may or may not have had a direct connection to the medical practitioners themselves prior to their death. As such, "patient's perspectives" serves as a conceptual tool that holds a diversity of perspectives within it, defined in this particular research by their being on the receiving end of a process of medicalization and medical objectification.

3.3 Affective encounters

The second foundational impetus of this research is a phenomenological interest in centering lived, embodied, and sensory experiencing as sources of knowledge and meaning-making. On the one hand, this serves to elevate the epistemic authority and value of those with illness and disabilities as "knowers" in matters of health, illness, disability and the body. This applies to the present as well as the past, thereby asserting their crucial role in the history and historiography of health and medicine. On the other hand, it also informs the theoretical and analytical approaches towards searching for "patients' perspectives". Their presence/absence is investigated by attending to the affective encounter between the audience and the bodily remains on display, as felt through the embodied experiencing of visiting the exhibit and mediated by the cultural, physical and institutional context and curation of the Vrolik itself.

By examining affective encounters between bodies, I prioritize the forces and intensities that move them, that impact and transform them, that affect their becoming (Truran, 2022). Affect does not quite belong to one body or another, but rather "it emerges from encounters between them that impede or facilitate either's ability to act, *to be*" (Ingraham, 2023, p. 3). Through these encounters we find and situate an affective realm involving all body-entities as well as the space itself—animating even seemingly inert materiality with a "liveliness of matter" (Truran, 2019). Following feminist new materialisms, materiality "is always more than "mere" matter: an excess, force, vitality, relationality, or difference that renders matter active, self-creative, productive, unpredictable" (Coole and Frost, 2010, p. 9). This conceptualization enables me to approach the bodies on display with an acknowledgement of their potentiality for agency, action and animacy; for what they can do, be and become; thereby blurring the boundaries between bodies as subjects and objects.

In her work on emotions, Sara Ahmed "connects lived experience, emotion and affective contact" (Truran, 2022, p. 29) by conceptualizing how "we are affected by "what" we come into contact with" (Ahmed, 2006, p.2) and how emotions "create the very effect of the surfaces or boundaries of bodies and worlds" (Ahmed, 2004, p. 117). Using the phenomenological concept of orientation, she highlights how emotions occur in the "contact" between bodies and thereby also shape how we approach, face, move and "turn" "towards" or "away" from them. She especially attends to how histories shape how we arrive to an encounter, how we "place" ourselves and are "placed" in relation to other bodies/objects. "Concepts, ideas, attitudes, are "sticky" with emotions and affects, so that we inherit or incorporate ideas that are not fully conscious and not our own" (Truran, 2022, p. 30). In this sense, emotions gather and "stick" to certain bodies/objects/subjects in an accumulation of instances, therefore influencing and being influenced by the social, collective and political. In this way, history and historiography play a vital part in mediating our present encounters: "it matters *how* we arrive at the places we do" (Ahmed, 2006, p. 2). In the context of the Vrolik, this allows me to attend to how I arrive at the museum, as well as how the context of the museum gives orientation to my affective encounters within it.

4 Methodology

This section explains how this research uses Embodied Inquiry to move from the affective encounter to creating usable data, which can be patterned and analyzed. The resulting data consists of my observed embodied experiences and rich descriptions of the exhibit, the textual material provided in the exhibit and museum website, and the historical and institutional context surrounding the exhibit. This is all analyzed via a narratological framework that takes museums as sites of story-telling and stories as essential human vehicles for meaning and interpretation.

4.1 Data gathering: embodied inquiry

"Embodied inquiry" as a methodological framework for data generation is outlined by Brown and Leigh (2020) in their work *Embodied Inquiry: Research Methods*. It sees the body as an essential part of data collection and analysis, while being combinable with other methods. The Vrolik is a space that is filled with bodies, fragments of human remains, or objects and preparations made to represent body pieces and parts; all that lies inside comes from or aims to represent the body, whether human or other animal. Therein, live bodies of the audience move around and gaze at the bodies on display: They experience an encounter, and subsequently engage in dialogue with or reading/interpreting the exhibit—mediated by the supplemental textual and spatial information provided. Embodied inquiry takes the researcher's body in the field and in interaction with its context and the other bodies present as a form of investigation and a method for generating meaningful data. Therefore, we can understand the Vrolik as a site of interaction in which meaning can be generated via the information gathered through the embodied responses of being part of the audience in this affective encounter, making my, the researcher's body, its senses and sensations, part of the material to analyze. This methodological approach follows Feminist New Materialist thought in acknowledging how "the researcher is part of the apparatus that produces the phenomena or event; they are entangled in the research events they create" (Truman, 2019, p. 4). Furthermore, it takes seriously Ahmed's claim that "knowledge cannot be separated from the bodily world of feeling and sensation; knowledge is bound up with what makes us sweat, shudder, tremble, all those feelings that are crucially felt on the bodily surface, the skin surface where we touch and are touched by the world" (Ahmed, 2014, p. 171). This embodied data was continuously translated into field-notes throughout my data-gathering visits. The field notes consisted of rich descriptions of the exhibit, the space of the museum and the matter within, stream of consciousness observations and reflections, attempts to simultaneously weave in internal and external stimuli, and contextualization in relation to excerpts of the exhibit texts.

4.2 Data analysis: mediation and stories

In analyzing the data generated by embodied inquiry, I have to attend to acts of mediation: Firstly, mediation of affect via senses, feelings and emotions, and secondly, the mediation of the encounter between the audience's bodies and the bodies on display via the context of the exhibit. Thinkers such as Massumi (drawing upon Spinoza & Deleuze) theorize affect as non-verbal, extralinguistic, noncognitive and nonconscious, always in movement and unfolding (Ingraham, 2023; Truran, 2022). As soon as it is cognitively interpreted, emotively defined and linguistically expressed, it ceases to be affect as it becomes "personal" and loses its undefinable excess and immediacy. In this sense, affect theory holds the potential to "force us to think about mediation" (Dernikos, 2020, p. 248) since affect itself escapes the confines of thought. I wish to address the issue of writing about the unlanguageable in this research by explicitly outlining how I apply my own interpretive filtering that is my embodied consciousness to the affective encounter. I do this in order to observe and subsequently verbalize how I relate and feel moved and affected by the bodies on display as well as by the mediating forces of the Vrolik as space and curator/narrator. This may no longer refer to affect in some of its theoretical senses, but to the material effects of affect that I am able to "read" and "express". In other words, placing this research in a broader conversation on affect, what I analyze is not the force of affect itself, but rather subjectively observable force-effects.

To attend to the mediation of affect via a researcher's embodied experience (and generate data from it), embodied inquiry depends on developing awareness, sensitivity and reflectiveness to one's own experiencing and positionality, generating insight into a phenomenon while situating it in the context of one's embodied socio-cultural position (Brown and Leigh, 2020). While no single experience can be universally generalized, it does add to, enrich and nuance the collective knowledge produced from various epistemic positions (Haraway, 1988). In the case of the current inquiry, my role as researcher is shaped by my experiences with chronic pain and illness which can be often and unpredictably disabling, as well as my role as a patient subjected to the medical gaze. In the practice of "data-generating/gathering", this aspect of my life leads me to affectively identify with, empathize, relate and be attentive to "patients' perspectives". In other words, it gives me an *a priori orientation towards* those whose bodies are exhibited at the Vrolik before I even enter the space. It also shapes my sensorial and physical engagement with the space, for example how much input I can process at a given time or how my body moves around the space. Conversely, this specificity also brings with it a degree of ignorance, on an embodied experiential level, of other forms of physical/mental impairment and living with more visible disabilities and bodily differences, which in turn shapes and limits my insight into lived aspects of such forms of disability and the degree to which I can interpret the exhibit from that vantage point. This is particularly relevant in the context of the Vrolik given the importance placed on vision and on making illness/abnormality *visible*, as well as with the focus placed on human remains that can illustrate physical "anomalies" and "deformities".

Thus, my particular orientation and position generates data that is both specific and insightful with regard to how the exhibit produces affective force-effects. This data can be analyzed to get at the second layer of mediation: that of the encounter itself. The ways the material of the exhibit is preserved, selected, arranged, displayed, lit, framed and placed in relation to each other; the information given by websites, books, information cards, brochures, walls and tour guides and how they refer to people and objects; the images, furnishings, paint, and layout of the space—all these act as "orientation devices", ways in which the museum guides the experiences of the audience. In order to approach this layer on the basis of my field notes, I am taking the museum as a whole as a site of storytelling with its curatorial techniques and texts acting as narratological frames and acts. This is because stories and narratives are essential forms of meaning-making (Bedford, 2001; De Fina and Georgakopoulou, 2015) and are fundamental tools for wording/mediating embodied experiences and sharing them with others. Stories "open up a space into which the listener's own thoughts, feelings, and memories can flow and expand" (Bedford, 2001, p.29) and so we (and our bodies) become the site for the emotional affect of the story to exist. It is in our emotions, our being moved, that the stories' embodied impact takes place. We become part of this performance of storytelling, bringing in our own point of view, engaging with the values and assumptions embedded in the narration. This is especially true in the museum setting, where audiences co-author the experience by how we choose to move through the space and engage with the information made available.

This approach follows recent impulses as part of the "narrative turn" in the study and practice of museums, which treat exhibits as texts to be read and analyzed in terms of the stories/myths/narrative strategies they produce and employ (Mason, 2006; Parker, 2013). Every piece of the exhibit, every preparation, every aspect of the museum, holds the potential for multiple stories of the different stakeholders involved. Looking at these different perspectives enables us to examine the relationships, hierarchies and value systems implicit within them. Hereby I make use of Niederhoff's definition of "points of view" as "the way the representation of the story is influenced by the position, personality and values of the narrator, the characters and, possibly, other more hypothetical entities in the story-world" (2014, p. 692). Most centrally, perspective refers to and results from the relationship between the teller, or "viewing subject", and the told, "a viewed object" (Niederhoff, 2014, p. 694). What and who is "placed" in the position of viewing subject and in the role of viewed object in the (hi)stories of medicine shows which modes of engagement with health are valorized or marginalized, which perspectives are seen as worth preserving and replicating and which are left unaccounted for, who is present as agents and who is reduced to passive roles, who gets to tell their stories and have them heard, and whose stories are absent. Therefore, this research inquires to what extent "patients" are cast in the role of agential subject, enabled to tell their own stories from their perspectives. How, in other words, we as audience are oriented in such a way as to perceive their (potential) animacy and agency.

5 Analysis: a multiplicity of stories

5.1 Arriving in the Vrolik: affectively experiencing dissonance

Edited excerpt from field notes:

> Walking into the large single room that makes up the Vrolik museum, the sudden quietness and the darkness cut by beams of light from angled spotlights through the rows and rows of cabinets are immediately impressing my senses. From floor to walls to ceilings, everything solid is painted in a matte black. The only sounds are those of visitors murmuring to each other, the venting air from above, and footsteps and the rustle of clothing as people move around. I cannot decipher what I smell; it feels neutral, a bit stale, enclosed. It also smells a bit old, like a second-hand shop or a library… that's probably the old wood. The cabinets are mostly glass prisms, but there are also many antique-looking and embellished wooden ones, what I imagined typical "cabinets of curiosities" to look like. They are all completely packed with anatomical specimens, skulls, bones, and some models and casts of different materials, I am guessing wax or plaster, but it is hard to tell with my untrained eye. The items inside tend to be of a faded yellow, cream, white color; with some reds, browns, and darker colors in the mix—but all in unsaturated aged hues. The lights from above and inside the ceiling of the cabinets shine a warm yellow glow. The spotlights in the darkness give the specimens a majestic quality.
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> The effect feels like being in a time capsule, wandering through a life-scale medical encyclopedia of the 18th-19th century frozen in time. The physical layout of the exhibit in the room reinforces this encyclopedic effect. The sections, rows of cabinets, are organized mainly by bodily systems and body parts and medical and scientific fields: starting with an embryonic section, fetal anomalies, gynecological material, followed by the cardiovascular system, the thoracic and abdominal organs, genitalia, the urinary system, shifting to tattooed skin, zoological and comparative anatomy, general anatomy, skeletal system and skeletal injuries and "deformities", the limbs, the musculoskeletal system, the head, neck, jaw and teeth, the brain and spinal cord, and so it goes. The air feels a little bit stuffy and there is a slightly heavy, enclosed and pressing atmosphere, perhaps because of the lack of windows and the darkness, combined with so much going on inside the displays. There are a few large 2x3m posters against the right wall at every section with an image that pleases my aesthetics senses, one of a palm print, another with some skulls, another showing a digestive system, each a simple white silhouette on light-blue negative space which looks very modern in contrast to the cabinets and their interiors. It helps to relieve the eyes. These posters, along with the clear sharp shapes of the frames and of the general architecture, give the feeling we are peering into the past, from the future. The eclectic mass of the collection, the dead organic material from times past is all contained behind glass, separating us from the contents, for us to look at and learn.
>
> I notice that both the cabinets themselves as well as the room we are in are black rectangles illuminated from above. And I slowly start to feel as if I become part of the exhibit, a performance of "the ill body still alive": sooner or later parts of me could end up in a cabinet too. I can already picture walking past the reproductive organs section, seeing pieces of my insides in a jar with a little explanation card of a disease.
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> About halfway through the right-hand side of the exhibit, my stomach begins to feel queasy—I suppose the stuffy smell is getting to me. That and gazing at specimen after specimen of dead human matter—not simply via my computer screen or book (which during my preliminary research I thought had desensitized and prepared me), but in the flesh. This is combined with the practical bombardment of sensory information that comes with examining around two thousand

> anatomical preparations that the museum says are on display. After an hour, my brain feels jittery at the impossibility of taking it all in, while my gaze jumps from one object to the next.
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Living with chronic illness has a knack for changing one's self-concept away from the assumed norm of being healthy and able, towards a familiarity with the realm of sickness, pain, illness and disability (Charmaz, 1983). As a chronically ill audience member and researcher in the Vrolik, I found myself entering the encounter with an urge for relating to those medicalized rather than to the doctors or anatomists doing the medicalizing. Yet at the same time, scientific and medical frameworks of knowledge also feel culturally and epistemologically familiar and authoritative. Thus, these orientations I arrive with are shaped by my own history (Ahmed, 2006), and their potential for contradiction took shape in a recurring embodied response of dissonance. The historical context of the medical museum, the Vrolik's curation deploying cues that immerse us into Europe's era of scientific cabinets of curiosities, and the artificiality and strangeness of seeing a prepared piece of a dead body undecomposed, serve as "orientation devices" (Ahmed, 2006) that encourage a medical gaze/approach. They decontextualize the remains as part of a body or person, and recontextualize it into a different narrative. The associated perspective and protagonism is that of doctors, medicine, anatomists, and the large texts on the walls narrating their biographies and careers reinforce this assertion. However, our own experiences as patients, embodied and in the flesh, and the self-awareness of the vulnerability of our bodies and health encourage a different kind of orientation, one of identification or empathy with the material on display as belonging to persons with perspectives of their own.

In reference to a specific "specimen", a respective info card would state the disease or name the physiology. It would say "osteogenesis imperfecta" or "fetal development", and my brain kept juxtaposing: "person". I would look into their dead eyes and be all too aware and confronted with the uneasy feeling that this is someone, was someone, with their own story and experiences. This would be more pronounced the more I could recognize the exterior of the body which I am used to seeing as and associating with personhood. The skin, the eyes and the face were particularly evocative for this, as that is where our eyes are often drawn when we look at other beings. This effect also increased the more "whole" the body piece was, like a hand or an injured foot, or full-sized developed conjoined fetuses, thus becoming cognitively recognizable as being or belonging to *someone*. The more sliced or dismembered, and the deeper we delved into the body and saw pieces outside and disconnected from where they would be in a live body, the less pronounced this awareness was of the piece as "person", the less I could recognize or identify with "it/them". Starting from my own vantage point, what I could see/feel is that these specimens, or preparations or objects, are more than just that. More than their physiological or pathological name or definition, more than a trophy, oddity, curiosity, illustration of a technique or craftsmanship, more than an item collected by a mister Vrolik, a mister Bonn, Vesalius or Weber, more than a person or a body, more than dead matter, and more than the being they used to be in life. They are all of these things at once: a multiplicity, with new facets revealing themselves as you move to look at them from different angles.

There is thus a dissonance between the affective orientation I bring into the space due to my own situated-ness and the orientations prompted by the museum's frames. This led the pieces that made up the museum to be dressed in simultaneous roles: the body as material history, biological organic matter, medicalized anatomy, curiosity, anomaly, work of art, property, possession, commodity, trophy—clashing with the body as person, its identity, agency, and subjectivity. Dead or alive, subject or object, the very nature of the material that made up the exhibit kept on shifting, depending on the narrative context of each piece, their at times contradicting and overlapping stories, and the perspective through which they were told and seen. In the following sections, I employ narratological tools to make sense of how these conflicting frames have come to be and continue to operate, as well as to investigate why the multiplicity of narratives I encountered created an affective dissonance and how that dissonance might be mitigated or bridged.

5.2 The Vrolik's telling of medical history

A pivotal framing to these multiple stories is given by the Vrolik as a mediating context, which affords historical value and meaning to the materials and objects found within. It elevates the epistemic status of the stories it tells as a part of history, based on legitimate sources of material evidence, documentation and physical remains. It facilitates placing its contents as a part of a larger story of evolving medicine and medical knowledge production: "enabl[ing] lumps of brute matter—instruments, wax models, pieces of furniture, anatomical specimens and so forth–to come to life as parts of cultural and social history" (Arnold, 2004, p. 145). In effect, this simultaneously serves to animate/cast the specimens into a particular role as objects of medical history, and to orient us as audience towards looking at them as such, taking on a medical/scientific perspective/gaze. The layout, packed old wooden cabinets, and the aforementioned "time capsule effect" transports us to a context which facilitates this relationship. The "majestic" atmosphere of the museum installation I felt in my visits further served to advance this narrative: eliciting *awe*, triggering *curiosity* and suggesting *wonder* at the scientific feats of our ancestors, upon which current science was built.

This framing capacity can be noticed rather viscerally in light of the contrast experienced while walking around the surrounding corridors outside the exhibit proper, within the university hospital. An eclectic mass of specimens and objects reside around these outer walls. Contrary to the items inside the museum, these pieces do not have spotlights to illuminate them, nor the darkness to protect them from natural light, nor info cards to name or explain what they are. They felt haphazardly put together, with blank patches between them, unlike in the museum where every centimeter of space seemed intentional and used to maximum capacity. They carried an air of being forgotten, while inside the museum walls the air spoke of importance. It was walking along this back wall that I stumbled upon a dead bird, or several, technically speaking. There were the bird skeletons inside the cabinets, important enough to be enclosed but perhaps not enough to be with the other skeletons inside the museum itself. Then there was another bird behind glass that caught my attention. On the pavement, through a window to the outside of the hospital, it lay decomposing with most of its feathers still attached. Seeing the same kind of animal remains facing each other behind their respective glass walls, while some are in glass crypts, and the other is lying without anyone's notice or interest, brought an affective awareness of the power of these walls to endow matter with meaning and to create hierarchies of meaning within them.

This sight brought my awareness to another aspect that differentiated the bird rotting outside to the remains preserved inside the Vrolik. The heritage function of the museum involves telling a story in which the remains and preparations on display are objects of medical knowledge. They have been turned into objects by the hand of humans, anatomists, "medical men" of the past. The preservation of these specimens is not so much about the individual beings the remains came from, but about the knowledge that scientists of the past could draw from the process and products of their dissection and preparations. It was about the study of the remains, what insights those insides could afford on the general inner workings and structures of the body and disease, how that contributed to medical knowledge at the time, and the skills and adeptness that is proven in elaborating these specimens. The individual as such only mattered in their specificity if they possessed a medical anomaly, so they could be *used to illustrate* said anomaly. The glass (of the hospital, the museum walls and the glass cabinets that hold the specimens) separates ordinary living and dying beings from preserved relics that form part of the history of medicine. By virtue of their being medically objectified, transformed into anatomic specimens, these dead remains are "re-animated" and given a new "post-mortem life" (Alberti and Hallam, 2013) endowed with esteem and importance. In the (hi)story of medicine, they take on a new role: to be seen, stared at, learned from, and evoke emotions of reverence and interest. This renewed animacy is however limited as they are used as vehicles for meaning "bestowed from the outside", rather than recognizing the "vitality" or "aliveness" they already have (Truman, 2019).

5.3 The anatomists as agents and authors

This transformation of "mere matter" into "specimens" is occasioned by the anatomists, their tools and skills. When we enter the museum, along the left walls there are large chunks of text giving us background information about the most pivotal anatomists who contributed to the collection and some historical information surrounding the developments of science and medicine at the time. These texts are not meant to be objects of history themselves; rather they frame the exhibit, written on the very walls that contain it. Similarly, the museum website's first page retells the story of the museum as originating from the collection of the Vroliks (About the Museum, 2024). These framing texts give the anatomists and medical practitioners ample space and recognition as protagonists of the history of medicine. And the space that is dedicated to them personally gives an impression of high regard and value. They are the acknowledged "contributors", and it is their identity, legacy and agency that is reaffirmed in the most visible and prominent form. There is extensive information on the website, in the museum brochure and info cards, about the techniques the anatomists used to create the specimens and preparations, thereby enabling new medical knowledge to evolve. They would dissect, slice, color and inject, use substances like alcohol and wax, and suspend pieces in jars. They were often pioneering preparation techniques, advancing scientific knowledge of the body thanks to their power to make the "unseen" *visible*. They would make choices about what to keep of the remains they had to work with and what to dispose of, and so acted as arbiters of value. In these capacities and roles, they are presented as agents and actors, emphasizing their ability to shape and transform matter.

In this transformative process and with the products they create, the anatomists also author stories, whether or not consciously or intentionally so. This is first done in the very procedure of dissection and crafting of specimens. They etch their vision into these bodies, as they inscribe their own meaning and understandings into them. Naming pieces along the way, separating organs from tissue and system. Determining where one anatomic and physiological piece begins and another ends. This procedure is physically both delicate and violent, as it involves the literal breaking and cutting apart of the body. When making corrosion casts for example, the material remains are injected with a hardening material, such as a metal or wax, which fills the cavities of interest to the anatomist. The next step is to get rid of the original organic tissue, to reveal the casted inner structures of which the tissue acts as the mold. This is a destructive process, often done via boiling, maceration, or using acid, enabling the anatomist to wash away the "unwanted" remains (Hendriksen, 2019). This transformation renders the specimen's original "personhood" less recognizable not only visually but also in their very matter. The violence involved in these processes is meant to be obscured by the new "product", yet I felt it continue to haunt and linger in the exhibit. By affectively empathizing with the matter on display, my awareness was brought to how the cuts, slices, injections, liquids and so forth distinguish specimens from live bodies such as my own, enabling me to trace the physically transformative processes the pieces have undergone in order to "arrive" and be placed here in front of us.

There is yet another story layer implicitly present revolving around how the specimens served as possessions, trophies and status-symbols, which can be read particularly clearly in "Hovius' cabinet of bones" (Figure 1), an important element of the Vrolik's exhibit. Hovius agreed to donate his collection of bones only if it would get a custom-made cabinet to be kept in to protect them. The bones are mostly anonymous. However, at the very top and center of the adorned cabinet lies a portrait of Hovius himself, a gesture arranged by the professor then minding the collection. The very convictions that led to enshrining a portrait of Hovius, looming over not his own remains, but the skulls and bones he collected, gives testament to how entrenched the notion of prestige and identity were in the practice of collecting and preserving anatomical specimens at the time, providing another layer for their objectification. When presenting a specimen, the people and bodies that they are derived from are no longer recognized, except in occasional records when medical histories were deemed relevant. They were displayed not for the

FIGURE 1
Image of Hovius's cabinet courtesy of Museum Vrolik (Wiersema, 2020).

remembrance of the dead, but to further serve medical study as objects: the embodied knowledge of "patients" was not seen as worthy of preservation as their actual bodies. It is likely that these identities and lives were not given importance at the time, since the only bodies that could be legally dissected were those of criminals (often as part of their punishment) or later on those of the impoverished, orphanages, or psychiatric or charity hospitals, unclaimed by family (Ghosh, 2015), as well as bodies of those who were colonized and enslaved at the time (Parry, 2021). This is also evidenced in some of the notes in the Vrolik catalogue, published by Dusseau (1865). Although many entries are indicated as having origins unknown altogether, at times it is mentioned that the bodies were originally of the poor (Dusseau, 1865, e.g., p. 19), or the convicted (e.g., p. 188), or foreign seamen (e.g., p. 29), and a significant portion belong to people of color subjected to European colonial projects (de Rooy, 2023; Dusseau, 1865). Thus, persons who already experienced societal exclusion or oppression were also the ones whose bodies were used in such ways that their identities and personhood would be erased. Instead, as specimens they represented the social, professional and scientific standing and achievement of the new owners towards their wider community.

The anatomists make further use of these specimens to advance new stories such as their theories about evolution, the genesis of a certain illness or fetal development for example, but also more sinister ones, about racial differentiation and phrenology (the study of skulls to determine a person's character) (About the Museum, 2024; Heiningen, 1997; de Rooy, 2023). Some stories are simply defining what "ill", "deformed" or "healthy" look like, separating the "normal" from the "pathological": "for vivid and tangible demonstration of what could go wrong with the body, as well as what a healthy body should look like" (Alberti and Hallam, 2013, p. 6). Hereby, they also authored stories that would reverberate and ripple into social and cultural perceptions of (ab)normality and bodily difference.

5.4 Addressing missing and troubled (hi)stories

Despite this historical baggage, there are several ways in which narratives centering "patient's perspectives" are part of the exhibit. Firstly, by sharing occasional non-medical information related to the body and health which enables the individual specimens to be seen in a socio-cultural context beyond the remit of the medical domain. Some examples include: A snippet on the website that acknowledges the history of keeping remains of saints as relics before the scientifically motivated collecting began in the Renaissance (Techniques, 2024), in the info card of a particular foot that explains an old and abandoned Chinese practice of "foot binding" to create "lotus feet", or the writing about Hovius' cabinet of bones that notes that life in the 18th century was different than today's with the kinds of illnesses, injuries or issues such as malnutrition that impacted many bodies at the time. By acknowledging the cultural, historically contingent and situated dimensions, these bits of information transported me in time and place, not to the medical laboratory or archive, but to sites of everyday life in which people navigated matters of health, the body and illness throughout history. However, these examples are few, leaving me with many critical questions: Who did these remains originally belong to and what are their stories? What would they have felt about pieces of their bodies being here? Would it have been exciting to be preserved for posterity, having a posthumous after-life on a pedestal or in a jar? Or would it have felt like a desecration? Their bodies claimed for reasons beyond them, and used in ways they had no say about.

Although the museum does not provide much material to answer these questions, this is not entirely a choice of omission. Current curators contend with a lack of historical information connected to the pieces in the collection, that which was never gathered, such as details of who they originally belonged to or how exactly they were acquired (de Rooy, 2023). In the cases where we do have this kind of information, we must also struggle with the ethical issue of privacy which is afforded by the anonymity of specimens. Not disclosing names and personal information can be a form of respect to the deceased whose remains are preserved, since the way some of these bodies have been used and are permanently displayed can be deeply invasive. Moreover, forever memorializing their names exclusively in this context has the potential to further reduce their personhood to objects of medical history. At the same time, it can also be seen as humanizing to tell stories of their life in such a way that acknowledges their subjecthood beyond medical objectification. This a significant limitation in the museum's ability to re-introduce "patients' perspectives" of the past, therefore further reflection, ethical considerations and research is needed to make informed decisions about what and when to disclose of the persons whose remains are in the Vrolik.

What can be addressed without ethical considerations about the privacy of individuals is the larger historical context within which the remains were gathered, and indeed Museum Vrolik has put effort into acknowledging and researching some of the problems surrounding its preservation and display of human remains. Specifically, in one of its information cards they acknowledge the ethical, moral and legal considerations around how the bodies were acquired at the time were very different from today's, and that we do not know to what extent consent was requested or given prior to death. The website notes that collections did afford "status" to the medical doctors who gathered them, but asserts that education, research, and now also medical material history, are its main purposes ensuring a respectful context (About the Museum, 2024; Human Remains, 2024). They also have an extensive statement regarding human remains from former colonies of the Netherlands, explaining why they are problematic and how they were used historically by anatomists, some of whom were contributors to their collection, in order to study and argue about their theories on "race". Hereby they also clarify the relevance of their conscious choice to not display racialized human remains. They further explain how this has a continued legacy of oppression today, and assert their commitment to researching this topic, and to repatriate human remains if this is requested by source communities. This was put into action in 2018 when the Vrolik returned remains to a Māori delegation (Remains of Māori Back in New Zealand, 2024), and continues currently via a partnership with the research project "Pressing Matter" which investigates "Ownership, Value and the Question of Colonial Heritage in Museums" (About the Museum, 2024). This grappling with colonial legacy is unfortunately not an active part of the physical exhibit, but can only explicitly be found on the website and in publications of the current curator (de Rooy, 2023).

However, other forms of historical oppression and marginalization are seldom addressed in the exhibit and would benefit from such conscious engagement. Specifically, the role of ableism is missing considering how the Vrolik is a setting where anonymous individuals with physical differences and/or disabilities are displayed to be stared at and used to give a visual representation of "abnormality" to the public. It orients us—the presumed (able/healthy) viewer—at the center point of reference, relegating the disabled to "some faraway edge of the world" (Garland-Thomson, 2009, p. 42) which we get to meet in a staged encounter that encourages medical objectification with little humanizing context. In the Vrolik's self-published book *Forces of Form* the massive collection of the Vroliks' fetuses are described as "wonderous little curiosities preserved in its jars," that "are keeping science alive" (Oostra, 2009, p. 120), reinforcing concerns that even when an educational context and "respect" is emphasized, this is limited when we do not talk and reckon with our troubled histories and language that sensationalize disability as "other".

Furthermore, taking the museum as a context of education of history of the body, health and medicine, we are missing not only the voices but also more historical context regarding the other stakeholders involved. Although this is hard to find for specific specimens, Laurens de Rooy, current curator at Museum Vrolik, through a close investigation of the skulls in the collection highlights how "most non-European skulls reflect the (expanding) colonial exploits of the Kingdom of the Netherlands in the first quarter of the nineteenth century, and Gerard's social position within this colonial network" (de Rooy, 2023, p. 316). He also hypothesizes that the military conflicts in the Northern and Southern Netherlands during the collectors' lifetimes may also have provided a source for human remains gathered by military doctors working in field hospitals (p. 318). The Vrolik catalogue gives us further insight into how many of these remains were acquired: Directly from burial places, through purchase, or via donations from other anatomists, physicians, collections and from (field) hospitals, especially overseas (Dusseau, 1865). We can also embed the exhibit into a larger European historical socio-cultural context of the collection of human remains for anatomical purposes. Laws needed to emerge to avoid the unethical handling of human remains, such as the practice of grave-robbing which became common in the 14th century, and continued into the 19th century (Ghosh, 2015). Being dissected was historically considered part of criminal punishment, and was often used as a deterrent for crime, which gives insights into how negatively it was viewed by the public for one's body to be given that fate (Brenna, 2021). There are brief moments when these darker histories are touched upon, for example one info card states that when there was no money for a burial of an orphan child their bodies would be used for science. However this kind of historical legacy is not actively engaged with and seems to receive only anecdotal mention in the exhibit itself. This leads the educational approach and declared sensitivity and respect towards human remains to seem limited in practice.

The most immediate way in which I experienced "patients' perspectives" to be made present throughout the exhibit involved the Vrolik's role as a site of education about the human body wherein a physical connection was drawn between the bodies on display and my own. The museum displays the human body and its insides in such a way that we can gaze inside, beyond the boundaries usually provided by the skin and social appropriateness. Through this physical insight and the enabled intimacy, the "objects" can be seen as having an inherent capacity to "invite the viewer to reflect on themselves" (Alberti and Hallam, 2013). The viewer is brought into the matter examined, as we can relate to what we see on the basis of being a body ourselves. As a site for scientific and medical education about the body, the Vrolik actively deploys the potential of its contents to invite the viewers inwards via the information cards provided along with the displays by naming each of the items and then giving the physical context of where it lies anatomically. These specifics enabled me to see the specimens, which at first sight felt eclectic and random, not only for their abstract biological significance but for their relationship to my own body. This effect was more present the more detailed and embodied the information was on the info cards, making direct links between what is on display and the audience's own body, for example: "see for yourself how your tongue changes in shape and position when pronouncing all of the letters of the alphabet" to explain how the tongue muscles (that you can see in front of you) also feel and function, so you can experience how they matter to your embodied reality. Another example, "when you have a cold the first thing to become inflamed is the mucous membrane of the nasal cavity…one of the symptoms is a throbbing pain on the forehead and left and right of the nose" is the text that illustrates the connection between the nose and sinuses, and how the symptom of that localized pain can point to embodied knowledge of being ill.

These kinds of statements do not only draw the reader in to reflect on themselves, they also assert the epistemic capacity and authority we hold in experiencing our bodies, in a spectrum of health and illness. In these small gestures, we, the audience, are acknowledged as embodied knowers with epistemic agency. This was for me the most effective way that "patients' perspectives" were made present, where I felt really a part of the exhibit, not as a potential object but as a participant, as a knower, and where my body was explicitly involved in that knowing. It was also at the same time a reminder that its contents are also made up of bodies, just like us, inviting empathy with their past sentience. We are explicitly made aware, as we gaze at an anonymous tongue, of our own tongue, drawing a direct pathway for connection rather than objectification. There is still so much potential for the Vrolik to engage this way with its contents, telling more stories that integrate and protagonize the relationship between the audience and specimens, based on our shared embodied and epistemic agency. This, together with a more active engagement with the existing legacies of the people whose bodies are on display and the historical and political contexts in which the museum's "specimens" were "produced" would contribute to significantly reducing the affective dissonance I experienced. It would also help others who do not share my particular positionality experience themselves in relation to the people whose remains surround them as agential subjects in the present and history of medicine and illness—opening up perspectives beyond the previously prescribed observer-object dynamic.

6 Conclusion

In analyzing my field notes, the most central pattern emerged as a feeling of dissonance. Although the exhibit succeeds in immersing and transporting the audience to learn about a particular time and place in the production of medical and scientific knowledge, when searching for "patients' perspectives" I often felt at a loss, even though their bodies were right in front of me. I was searching for something I could catch glimpses of at times, but mostly felt in its absence. The remains on display have been decontextualized from their original home as a part of someone, and through the processes of death, dissection, preservation, preparation, and later curation, they became re-contextualised, transformed and "emblazoned" (Sawday, 1995) into specimens in a museum. At the same time, my lived experience and identity as a medicalized person with chronic illness brought an impulse/intensity towards identification and closeness to the "specimens", grasping for a sense of their agency, voices, perspectives, personhood. From these simultaneous orientations, the remains exist as multiplicity and assemblage, more than who they were in their previous life, and more than what it is presented as today, with new sides revealing themselves at every angle (Ahmed, 2006). These dissonant natures coexist, and cannot be neatly reconciled. What was once human remains is now also an anatomic specimen. Making sense of and grappling with this dissonant multiplicity brings us to a fundamental concern: whether the body is taken as an "object" to gaze at, learn from, act upon; or whether it is seen as an agential subject with perspective of its own. When we are oriented towards the displayed bodies with an objectifying gaze, I am turning to face them as opposed to myself, to be in some way used. When I look at them as potential actors with their own perspectives, I turn not only towards them but I also place myself beside them, and attempt to gaze out at the world from their vantage point, involving a cognitive-emotional act of empathy (even though empathy with the dead involves of an inherent amount of projection and uncertainty). Throughout the research process, it became clear to me that the sense of incongruity I experienced was not merely because of co-existing clashing meanings and orientations, but rather the dominance of medical scientific frames and neglect of "patients perspectives" alongside them. The more I realized the extent of the presence and authority of scientific narratives and absence of the identity and personhood of the remains, the more I felt the affective dissonance magnified.

The neglect of "patients' perspectives" as another narrative that is curatorially woven into the exhibit led to a sense of dehumanization. My stomach churned not only because I was seeing cut up dead bodies in jars, but also because their "personhood" seemed like a footnote to the exhibit as a whole. How the exhibit is curated serves as a re-enactment of a historically troubled narrative which the Vrolik insufficiently addresses while it tries to distance itself from the unethical acts in its history. Medical frames do not necessitate dehumanization, if patients are understood primarily as persons, and their subjective quality of life, experiences and epistemic authority are given their due importance. Although the museum clearly states their intention of respect and care towards those whose bodies are on display, to shy away from the role dehumanization has played in medical history and to reproduce the asymmetry between the agency and authority of the stakeholders involved reinforces the continued objectification of the remains on display (and the erasure of their former owners' personhood). We are encouraged to see them as objects of medical knowledge or of medical history rather than to recognize them as (also) persons with perspectives and epistemic authority of their own, not orienting us towards imagining what a story in their own voice might sound like, what seeing through their own eyes may look like, what living in their own bodies may feel like. This dynamic supports both the historic and ongoing epistemic hierarchy between those who study the body, illness, disability, and those who live and experience this first-hand in their own bodies, between those who enact medicine and those whom it is enacted upon.

A first and fundamental step in the direction of making "patients' perspectives" present can be to start to acknowledge and engage with the multiplicity of possible narratives in medical history, and from there to bring more stories, voices and perspectives into the telling of (hi)stories of health and disability. Specifically, to acknowledge the perspectives of those who have lived with embodied experiences of health, illness and disability, and those who are put on the receiving end of the medical gaze. It also means grappling actively with problematic aspects of the legacy of medical research and medical museums and discussing how this heritage shapes our world today, without yet having all the answers (Majerus, 2017; Parry, 2020; Tybjerg, 2018, 2019; Whiteley et al., 2017). Engaging in this process can be a much stronger statement than trying to reassure visitors that "things are different now" (Birdsall et al., 2015). We can also take other projects as references for dealing with these complex challenges, such as the reinvention of the Anatomical Collection at the University of Jena which was "based on ethical considerations" (Lötzsch and Redies, 2023) and draw on their shared knowledge and experience. Another example is a recent proposal of "*Recommendations for the Management of Legacy Anatomical Collections*" (Cornwall et al., 2024) aiming to centrally address moral and ethical concerns. Furthermore, involving those whose bodies are at stake to have access to shaping the museum setting and bringing in their critical knowledge and perspectives for navigating this murky terrain would serve to both acknowledge their epistemic authority in the matter, but also to avoid unnecessarily taking pieces off display in order to sanitize the exhibit and avoid controversy, as this could lead to a misrepresentation of our problematic collective heritage.

There are many further avenues for exploring the integration of "patients' perspectives" beyond what has so far been discussed in this research. One very accessible practice is the display of medical instruments and research tools, which have the potential to trigger visceral empathy, depending on surrounding curatorial decisions: "objects also bring to mind the bodies of those they were used upon, and can encourage visitors to project their own bodily experience into either position", (Whiteley et al., 2017, p. 61) not only the doctors'. Further engaging with other senses than vision, which in this context carries with it the associations with the medical gaze, can also encourage audiences to connect with the exhibit with more embodied and sensorial awareness of their own body and therefore the lived experience of health and illness. An example of this in practice is the use of soundscapes that has been suggested to also bring in literal voices of those previously silenced (Birdsall et al., 2015). In addition, the use of imagination and creative practices which protagonize bodies and patients or narrate from "patients' perspectives", hold great potential for creating avenues of empathy and connection, a feeling *with*, rather than the sympathetic and distancing feeling *for*. This can pull from the rich work on narrative illness by thinkers and writers such as Frank (1995), Charon (2006) and Lorde (1997) that have developed extensive hermeneutic tools through which to make sense of illness experiences.

Furthermore, the use of embodied inquiry such as the one exercised in this research project can also serve as an avenue for generating embodied knowledge from more diverse perspectives than those whose stories are so far represented in the exhibit. It can also be a fruitful tool to encourage connection and sensitivity in the audience no matter their positionality and experience. Acknowledging that there is an absence of voices and perspectives, to make an effort to listen to that void making the absence tangible, may serve as a first step in making patients, the ill and medicalized, more present as subjects even in their silence. To move forwards from there, persons with disabilities, illness, bodily differences, impairment and injury, need to be included and recognized in their capacity as knowers, as having vital embodied knowledge via their lived experiencing, as narrators and subjects in the stories that are told. From these stories, we can generate new avenues of understanding health, medicine, illness and disability, of curating and framing museum exhibits, of making sense of our past and present, and of understanding ourselves and each other.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author/s.

Author contributions

AL: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Writing – original draft, Writing – review & editing.

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Conflict of interest

The author declares that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Ableism-sensitive, self-reflective emotion work as part of inclusive teacher education

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In this perspective article, emotions are considered as an inherent component of ableist practices, and the question is explored of how ableism-sensitive, self-reflective emotion work can be designed for inclusive teacher education. In this process, connections to the Sociology of Emotions are established, with particular emphasis on the collectivity and sociality of emotions. Within this context, self-reflective emotion work is integrated into the concept of “unlearning ableism” and argued for its implementation as a systemically oriented group process. Finally, questions regarding the design of emotion work and its implementation in a manner critical of ableism are discussed.

KEYWORDS

emotion work, inclusive teacher education, unlearning ableism, sociology of emotions, group process, reflexivity

1 Introduction

Emotions are an inherent part of ableist practices (Wechuli, 2022) and manifest in various forms across all levels of educational relationship and interactions within the school context, significantly influencing teaching and learning processes (Zhongling et al., 2022). For this reason, engaging with (one’s own) emotionality is also significant for inclusive teacher education. Inclusion as a key concept in Disability Studies refers to the equal access, participation, and involvement of all individuals in all socially relevant domains. The pedagogical practice of segregation maintains separating structures of thought and action and it reproduces ableism as an order of difference characterized by the valuation and devaluation of individuals in relation to (dis)ability expectations and attributions. The concept of ableism was initially developed within the disability movement and further elaborated in Disability Studies. The segregating education system and the teachers acting within it are identified as central to ableist subject production, while inclusive pedagogy is conceptualized as its counter-strategy (Buchner, 2022). Embedded in this is the demand on teacher education for inclusion to critically reflect upon the often deeply sociocultural and biographically rooted and internalized “expectations of abilities and ableist assumptions” (Buchner, 2022) and associated emotions and emotional patterns. Therefore this perspective article aims to explore how self-reflective emotion work can be designed within inclusive teacher education. For this end, references to the Sociology of Emotions will first be outlined, followed by a description of self-reflective emotion work as part of a process of unlearning ableist ways of thinking, feeling and acting. This will involve raising potential perspectives and questions regarding the implementation of self-reflective practices in teacher education.

2 Fundamental ideas from the Sociology of Emotions

Fundamental to my discussion are conceptual frameworks that guide the Sociology of Emotions, with three aspects of particular relevance.

(1) The sociological perspective on emotions implies that emotions carry cultural significance and manifest their expression in the formation of social relationships and emotions "are shaped, and in fact constructed, by social conditions" (Holmes, 2010, p. 144). This means that social arrangements are inherently emotional arrangements (Illouz, 2004), and social practice is invariably emotional practice. According to Neckel (2006), emotions represent the most immediate manifestation of the "social perception of societal conflicts about power and morality" (Neckel, 2006, p. 133, author's translation). This is because emotional responses to violations of moral norms and the associated normative expectations occur spontaneously, and they provide clues about their presence as well as their structure and order. Thus, emotions represent fundamental normative dimensions of meaning within the cultural practices of social groups and are a reflection of social conditions and inequalities. This aspect can be linked to one of the main concerns of Disability Studies: to investigate "how society and culture shape the way we react to dis/ability and what this tells us about underlying norms" (Wechuli, 2022, p. 143).

(2) Building upon this approach, emotions must be conceptualized as highly complex, context-dependent phenomena (Ahmed, 2004). This implies that emotions are not confined to the individual level of the perceiving subject but are deeply interwoven with ableist structures and cultures as collective emotions and they are far from being "merely reflexes of social positions, outcomes of physiological stimuli, and subjective correlates of role expectations" (Neckel, 2006, p. 134, author's translation). According to Ahmed (2004), emotions in this sense are to be understood as relational, and the subject's sensations are influenced both by the internal context, such as past subjective experiences and interpretations, and the external context, such as collective history or structures. In doing so, Ahmed breaks with "foundational distinctions in Western philosophy between reason and feeling as well as between intellect and emotion" (Ural, 2023, p. 34, author's translation). Furthermore, Ahmed's perspective on emotions as responsive is significant. Emotions are not purely subjective and individualistic. Rather, the emotions subjectively experienced are socially mediated and are in contact with emotions that circulate in a particular social and culturally influenced manner: "They move and they are not just social in the sense of mediated, but they actually show how the subject arrives into a world that already has affects and feelings circulating in very particular ways" (Schmitz and Ahmed, 2020, p. 98).

(3) This assumption is accompanied by the idea that emotions are not limited to affective, unconscious states but also encompass reflexive-cognitive components as well as motivational and action-related aspects. Emotion and cognition are in an interdependent relationship and following this perspective, it becomes possible to access one's own emotions and engage in reflective processing of them.

3 Self-reflective emotion work within the context of "unlearning ableism"

For the self-reflective work on one's own emotions, the term "emotion work" can be used, tracing back to the works of Hochschild (1983). The term refers to processes of emotion regulation, involving the production and display of desired emotions while suppressing undesired emotions and emotional states (Werner, 2016). Hochschild summarizes the processes as "the management of feeling to create a publicly observable facial and bodily display" (Hochschild, 1983; Werner, 2016, n.p., author's translation) captures them as "intentional generation, influence, representation, and regulation of one's and others emotional states" and concretized: "Who, when, in which situations what one feels, and how the individual expresses these emotions to others constitute a socially determined and power-permeated, complex process." So-called "feeling rules" define the norms of emotional behavior in various situations and provide a valuable approach to understanding emotions as social phenomena (Holmes, 2010).

Below, I draw upon the ideas of Hochschild (1983) and Werner (2016), connecting them with the notion of self-reflective work with and on one's own emotions. I aim to specify approaches and meanings of emotion work for the professionalization of teachers for inclusion. In this regard, it involves empowering prospective teachers to become aware of unconscious, prereflective emotional aspects, to resist feeling rules, and to acknowledge all facets of emotions independently of social evaluation. This entails allowing oneself to experience emotions and influencing emotions through reflexive engagement. This process of recognizing and influencing individual and collective (ableist) emotional patterns can be considered as part of a persistent and intensive process termed "unlearning ableism" as described by Buchner (2022) and used by Disability Studies to question and transform ableist practices and policies (Danforth and Gabel, 2016).

While this process can be initiated during teachers' training, it should never be regarded as complete due to its complexity and socio-cultural conditioning. Unlearning is like learning an essential part of educational processes and, according to Spivak (1996), contributes significantly to the repoliticization of pedagogy. Spivak (1996) coined the concept of unlearning as part of postcolonial theory, with reference to epistemic violence, and understands it from a deconstructive perspective. It involves recognizing the "interweaving of learning and education with power and domination" (Castro Varela, 2017, n.p., author's translation) and developing an awareness of one's own position within it, as well as an understanding of the historical and social conditions that led to and continue to shape this position. Central to this is the perspective of viewing one's own privileges as loss. "Unlearning one's privilege as one's loss" (Spivak, 1996, p. 4) entails not simply relinquishing or feeling ashamed of one's own privileges, but rather examining them within their historical context, questioning and reflecting upon them, and in this sense, not forgetting them but remembering them. In this context, "unlearning ableism" addresses the inquiry and questioning of the aforementioned "internalized expectations of ability and ableist certainties" (Buchner, 2022, p. 204, author's translation) because they too are part of the violent relations of knowledge and knowledge production, manifesting themselves in educational contexts through form, content, and pedagogical interaction. Self-reflective emotion work could be seen as a facet of learning to unlearn, as it is a part of epistemic change, for "shifting epistemic boundaries is never solely a matter of the cognitive-rational, but always involves aesthetic resources, emotions, and affects" (Brunner, 2020, p. 113, author's translation).

4 Self-reflective emotion work as a systemically oriented group process

Since the 1980s there has been a reflective turn in teacher education, which brought reflexivity to the forefront of discussions about the professionalization of teachers (Haecker, 2022). However, despite the overwhelming emphasis on reflection requirements, they often remain too undifferentiated and abstract in the practice of teacher education, which influences school practice. According to a study by Wyss (2013, as cited in Haecker, 2022), reflections by teachers appear to be "individual, little structured, predominantly purely mental" (Haecker, 2022, p. 100 f., author's translation). This may be due, in part, to the fact that reflexivity in teacher education is often conveyed as an *individual* strategy and competence—closely linked to the individual-oriented reflection models and tools frequently used in this field and the tendency that "theories of reflexivity are too individualistic and rationalistic" (Burkitt, 2012, p. 464).

At this point, I would like to outline a potential approach for self-reflective emotion work that integrates the aforementioned ideas from the Sociology of Emotions with the process of "unlearning ableism." The noted proponents of the Sociology of Emotions emphasize the sociality and collectivity of emotions. Social collectives can exhibit various connections depending on the perspective and analytical approach, such as "groups (by way of social category), organizations (by way of formal membership), crowds (by way of physical co-presence), communities (by way of social bonds), or nations (by way of citizenship)" (von Scheve, 2017, n.p.). According to von Scheve (2017), collective emotions are triggered by social identity, social categorization, and the relevance of group concerns, even though they can be experienced situationally by individual subjects. This means that the emotions of individuals and collectives are not viewed individually, but are, as outlined with reference to Ahmed (2004), in a relationship to each other. In the context of Reflexivity, Holmes (2010) views emotions as relationally constructed and emphasizes relationships as central to reflexive practices: "Feelings about and connection to others are crucial to reflexive practices" (Holmes, 2010, p. 143). Shared values, which are also reflected in social norms, now contribute to the fact that individuals "interpret events and situations in similar ways and thus to converge in their emotional reactions" (von Scheve, 2017, n.p.). In the context of ableism, the social collective can be determined through the dominant society, shaped by its structure and culture. The associated collective emotions contribute to the production of social inequalities, "privileging or disprivileging individuals and groups based on the recognition or denial of abilities and legitimizing specific practices of inclusion and exclusion" (Buchner, 2022, p. 203, author's translation). Teachers—as well as teacher educators—are in most cases part of the dominant society and, due to their specific educational backgrounds as high school graduates and college students, as well as their professional status, they are generally more oriented toward logics of ability and meritocratic principles than other individuals or groups. This description is not intended as an attribution but rather as an attempt to explain ableist practices in schools, which also manifest through the actions of teachers.

In the context of training teachers for inclusive education, which aims to counteract the production of ableist subjects, the exploration of (future) teachers' own thinking and behavioral patterns, their own concepts of identity, and the embedded emotional patterns should therefore be a core aspect. Building upon the previously outlined aspects of the sociality and collectivity of emotions, the focus here is particularly on self-reflection as a group process that also delves into systemic points of orientation. Because in the relational determination of individual and collective, a systemic principle emerges: contextual orientation, according to which the individual is not viewed in isolation but in the context of their historicity, experiences, social and cultural influences, and social integration.

Accordingly, a systemically oriented group process is designed for participants to experience themselves "much more as social beings than as individual beings" (Mosell, 2016, p. 26), and reflective work is conceptualized as a social practice. Within the framework of applied group dynamics, "situations are created in which the individual can engage with their own experiences and behavior in the group, and from the insights gained in this process, new behavioral possibilities can emerge" (Gilsdorf, 2004, p. 329).

In the context of self-reflective emotion work, this also includes becoming aware of emotions that are closely tied to moral norms and normative expectations, which often unconsciously and pre-reflectively shape the actions of individuals and the group. Additionally, it involves acknowledging as many facets of emotions as possible, which, given the influential nature of feeling rules, is no easy task. However, it is essential if they are to be influenced through reflective engagement. For this purpose, and as designed in applied group dynamics, it is necessary for the individual and the group to be in constant exchange, with the individual's experiences and reflection processes being relationally linked to the group's experiences and dynamics (Gilsdorf, 2004). This allows individuals to perceive their own emotional positions and experiences within the context of social relationships, making the social and cultural conditioning of emotions experiential and reflexively accessible. It should be taken into account that the designed reflexive process is itself influenced by emotions, a phenomenon that Burkitt (2012) describes as "emotional reflexivity": "[…] emotion colours reflexivity and infuses our perception of others, the world around us and our own selves" (Burkitt, 2012, p. 458). This implies a dual perspective for the design of processes in self-reflective emotion work, as reflecting *on* emotions always also involves reflecting *with* emotions.

5 Discussion

As has been shown, it is necessary for prospective teachers to engage reflexivity with their own emotions in order to develop a critical understanding of oneself and the social world. In this process, self-reflexive practice itself is shaped by emotions: "Feelings of trust or liking or pleasure, or their opposites, frequently guide reflexive practices" (Holmes, 2010, p. 149). And self-reflexive practice is also shaped by the idea of "what others may be thinking and saying about us and the moral or evaluative stance they may take toward us and our actions" (Burkitt, 2012, p. 469). Two selected aspects are outlined for the discussion, which are to be understood as open questions and topics for discussion regarding the approach of emotion work and its ableism-sensitive implementation and the fact of the emotionalization of reflexivity.

(1) Firstly, there is the question of the heterogeneity or homogeneity of the group settings in which (prospective) teachers would work, either with or without individuals with different experiences of marginalization, and what consequences this might have for ableism-sensitive, self-reflective emotion work. The power of feeling rules in a heterogeneous setting could potentially lead to questions about whether the experienced emotions can be allowed. Or the process could be overshadowed by feelings of shame, due to the imagination of value judgments by others, perhaps more so than in homogeneous group settings. Burkitt (2012, p. 462) writes on this: "the uncomfortable emotions that torture us, such as shame, are as much a product of a hyperactive *consciousness* of how others might see us, as of the failure of the unconscious to adequately manage this anxiety." This could mean that unconscious and pre-reflective emotions and emotional patterns remain concealed and thus evade critical reflection or that the process of unlearning, in Spivak's sense, is hindered by the feeling of shame (Spivak, 1996; Castro Varela, 2017). However, if teachers, as representatives of the dominant society, work as "equals among equals," in group processes, there is a risk of reproducing ableist emotional patterns, which in turn undermines the process of "unlearning ableism" and misses the opportunity to "change participants' relations with others and [to] change how they feel." (Holmes, 2010, p. 148). Regardless of how we answer the question of group composition, every reflexive process is, as previously mentioned, shaped by emotions (Burkitt, 2012). This requires, in the sense of a reflective cycle, a recurring reflection on the emotions that emerge, and a corresponding methodological response to them.

(2) The second question concerns the normative tint that reflection requirements can take on. Critical reflexivity is discussed as a "core element of pedagogical professionalism" (Haecker, 2022). However, the demand for self-reflection also carries the risk of becoming an ableist injunction and practice itself, especially when it becomes established as a norm of reflection. As important as self-reflective competencies are in teacher education for inclusion, they are situated within a professionalization context that aligns with certain concepts of ability and expectations for students. These expectations of ability can be understood as "work on the pedagogical self," as a call for self-optimization, and thus can also be seen as ableist (Hirschberg, 2016). This not only increases the risk of resistance and refusal of the offer of reflection but also blocks the path for ableism-critical emotion work. Even though resistance is, from a systemic perspective, an essential element of the reflection process, it is important to design the reflection requirements as an open process that incorporates a critical perspective on normative expectations. Haecker (2022) also suggests demystifying and concretizing the so-called reflection competence. In this context, it would be necessary to critically examine what is considered "successful reflection" in the context of ableism-critical emotion work—a question that requires an interdisciplinary, intersectional and process-oriented approach that consistently incorporates the perspective of Disability Studies.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Author contributions

MH: Conceptualization, Writing – original draft, Writing – review & editing.

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Delegated disabling affects in partnership

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The social and cultural understanding of disability has indicated that it is primarily a consequence of attributional processes, idealized and generalized conceptions of ability, and structural discrimination. Assuming the validity of these conceptualizations, the focus shifts to relational dynamics that determine how and if disability is ‘felt.’ This study explores this relationality in the context of couples parenting a child with disabilities. Intersections of gender and disability associated with self-positioning as ‘special parents’ include specific affective couple arrangements. This study reports on a qualitative study using in-depth interviews with couples who were interviewed first together and then individually. The results indicate a subjectivation of couples as ‘special parents,’ which is difficult to reject and includes affective aspects as well as gendered inequalities in care. Disabling affects are delegated to and felt by the female partner, leading to *affective inequalities* in the partnership. The couple positions the mother as the one who ‘suffers,’ which is part of a well-known affective repertoire that is implied by ableism to feel. The theoretical implications of these empirical results will be discussed as twofold: first, as an entry point to understanding *disability via affection*—how to be affected by disability along intersected cultural attributions; and second, as a suggestion to bridge cognitive and behavioral approaches to emotion by elaborating on how *disabling affects become felt and enacted in subjectivation and relation*.

KEYWORDS

disability, parenting, couples, affect, subjectivation, gender, emotion

1 Disabling affects felt in subjectivation

One may state that disability studies contribute to the decentering of an individualized, relatively autonomous subject. With a conceptualization of disability as a matter of inequality in social structure on the one hand (Hughes and Paterson, 1997) and in turning toward an understanding of (dis-)abled subjects as cultural appearances on the other (e.g., Waldschmidt, 2017a; Goodley, 2014). Studies on (dis-)abling subject formation deconstruct essentialist and medicalized attributions to individuals. They illuminate the historical embedding of knowledge and power production around disability and the (re-)production of difference through othering. Furthermore, they facilitate linking the institutionalization of discursive knowledge on disability to understand (missing) actions or social self-positioning (e.g., Pfahl, 2011; Karim, 2021; Buchner, 2018; Czedik and Pfahl, 2020). However, an aspect that is largely overlooked is *affective formation as part of subjectivation*. It is suggested in this study that the “productive power” in a Foucauldian sense (Foucault, 1989 a. o.), the “interpellation” (Althusser, 1977), or the subjection of “The Psychic Life of Power” (Butler, 1997) does not end with social positioning. It also generates frames of desire, perception, and affect. As Traue and Pfahl (2022) put it, *“Subjectivation, we might say, requires an activity from the individual, which is not simply a ‘mirroring’ of expectations but an affective action through which being-affected, relationality, and valuation ‘become felt.’”* (ibid. 34). Since empirical and theoretical elaborations on (dis-)abling formations of subjects' affectivity are still largely missing, the study contributes to this perspective.

Empirically, I report on a study on heterosexual couples parenting a child with disabilities (Tröndle, 2022a). The position of parents has been critically discussed by the disability rights movement with regard to power relations in care (Carey et al., 2020; Goodley and McLaughlin, 2008; Ryan and Runswick-Cole, 2008). This study takes this discussion into account and understands parental ambivalences as part of the disabling process of (socially speaking) becoming 'special parents.' This study integrates research on subjectivation with perspectives from the sociology of knowledge, thereby building upon extant work in the domain of empirical research on subjectivization (e.g., Traue, 2010; Pfahl, 2011; Schürmann, 2013). The phenomenological-interpretative approach facilitates a comprehensive reconstruction of emotional meaning-making at the level of text and performative interaction (in interview transcripts). In the reconstruction of emotional meaning-making, the manner in which emotional content is expressed, the timing of its articulation, and the addressee of this expression are of significance. Although the majority of research on parents of children with disabilities has focused on mothers, the present study included data from couples and individual interviews with both mothers and fathers. This study elucidates the affective dimension of this process of becoming. Following an overview of the conceptual framework, the study results on affectivity are presented. Based on the results, I suggest an understanding of disabling affect as part of a process of subjectivation and discuss how affection and its rejection, contribute to gendered inequalities in the couple. Furthermore, this will be conceptualized as a component of "emotional inequality" (Illouz, 2012, 2008, 2007) and as *affective activity*. In the last part of this study, this interpretation is discussed in light of recent theorizations in the field of sociology of emotions and disability studies. It is argued that, albeit from different entry points, both research fields share the aim of approaching the interrelations of materiality, bodies, and cultural frames of interpretation.

1.1 Disabling affect

What can be considered a 'disabling affect?' There are certainly several answers to this question, ranging from others' affection and affection toward othering to othered affection. Despite contributions toward an understanding of disabling affect (e.g., Wechuli, 2024, 2023a, 2023b) and affect and feeling from the perspective of disability studies (e.g., Goodley et al., 2018; Jackson, 2021; Liddiard, 2014; Runswick-Cole, 2013; Hughes, 2012), the systematic connection of these concepts and a consistent theorization of their forms of appearance in processes of subjectivation are still missing. However, the question of how disability is felt, or how this affection can be rejected, remains unanswered, although it can be expected to add important perspectives to disability studies. A concept of disabling affect, I argue, potentially mitigates theoretical divisions of bodies (impairment), social-material structure (social model), culture (cultural model, ableism, othering), and materiality (barriers, assistive devices). Focusing on affectivity offers new perspectives on the interplay of social structure, cultural interpretation of (dis-)ability, somatic sensation, and experience. Gregg and Seigworth (2010, p. 3) put it: "With affect, a body is as much outside itself as in itself — webbed in its relations—until ultimately such firm distinctions cease to matter." The 'muddy' position of affect between body and mind has been approached through a multitude of interdisciplinary conceptualizations. Hence, empirically approaching the disabling affect level is not evident, nor is it an answer to the theoretical gaps in the field *per se*. This requires conceptualization of affect and disability in empirical approaches. I will refer to affect when approaching the empirical phenomenon of being affected by disabling interpellation. I also recognize the variety of terminologies in the field because they include inseparable aspects. The specific potential of orienting attention towards affect in subjectivation addresses existing theoretical divisions between bodies, social structure, and culture. In the words of Sarah Ahmed, affect "sticks… sustains or preserves the connection between ideas, values, and objects" (Ahmed, 2010a, p. 29). Affect becomes felt by subjects and is, at the same time, part of historically specific knowledge formation that contributes to subject formation. Additionally, emotion is used in this study as an umbrella term with regard to specific concepts that I consider helpful in approaching disabling affect, namely the theorization as "embodied emotions" (Hufendiek, 2016) and the suggestion of "emotional inequality" (Illouz, 2012, p. 107).

Based on theories of enactment and embodiment, Hufendiek (2018, 2016, 2014) suggests an approach that allows a general location of affect between cognition, body, and the normative structured environment. She argues that "affordances allow for an enactive account of emotions, externalized social norms allow for an embedded account of emotions, and embodied reactions constitute the skillful knowledge through which we grasp the social rules and norms that form emotional content. Taken together, this leaves us with a picture of emotional reactions that do not exist in the head alone but are rather constituted by the structured environment and the skillful embodied agent" (Hufendiek, 2014, p. 377). This theoretical localization of affect as embedded and embodied allows for the connection of emotion to the structured environment without rejecting the idea of a skillful agent toward social norms.

The concept of "emotional inequality" introduced by Illouz (2012, 2008, 2007) refers to a historicization of emotion that sheds light on capitalist and gendered orders of emotion. The seminal study by Arlie Russell Hochschild also represents an important point of reference in this context. In her study, she develops the concept of "emotion work" (Hochschild, 1979, p. 572), which she also discusses as "emotion management" (Hochschild, 2012 [1983], p. 7) or, most prominently, as "emotional labor" (ibid.). She defines emotional labor as "[…] the management of feeling to create a publicly observable facial and bodily display; emotional labor is sold for a wage and therefore has *exchange value* […]" (ibid. emphasis in original). Moreover, she states that she employs the terms "emotion work" and "emotion management" synonymously to "[…] refer to these same acts done in a private context where they have *use value*" (ibid. emphasis in original; see also Hochschild, 2012 [1983]). This empirical analysis can be described as a groundbreaking achievement in the marking of class- and gender-specific usage of emotions and their physically and visibly expressed forms. In the case of the study this research reports on, however, the aspect of emotional use is not the focus. In the context of the study results, the couple-interactive attributions of emotional experience do not appear to be a value that is used. Instead, emotion becomes evident at the couple level, where gendered attributions are reproduced. It is negotiated as belonging to one of the two partners, which manifests gendered inequalities between the partners.

Furthermore, Hochschild posits that "By 'emotion work' I refer to the act of trying to change in degree or quality an emotion or feeling" (Hochschild, 1979, p. 561). The act of changing emotions is not applicable in this case. Instead, as will be discussed later, subjectivation processes are pivotal. These do not result in an act of feeling differently; rather, they merely permit specific "affective repertoires" (von Poser et al., 2019). These, it can be argued, are shaped by gendered and disabling norms of care and heterosexual partnership. At last, Eva Illouz's notion of emotional inequality appears to be particularly pertinent here, given that it was developed with a view toward elucidating the historical and affective transformations occurring in romantic relationships. While some studies in the field of disability studies have already shed light on gendered care in parenting (e.g., Traustadóttir, 2006, 1995, 1991; Goodley and McLaughlin, 2008; McLaughlin et al., 2008; Ryan and Runswick-Cole, 2008), studies on affects in parenting a child marked as disabled are still largely missing. This is mostly due to restraints toward research of care relations in disability studies (exception, e.g., Jackson, 2021). Hence, this study elaborates on the affect around intersected disabling and gendered interpellation that couples parenting a child with disabilities confront. In their responsibility for, and the literal bodily and emotional closeness to, their othered child, include their experiences of othering and discrimination within ableist societies. Furthermore, the couple as a—still—romantic, heteronormative construction includes gendered inequalities. It also comes along with a specific "set of affects," attached to cultural interpretations and expectations. These "affective shimmers" (Gregg and Seigworth, 2010) were reconstructed in the interpretive analysis of the narration and interaction in and through language. With this approach, disabling affects are considered as appearances in couple relationships—more precisely, as *felt parts* of a specific subject formation as parents of a child with disabilities. With the example of parenting couples, becoming subjected as "special parents," the study relies heavily on the explanatory framework of a social and cultural understanding of disability (Waldschmidt, 2017a, 2017b; Waldschmidt and Schneider, 2012; Mik-Meyer, 2016; Oliver, 2009; Campbell, 2008; Snyder and Mitchell, 2006; Hughes and Paterson, 1997 a. o.). Furthermore, it relies on theoretical and empirical work on subjectivation studies (specifically Bosančić et al., 2022; Traue and Pfahl, 2022; Ricken, 2013; Pfahl, 2011; Meißner, 2010; Butler, 1997).

Empirically, this study reports on co-constructed narration and the interaction of couples as entry points to affect. It focuses on performative presentation, relation, and interaction (via language) in interviews with couples and parenting a child with disabilities (Tröndle, 2022a). The position of parents of a child marked as disabled is of specific interest. It is potentially attached to 'both sides' of an othering along disability as a line of difference. Parents can (in a nearly forced way) play a role in the othering of their child. At the same time, they themselves become othered along disabling attributions in their position as 'such parents' (Ryan and Runswick-Cole, 2008; McLaughlin et al., 2008). Disability is thus understood as—on the one hand—connected to experienced barriers and discrimination within the social-material structure of modern, industrialized societies. On the other hand, it is an attribution, appearing against the background of idealized concepts of bodies and abilities, which are associated with suffering, dependency, and need for acceptance. Both analytical levels are considered equally relevant and interdependent. For the case of couples parenting a child marked as disabled, I will foremost refer to disabling affect as the affection along with attributions to disability: The affective repertoire (see also: von Poser et al., 2019; Wechuli, 2023a) is attached to disability markers. From disability studies, we know this affect ranges from the suggestion of "suffering" (Payton and Thoits, 2011; Maskos, 2015).

"Shame," Marks (1999) as resonance to the relational counterpart of the other's affection, like "pity," "fear," or "disgust" (Hughes, 2012). And as its (if available) resisting equivalent, disability pride and celebration of diversity. Only a few studies have specifically addressed the emotional distress of parents of a child with a disability. For example, Jackson (2021) examined the emotional lives of fathers of children with disabilities. Lassinantti and Almqvist (2021) elaborated on gender expectations and pressures to possess certain cognitive skills, which are linked to diagnostic discourses. In addition, they refer to the concept of emotional responsibility (Doucet, 2001, 2015) as a concept related to gender equality. Kwok and Kwok (2020) discuss the emotional work of parents of children with autism in Hong Kong, and Courcy and Des Rivières (2017) elaborate on mother blaming experienced by mothers of children with autism spectrum disorder. Gray (2002) discussed felt and enacted stigma among parents. In short, with the exception of a greater emphasis on blame, these studies discuss quite similar affective repertoires to those of disabling affect, as far as the limited research on the topic can be said to indicate.

1.2 Subjectivation as 'such' a subject

The concept of subjectivation has gained importance in social sciences, philosophy, and educational science, and it relates to different theoretical traditions (for an overview, see Traue and Pfahl, 2022). Subjectivation understood as a process of subject formation is close to the understanding that Judith Butler (1997) suggested by referring to Hegel, Nietzsche, and Freud as the subjection in "doubling back upon itself" (ibid. 22). She argues that "whether the doubling back upon itself is performed by primary longings, desire, or drives, it produces in each instance a psychic habit of self-beratement, one that is consolidated over time as conscience" (ibid.). From this perspective, the subject and its conscience are constituted by interpellations into a specific subjectivity. Discursive knowledge and symbolic order enable the subject to recognize itself as 'such a subject,' intelligible, depending on and related to others. From this perspective, the subject can be understood as constitutively social and relational (Donati, 2015). Within subjection, the subject becomes recognizable and able to recognize itself. In addition to Honneth's sense of recognition as valuation in different social spheres (Honneth, 1995), this is also meant as being seen as such, becoming addressable as an intelligible subject. Through subjectivation, the individual becomes able to act, to experience, and—of particular interest here—to be affected. This is, according to the 'doubling back upon itself,' part of the constitutive rejection of what is not part of the subject's formation and therefore not available as conscience, or a loss to be mourned: "Is there not a longing to grieve—and, equivalently, an inability to grieve—that which one never was able to love, a love that falls short of the 'conditions of existence'" (Butler, 1997, p. 24). From this perspective, affect is not located in emotional space that can be understood as chosen. The internalization of cultural norms creates interior space; it "fabricates the distinction between interior and exterior life, offering us a distinction between the psychic and the social that differs significantly from an account of the psychic internalization of norms" (Butler, 1997, p. 19). Accordingly, affection is embedded in this understanding of subject formation but is open to a collective transformation of discursive knowledge and an iteration of norms (Butler, 1990, 1993). As argued before, this is not understood as a simple "mirroring" (Traue and Pfahl, 2022) of 'obligations to feel,' but also an *activity* to bring about a turn toward the subjecting call (Althusser, 1977) or the iteration. A growing body of literature was developed in German-speaking social and educational science in about the last 15 years to reconstruct processes of subjectivation as empirical phenomena (e.g., Bosančić et al., 2022; Traue and Pfahl, 2022; Bosančić and Keller, 2019; Geimer et al., 2019; Bosančić et al., 2019; Spies and Tuider, 2017; Pfahl et al., 2015; Alkemeyer et al., 2013; Schürmann, 2013; Reh and Rabenstein, 2012; Traue and Pfahl, 2012; Pfahl, 2011; Spies, 2010; Traue, 2010). The empirical study on which this study reports is located in this field of empirical research on subjectivation and methodologically refers to biographical and interpretive methods within the scope of the sociology of knowledge.

2 Couple narration as affective interaction

The reported empirical study on couples parenting a child with disabilities is based on a qualitative research design with the interpretive analysis of 15 narrative biographical in-depth interviews with five heterosexual couples in Germany (Tröndle, 2022a). An initial interview with each partner on their story as a couple was followed by an individual interview with each partner on their respective life stories. This dataset was also used in other sociological studies on couples and work-sharing arrangements. It enables the reconstruction of complex couple arrangements by contrasting the co-constructed couple narration with the individual 'stand-up-narration' of each partner (e.g., Wimbauer and Motakef, 2017; Wimbauer, 2012). Field access was made via parent organizations and led by the search for couples who described themselves as parents of a child with disabilities, without focusing on specific impairments. This study focused on the 'accepted social attribution' of being parents of a child with disabilities. The interviews were supplemented by a questionnaire on biographical information, diagnoses, and support for health care. Due to the focus on work-sharing arrangements, the dataset includes only couples with dual-employment. Between 2014 and 2018, 15 interviews were conducted over 1–4 h and were fully transcribed by the author. The case presented in this study is based on the level of *couples* in focusing on work-sharing arrangements. The sample is relatively homogenous in terms of lived sexual orientation, the lack of international mobility, as well as with regard to the stability as a couple (no explicit stories of separation), and in their romantic and biological framing of parenthood (no co-parenting, adoption, etc.). The sample is heterogeneous in terms of place of residence and local infrastructure (urban, rural), as well as in terms of educational background, diagnoses of children, and the level of daily use of care support.[1] The survey was conducted as part of a dissertation at the Humboldt University of Berlin and was conducted in accordance with the applicable ethical considerations of the university as well as with the Code of Ethics of the German Sociological Association (DGS)[2] (e.g., informed consent, critical review of necessary data, and data protection). Regarding the German research context, Germany has a differentiated welfare state system to support families with a child with disabilities. However, it is characterized by a high level of segregation, which is vehemently defended, especially in the education system (Biermann, 2021; Powell et al., 2021). Furthermore, in the German context, significant differences remain between West and East Germany (old and new Länder). On the one hand, incomes are still comparatively higher in western Germany; there in eastern Germany, there are more extensive childcare structures, since in the former GDR, dual incomes were the norm for both partners. These structural conditions also affect how couples choose to share work and care. Consequently, the sample encompasses couples from both geographical regions. To ensure anonymity, all sensitive data was pseudonymized. The sequential analysis of the extensive narrations was conducted in collaboration with different interdisciplinary interpretation groups of researchers and structured as a successive process of theoretical sampling (Glaser and Strauss, 2017). The analysis is based on interpretive and biographical methods (Rosenthal, 2018; Denzin, 1989; Akremi et al., 2018), focusing on the content and interaction patterns of abduction and narration. Thus, it is based on methodologies derived from phenomenology and the sociology of knowledge and is guided by the hermeneutic interpretation of experience and interaction (Schütz, 1972). Specifically, the enacted interaction during the couple interview shows negotiations within the couple *in situ* and is, however, particularly suitable for approaching affective expression. Such negotiations become visible in occupying or staying silent about topics, in interrupting, and in expressing affection or marking it as not belonging to oneself, as only others feel. These practices of affective interaction are related to stories about and by the couples on the level of content. The empirically based theorization of the analysis finally suggests an understanding of the couple's (also affective) arrangements as subjected as 'special parents' along the lines of gender and disability. The results were also related to historical discourses on parents of a child with disabilities in pedagogy and special education to shed light on institutionalized knowledge, becoming part of their presentation as parents. Thus, the reconstruction of (disabling) affects, in the case of this study, is based on narration and the interaction in narration. In addition to the presentation and interpretation of the couple, the embedding of interactively performed activity in narration was interpreted in terms of discursive knowledge.

3 Subjectivation as 'special parents'

The study revealed that, on the level of narrative structure (what kind of story has been told and how), the couples presented themselves from the position of 'special parents.' This is not trivial at all if we consider that the interview was about *their story as a couple* and that the aspect of dual employment was as much part of the sample

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[1] More detailed information can be found in the table in the Appendix.

[2] https://soziologie.de/fileadmin/user_upload/dokumente/Ethik-Kodex_2017-06-10.pdf

strategy as the aspect of being parents of a child with disabilities. Without space to present the whole picture here, this was interpreted as a quasi-unavoidable formation along the discursive form of 'special parenthood' within excluding and ableist structures of society. Couples find themselves constantly addressed as a specific other, as 'special parents,' and as not fitting into the expectation of parenthood. This happens in everyday life as well as in education, organizations, and medical health care. Experiences of othering include all the ableist reactions we know from disability studies, such as pity, avoidance, aggression, staring, and exclusion. Being constantly confronted with othering is also associated with professionals in medical and specialized health care who are considered co-therapists and specialists for their child. The experience of a subject position as 'special parents' is thus twofold: exclusion via othering and discrimination on the one hand and acknowledgment of a special expertise on their child on the other hand. The latter includes being pushed toward an othering of their own child. This approach has been criticized by disability studies and led to the positioning of parents as "part of the problem" (Goodley and McLaughlin, 2008, p. 6). At the same time, this positioning excludes parents from subversive and empowering positions as allies for their child, connected to pride and anti-oppressive practices (Tröndle et al., 2024; Carey, 2020; Ryan and Runswick-Cole, 2008). Disability movements are critical to parental perspectives because of power imbalances in care relationships. Additionally, processes of subjectivation urge them into 'special parenthood,' including involvement in segregating practices. The couples learn to identify with 'special parenthood,' although it comes along with othering and discrimination (Tröndle, 2022a). Additionally, this subjectivation as 'such a subject' concerns not a single subject but a collective (parental) subject (Tröndle, 2022b). However, how does this subjectivation shape affect? How does it become felt to be 'special parents?' I address these questions with some illustrative empirical examples of negotiating affect in partnership.

4 Delegating the disabling affect in a partnership

The reconstruction of the interview data revealed that the disabling categorization of a child also shapes affection and specific forms of emotional self-understanding as its cognition. Mediating institutionalized structures of segregation and shapes of knowledge on disability, parents can hardly resist representations of themselves as suffering, accepting, and coping, or special. Within the reconstruction of couple narrations, a specific interactive practice of negotiating disabling affect appeared, which is illustrated by the following (anonymized) sequences. In one of the couple's interviews, a woman (who is named here as Jannike Michaelis) is talking about a difficult situation after the birth of her daughter. Due to complications during birth, the child may develop an impairment. To clarify this in advance: The sequence is not chosen due to the narrated event but to illustrate the structural dynamic of this negation of affect in the couple, which becomes especially visible in that part of the interview. Mrs. Michaelis states about the experienced situation:

> Mrs. Michaelis: *"[…] really, really hard, the biggest crises in my life (-) very terrifying, (---) I was in a state of emergency, helpless, powerless, (5) mh these are all characteristics and behaviors, which I had absolutely never known in my life before. […]"* (Interview with Ms. Michaelis and Mr. Löbe, translated).

The perspective from which this period is narrated is striking. The affective state presents as if the patient were completely alone. It is *her* crisis, *her* anxiety, and *her* feelings of great alarm and powerlessness. The phrase feeling "helpless" is also an explicit expression of being alone. Later in the interview, she explained her feelings of loneliness and feeling overwhelmed.

In the individual biographical interview, the male partner (who is called here Wolfgang Löbe) discusses his reaction to the same situation after the birth of his child:

> Mr. Löbe: *"[…] yes (--) and (-) it was then, (-) well a shock, the birth was a shock, yeah it was like that. (--) and erm (--) I mean (-) I was not ready for this (---) yes, well I (-) withdrew myself inside somewhere (-) yeah, because I could not bear this. Hospital and (---) yeah, (--) well I know that Jannike [his wife] erm has not felt cared for by me, but I wasn't able to do it differently yeah, I was escaping into getting things done, I would say, but then, to be there at her side at all times that wasn't possible. […]."* (Interview with Mr. Löbe, translated).

The narration structure highlights Mr. Löbe's difficulties in talking about the situation, his feelings, and his wife's interpretation of being left alone. He breaks up sentences, stops several times, and seems to search for the right words. According to his framing of the event as a shock, and as he is talking about his inability to stay with his wife in the hospital, we can imagine that he also experienced a crisis. His stated strategy to deal with this "shock" was to back away and leave his partner unsupported. Mrs. Michaelis, in return, does not see the possibility of backing away from the overwhelming situation. As a woman, she was supposed to stay with the child in the hospital, despite her own needs. In this respect, both partners refer to a very common gendered framing of needs: the man refers to the woman's need for support and his limitations in answering it. He does not mention his own psychological needs or those of the child. In return, the woman referred to her own needs and lack of support. The woman is expected to take care of the child, whereas the father is expected to take care of the woman. Simultaneously, gender-specific experiences regarding different types of physical involvement in childbirth should also be mentioned. Thus, the embodied and gendered affects are particularly ambiguous in this context. However, the experienced shock, performed in both narrations, takes on a very different connotation at the level of interpretation: On the one hand, we have an understanding of a fundamental crisis, that is, one's own, an overwhelming affect that belongs to the female partner. Conversely, shock is characterized as a compulsion to maintain distance (for the male partner).

The patterns of coping and interpretation of emotional affection are influenced by gender dynamics. The affection becomes gendered in the framing of the answer, the emotion, and the cognitive recognition of the specific feeling. The "shock"—as they both call it—is evaluated as a specific feeling or rejection according to gender norms (guilt versus suffering). Referring to Ahmed (2010a): the affect "sticks the subject and the norm" together; the gendered calling becomes part of one's own subjectivity—the affective aspect of subjection.

Additionally, "suffering" is also the most common emotional attribution to disability (e.g., Maskos, 2015; Hughes, 2012), which becomes relationally negotiated in the couple as the "female form" (Thomas, 1999) of affection. However, this gendered interpretation is 'felt as one's own.' This contributes to an understanding of subjects' affection as constituted by the rejection of what is "impossible to feel" (Butler, 1997) and by embodied norms that urge to feel specifically (Hufendiek, 2016; Ahmed, 2010c). They can be interpreted as impulses that create a turn toward interpellation (Althusser, 1977).

To provide further insights into how these feelings (as the interpretation of affection) are negotiated within the couple, I present another example from the same couple interview, where the partners discuss the woman and her therapeutic support:

> Mrs. Michaelis: *"[…] I got myself a therapist, but not because I was sick, (-) or psychologically damaged (-) It was just that I had to find a way of dealing with this whole feeling of being overwhelmed and with the strain on the partnership."*
>
> Mr. Löbe: *"and you- but you were traumatized. (-) That is definitely something where a therapist can help."*
>
> Mrs. Michaelis: *"Yes! And that was necessary, but beyond that, psychosocial counseling would have been helpful like a lot of other things in order to get orientation on how to live with a disabled child […]"* (Interview with Mrs. Michaelis translated).

In this sequence, the couple negotiates the psychological needs of the female partner. She is described as "traumatized"—and it is not to discuss whether that was the case or not—but it is crucial that in this situation of enormous strain for both partners, she is named as the one who is traumatized, suffering, and in need of help. Her therapy was legitimized in two ways: to overcome trauma and to deal with challenges in their partnership. Later in the interview, the couple discusses how they have found ways, again with therapeutic support, to share their feelings as well as their responsibilities in care. Additionally, they end up working full-time and have arranged options to reduce their work hours, if necessary. However, this process lasts several years, with a lot of support and a high level of reflection and, in both states, discussions around work-sharing tasks, which are frequently initiated by the women.

This is only one of several examples of the analysis. It appears to be always the woman who is named as the one who suffers, is traumatized, or has psychological problems. The couples seem to agree on locating these sorts of experiences and feelings to the women, while the men's own feelings are hardly even mentioned. This observation might not be solely applicable to couples experiencing ableism but becomes understandable as a more generalized gendered structure in romantic couples, which must be proven empirically. Nevertheless, the affective repertoire mobilized in the couples is an attribute of disability. That disability is associated with suffering, and psychological dilemmas are a common attribution, not only in everyday life. Within research on parents of children with disabilities in the field of special education, this became, at least until the mid-eighties, a generalized underlying assumption in research on a "family tragedy" (Risdal and Singer, 2004; Ferguson, 2002, 2001; Tröndle, 2022a, pp. 58–73). However, the act of disabling the 'call to suffer' is predominantly experienced by the mother. In the context of shared challenges faced by both partners, this suffering is often delegated to the female partner.

One possibility of framing this observation is to simply assume different strategies of coping with disability caused by traditional gender roles, as Hinze (1999 [1991]) suggests. However, I want to argue that it is more adequate to explain the observation through the lens of "emotional inequalities" (Illouz, 2012). Illouz discusses the term market patterns of romantic choices, arguing that they are related to gendered expectations of (not) expressing emotions. This would lead to a common form of gendered oppression in romantic partnerships that she calls 'emotional inequalities.' Although the concept is used in a different context, it is an adequate framing of what these couples perform: Disabling affects are negotiated in the couple as belonging to the female partner, while the male partner seems to identify them as not belonging to him. This is not a simple affective difference, but it can be addressed through coping strategies to overcome the disabling affects. These strategies varied across the sample, ranging from positive thinking, seeking therapeutic help, and developing skills and expertise to attending parent support groups. Mothers perform emotional tasks. The withdrawal strategy is not readily available to mothers because it relies on the other partner to assume responsibility for care work, domestic duties, and emotional engagement. The delegation of affect within the couple is connected to the readiness of both partners to care for and organize support for both partners. However, as explained above, the understanding used here does not aim at a purposeful and functional use of emotionality. Rather, it is interpreted as a gendered othering along the label of disability. Disabling emotional engagement on the part of mothers is thus a necessity, protected by the existential needs of care for a child and gendered delegations of responsibility, rather than a choice to fulfill. One may posit that the normative expectation of emotional restraint represents a form of emotional engagement assigned to fathers. In this manner, the avoidance of emotional involvement can be viewed as a form of emotional effort that is required in accordance with gender norms. However, from a pragmatic perspective, these gendered emotional demands at the level of action are intertwined with other forms of sustained care work and the recognition of care work in relation to paid work.

To give an example from another case, a couple of interviews with Mr. and Mrs. Huber illustrate that the expected burden and coping practice are in some cases also *explicitly* attributed to the mother. Mr. Huber states about his wife, after she mentioned that she had read about parents' associations:

> Mr. Huber: *"And then you also cheered up a bit more because you had a goal or an anchor for you, something to get involved <<Mrs. Huber: Mhm>>. That was quite good, I must say. (-) Otherwise, you would have fallen into another hole."* (Interview with Mrs. and Mr. Huber).

The "hole" Mr. Huber mentions refers to an expected emotional state of depression of Mrs. Huber's if she had not had this "anchor," represented by her involvement in the parental organization. Mrs. Huber partially agrees or at least does not explicitly disagree with the interpretation of her spouse. The mother further becomes the one caring about ambivalence within 'special parenthood,' coming along with othering and discrimination and in treating *her* 'suffering.'

In the context of this study, the empirical examples are illustrative of the specific phenomenon of co-produced emotional inequalities that occur alongside disabling expectations of fitting into a particular subject position as 'special parents.' These cases are part of a comprehensive case reconstruction that points to the same gender dynamics of delegating disabling affect in couples in different ways. The experience of being 'othered' and addressed as 'special' and the task of coping with it are in the analyzed cases mostly delegated to the female partner. In return, masculine attributes seem to enable the rejection of disabling affect. The mother becomes the one who feels the disabling interpellations and takes up the emotional burden of feeling and treating the disabling affect. Thus, it is an example of an affect that is entangled with intersecting markers of difference. This interplay becomes a part of subjects' affects. This intersecting emotional and gendered task in intimate relationships has been highlighted in disability research regarding "psycho-emotional disablism" in sexual relationships (Liddiard, 2014; see also Thomas, 1999).

Nevertheless, the delegation of affect in partnership is not confined to the couple. Societal rejection of disability, ableism, othering, and segregation contributes to the need for individual solutions in couples. Moreover, medical care systems can stabilize unequal arrangements in partnership by addressing mothers as co-therapists and as responsible for the organization and coordination of assistance for their children. At the same time, women experience discrimination in such organizations. Several women in the study talk about how they are treated in hospitals, where the father is praised for his commitment, while the mother is treated as a source of irritation and disruption. Besides the affection within the couple, several interviewees also reported strong emotions from the side of relatives. Some mentioned that their parents regularly cried on the phone about their children's disabilities and that they felt urged to comfort them. Mrs. Huber, for example, mentioned a phone call with her mother after she received a diagnosis for their son:

> Mrs. Huber: "And then I went home and called my mother and said Julian has a disability, he is mentally disabled. And my mother cried a lot on the phone. And I thought, why is she crying? She has no RIGHT to cry! Because it's not that BAD, it's not, he's not, he's still our JULIAN, I thought all the time. Why are they all so sad? He stays the way he is. (--) Maybe because it was also my feeling, that my mother was now DISAPPOINTED (-) disappointed in ME." (Interview with Mrs. Huber, translated).

Facing disabling affect after the diagnosis, this mother is confronted with signs that her child is now seen as 'someone else,' someone to be mourned. Strikingly, she interprets the grief of her mother as disappointment in herself. In such situations, parents, and mothers in particular, are once again asked to perform emotional effort for others, to overcome or accept the disabling affect (of others). According to Runswick-Cole (2013), mothers are asked to perform emotional engagement by "wearing it all with a smile." Lassinantti and Almqvist (2021) also referred to the potential of using gender discourses to resist or negotiate gendered responsibilities in parenting. For example, Bamberg (2022) elaborated on the concept of "counter discourses." These comments make us aware of "how subjects can 'talk back'" (Bosančić et al., 2022).

5 Affecting disability as activity in subjectivation

This study explored gendered emotional dynamics in couples with one child classified as disabled. This study demonstrates that through subjectivation processes, mothers tend to take the emotional burden of 'suffering,' which is attributed to disability and special parenthood. Fathers constrained by gender-specific norms of affection tend to withdraw emotionally. This study further highlights how medical and social institutions reinforce these gendered roles. It has been argued that these patterns reflect and lead to 'emotional inequalities' in partnerships, whereby disabling emotions are delegated to the female partner, leading to other forms of emotional effort and care work. The delegation of disabling emotions in partnership as part of a specific subjectivation also points to a shared interest in disability studies and the sociology of emotions: approaching interrelations of materiality, bodies, social structure, and cultural frames of interpretation. In disability studies, these interrelations are often pursued with regard to questions of ableism, othering, and discrimination, but also in regard to the potential forgetting of bodies in the light of social models and strong emotions evoked by the "Non-Disabled Imaginary" (Hughes, 2012) toward disabled bodies (Hughes, 2012, 2009; Hughes and Paterson, 1997). For example, by asking about disabling (material and social) barriers to inclusion and how they are historically gained and interactively performed. In addition, the entanglements of reifying knowledge on disability with generalized and idealized concepts of ability and bodies are examined (Campbell, 2008; Goodley, 2014). In the sociology of emotions, these interrelations between materiality, bodies, and cultural frames of interpretation are primarily discussed as transmission, mediation, bodies, and forms of emotions and affect (e.g., Brennan, 2015; Brinkema, 2014; Anderson, 2014; Gregg and Seigworth, 2010). In more recent contributions, affect has been discussed as situated between cognition, bodily affection, and the culturally enabled affordances of affect (Hufendiek, 2018; Ahmed, 2010c). We already see several overlaps between cultural studies and the sociology of emotion, often with regard to questions of identity and emotion, and primarily from perspectives of feminist and gender studies (Pedwell and Whitehead, 2012; Ahmed, 2010b). Theorization of embodied subjects is also discussed in both fields (for disability studies, e.g., Marks, 1999; for the theory of emotions, e.g., Hufendiek, 2018, 2016, 2014; Fuchs, 2024). For the case of romantic relations, the conceptual framing "emotional inequalities" (Illouz, 2012) serves to create a deeper understanding of gendered and ableist affective interactions in the couple (on working families see also Hochschild, 2012 [1989]). The empirical example of couples parenting a child with disabilities touches (at least) two cultural forms, associated with a specific powerful suggestion of an "affective repertoire" (von Poser et al., 2019; Wechuli, 2023a): Romantic partnership, including parenting, is an idealized "promise of happiness" (Ahmed, 2010c) on the one hand, and ableist affects associated with disability, as a 'promise of suffering and dependency,' along idealized concepts of ability on the other (Maskos, 2015; Campbell, 2008; Goodley, 2014; Buchner et al., 2015). Both frames participate in subject formation and affective activities to turn toward the recognition as 'special parents.' The intersecting affective attributions that take part in the acceptance of mothers to be 'special parents' encompass ambivalence, othering, and discrimination (Tröndle, 2022a).

I also want to argue that *affection* can be understood as the *activity of affecting* disabling interpellation. Thus, I understand disabling *affection* as being evoked by ableist cultural norms and attributions and as an embodied activity. From this perspective, affectivity is not necessarily a passive experience. It is rather an affective (body-)movement, an engagement in opening up toward change and formation that involves the whole, embodied subject. Furthermore, this activity of affecting bridges the contradiction of standing 'alone' for an othered collective subject. The mother is urged to, but also 'ready to affect' the disabling interpellation, while the father is partly enabled to reject it—not feeling or delegating the affect. The disabling affect helps both partners adhere to the cultural framework of romantic partnership. The couple is addressed together as parents, but 'affecting and enacting a special parent' is especially performed, acknowledged, and 'felt' by the mother. This involves consequences for the readiness to deal with interpellation. The recognition of oneself as 'suffering' and 'coping' can become a form of compulsion, while its rejection is not available due to the involved gendered power dynamics in couples and the dependency of the child on care. This could be understood as a way of not jeopardizing the 'promised happiness' as a romantic couple and family. I further suggest understanding this as *affective activity*, a practice related to what Sally Haslanger calls "cultural technē" in order to "[…] organize information and coordinate action, thought, and affect […]" (Haslanger, 2021, p. 63). This broad understanding of "ideology" allows us to capture disabling affect as an activity of a subjectivated feeling that is informed and organized by "clusters of concepts, background assumptions, norms, heuristics, scripts, metaphors […]" (ibid.), which are to be reconstructed in their relevance for the respective affection. Besides the theoretical framing of affect 'sticking to objects' as a practice used via "cultural technē." I want to argue that the theoretical frame of subjectivation as subjection (Butler, 1997) is helpful to grasp the embodiment of disabling interpellations as part of the formation of subjected affectivity. The "open-ended in-between-ness" (Gregg and Seigworth, 2010, p. 3) of affect, as well as an understanding of *affective activity in subjectivation,* challenges longstanding theoretical dualisms such as body and mind in disability studies and affect theory.

The study on couples parenting a child with disabilities shows how affective activity can be performed in couple arrangements: disabling affect, attached to the collective subject of 'special parents,' becomes negotiated, accepted, rejected, or delegated in partnership (Tröndle, 2022a). This suggestion provokes an engagement with *subjects' affection as relational activity informed by cultural technē, becoming felt and enacted in subjectivation.*

Data availability statement

The datasets presented in this article are not readily available because sensitive raw data cannot be shared. Requests to access the datasets should be directed to judith.troendle@uni.lu.

Ethics statement

Ethical review and approval was not required for the study on human participants in accordance with the local legislation and institutional requirements. All study participants have signed a written informed consent.

Author contributions

JT: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Writing – original draft, Writing – review & editing.

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Conflict of interest

The author declares that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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Appendix: Anonymized core sample couples and core characteristics

Couple		Employment constellation	Children (age, disabilities, lives in the household)	Residence
Core sample	Förster	**Employment arrangement** At the time of the first and second interviews, they were practicing a supplemental income arrangement: Mrs. Förster is 40% employed; Mr. Förster is 100% employed. At the time of the third interview, they were practicing a breadwinner housewife arrangement: Mr. Förster is 100% employed; Mrs. Förster is 0% employed. **Education and field of employment** Mr. Förster has an academic education and works in a highly skilled technical job. Mrs. Förster has a high school diploma (German: Abitur) and works in a skilled job in the health sector.	Child 1 is 14 years old. It does not have a disability. Child 2 is 12 years old. From, has a complex disability and requires extensive day and night support and care.	Rural area near a larger city in West Germany
	Michaelis/Löbe	**Employment arrangement** Dual career arrangement: Mr. Löbe is 100% employed; Mrs. Michaelis is 100% employed. **Education and field of employment** Mrs. Michaelis has an academic education and a highly qualified job in the field of international cooperation; Mr. Löbe has an academic education and a highly qualified job in the field of law.	Child 1 of Mr. Löbe from a previous relationship is 22 years old. It does not have a disability. It lives with the mother most of the time and in the couple's household on a daily basis. Child 2 is 5 years old and has a complex disability. It lives in the couple's household and requires extensive support and care (day and night).	Medium-sized town in West Germany
	Huber	**Employment arrangement** Supplementary income/dual-income arrangement: Mrs. Huber is 50–65% employed and also supports her husband's business; Mr. Huber is approximately 100% self-employed in his own company (depending on the order situation). **Education and field of employment** Mr. Huber has a high school diploma. He has an apprenticeship and is self-employed as a locksmith; Mrs. Huber has a secondary school diploma. She has an apprenticeship and works in administration.	Child 1 is 19 years old and has a chronic illness that is not acute (no need for support). It does not live in the household anymore. Child 2 is 18 years old and has a cognitive and mild physical disability. It lives in the couple's household and has a slight need for support in everyday life.	Rural area in West Germany
	Balke	**Employment arrangement** Supplementary income arrangement: Mrs. Balke is 50% employed; Mr. Balke (over 100% employed, only at home at weekends). **Education and field of work:** Mr. Balke has an academic education and a highly qualified job in the technical field; Mrs. Balke has an academic education and a highly qualified job in the technical field.	Child 1 of Mrs. Balke from a previous relationship is 28 years old. It does not have a disability and is not living in the household. Child 2 of Mrs. Balke from a previous relationship is 26 years old and has a cognitive and physical disability. It lives in the couple's household and has a slight need for support in everyday life. Child 3 is 7 years old and has physical disabilities. It needs support in everyday life and health monitoring day and night.	Small town in West Germany
	Winkler	**Employment arrangement** Dual Employment arrangement: Mrs. Winkler is 75% employed; Mr. Winkler is 100% employed. **Education and field of work:** Mr. Winkler has an academic education and a highly qualified position in the field of education; Mrs. Winkler has a high school diploma (German: Abitur), an apprenticeship, and a qualified position in the field of education.	Child 1 is 30 years old. It does not have a disability and does not live in the household anymore. Child 2 is 28 years old and has a cognitive and physical disability. It has a moderate need for support in everyday life.	Big city in East Germany

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Toward a politics of shame: cripping understandings of affect in disabled people's encounters with unsolicited advice

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The prevalence of unsolicited advice in the lives of disabled people is well-catalogued in the mass of articles and social media posts dedicated to the issue. However, less is known about the affective impacts of this advice on disabled people and the potential resistance that may be enacted, such as shame, toward affects labelled negative. The present manuscript builds from original qualitative research to explore the links between emotion, mind, and body that occur in interactions involving unsolicited advice between disabled and non-disabled individuals. Non-probability convenience sampling was used to recruit 15 disabled individuals in Ontario, Canada for participation in semi-structured qualitative interviews that were inductively coded and narratively restoried. Building from these narrative accounts, the research addresses (1) the affective impacts of unsolicited advice on disabled people and (2) how disabled people negotiate the emotional impact resulting from unsolicited advice and *blame culture* individually and collectively. Ultimately, this research argues that, while unsolicited advice acts as a method of blaming and shaming that has the potential to structure disabled peoples' lives, disabled people resist feeling *ashamed* and instead bridge from initial responses of fear and shame toward other emotions such as apathy and sadness in resistant and potentially empowering ways.

KEYWORDS

disability, unsolicited advice, emotion, affect, shame, resistance, blame, apathy

1 Introduction

The prevalence of unsolicited advice in the lives of disabled[1] people is well catalogued in the mass of articles and social media posts dedicated to the issue (e.g., Graham, 2011; Blahovec, 2017; Pulrang, 2020). Unsolicited advice is often outlined in posts as coming from well-intentioned desires to help but ultimately positions disabled people as in need of cure or as having caused the circumstances of their disablement through either action or inaction. This is exemplified by chronically ill content creator MB Marshall who, in a 2024 Instagram reel captioned "Things people have actually said to me (as an chronically ill person)" [sic], lists the unsolicited and often contradictory advice they have received. Some of the examples include "I think you can cure that if you go gluten free," "have you tried positive affirmations?," "you should lose weight," and "you should gain weight." With over 750 comments from other chronically ill and disabled people commiserating over similar experiences, and jokingly suggesting ever more ludicrous ideas mocking unsolicited advice including "summoning ancient eldritch beings," these interactions

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[1] I use identity-first language as opposed to person-first (e.g., persons with a disability) in alignment with disability justice activists and scholars as well as out of my own preference as a multiply disabled person.

are a microcosm reflecting broader dynamics of disability and unsolicited advice. In particular, these examples reflect persistent ableism that aims to make disabled people responsible for their disability (and thus "fixing" it) while simultaneously constructing them as infantile and incapable and thus in need of advice and/or rescue.

Despite the plethora of online anecdotes surrounding disability and unsolicited advice, less is known about the affective impacts of this advice on disabled people and the potential resistance that may be enacted toward negative affects such as shame. In this work, I conceptualize unsolicited advice as advice given without explicit solicitation of, or requests for, guidance and which is largely understood to be unwanted by the recipient. Unsolicited advice may take the form of explicit advice giving (e.g., "you should…") but can also come across in less explicit discursive terms such as questions (e.g., "have you tried…?"). Research on advice, primarily undertaken in the disciplines of medicine and cross-cultural psychology, has largely focused on solicited advice and the "potential problematic side-effects of social support interactions" (Boutin-Foster, 2005, p. 5). As such, very little is known about the factors leading to unsolicited advice giving in personal relationships despite prior research indicating that unsolicited advice "tends to have more negative effects than receiving solicited advice" (Feng and Magen, 2016, p. 752).

While this prior research on advice offers insight into the potential affective motivations for the *giving* of unsolicited advice, very little is known about the actual affective experiences, emotive consequences, and resistant strategies of disabled people who *receive* such advice (Ingram, 2023). In articulating affective experiences, I conceptualize affect as articulating the same concept as *emotion.* Both terms work to solve the same problem: "that of distinguishing first-person from third-person feeling, and, by extension, feeling that is contained by an identity from feeling that is not" (Ngai, 2005, p. 27). For this reason, I use affect and emotion interchangeably, viewing them as differing intensities of the same structuring of feeling. Ultimately, what is at issue in the giving and receiving of unsolicited advice is the availability of emotional responses to different parties within the interaction. Understanding what emotions and outward affective performances are available within interactions is crucial due to their capacity to indicate the *political horizon*—what is considered politically desirable within a collectivity (Gould, 2009; Kolarova, 2012).

Scholars working at the intersections of disability and affect have indicated that *shame* in particular is an emotion with considerable political power, particularly within the context of disability (Jóhannsdóttir et al., 2021). Disability's positioning at the heart of the 'moral economy'—in which moral sentiments interact with broader sociopolitical contexts—shapes the interpersonal contexts and ways in which disabled people show up in the world (Hughes, 2012). Unsolicited advice is one such example of "a moral tool" (Tabin et al., 2019, p. 90) that emerges from this context as a way to respond to the perceived threat that disability poses to the "carefully constructed myth of the 'able' body and self which is foundational to a neoliberal social order" (Liddiard and Slater, 2018, p. 3).

Existing research on disabled experience and affect largely focuses on the solely negative impacts of disablism and moral tools (such as unsolicited advice) or, conversely, seeks to tell a positive story about disability pride. Such research not only positions positive and negative emotions as an intractable binary but further positions emotions labelled negative, such as shame, as the unfortunate but inevitable result of deviating from normative ideals in a disablist society (Jóhannsdóttir et al., 2021). While this binary remains dominant, scholars such as Sarah Ahmed and Sianne Ngai have argued for a move away from these dichotomous classifications. This study resisted this binary classification of emotion and instead sought to explore the following questions with attention to the plurality of emotion that can arise in interpersonal interactions: (1) What are the affective impacts of unsolicited advice on disabled individuals? and (2) How do disabled individuals negotiate the emotional impact resulting from unsolicited advice and 'blame culture', individually and collectively? To answer these questions, 15 narrative semi-structured interviews were conducted with disabled individuals in Ontario, Canada.

In the following analysis, I first outline the conceptual framework that shapes the theoretical structure of the analysis (section 2), drawing on diverse literature from across disciplines. I then present the methods used, including semi-structured qualitative interviews, and participant demographics (section 3). This is followed by the presentation of the interview data, in context of the conceptual framework (section 4). This discussion traces the timeline of affective response to unsolicited advice, beginning with initial responses such as fear and shame and bridging over time to emotions such as sadness and apathy, which are experienced and deployed in potentially resistant and empowering ways. In the final section, I present a discussion of the findings and my articulation of what they mean for a crip politics of shame; I then conclude with a brief discussion of research beyond binaries.

2 Conceptual framework

2.1 Face-threatening acts and politeness theory

Extant literature on advice broadly conceptualizes the interpersonal challenges it poses as originating "from its nature as an intrinsically face-threatening act" (Feng and Magen, 2016, p. 752). Goffman defines 'face' in his seminal work *Interaction Ritual* as the "positive social value a person effectively claims for" themselves in a particular contact (Goffman, 1967, p. 5). One's feelings and sense of self become connected to one's face, emerging in concert with the ways that one perceives and is perceived in social interaction. Crucially, face is claimed. As a socially situated identity, it does not arise naturally but is claimed when one enacts the behaviors that align with a given role in an interaction *and* when others act toward them in a way that sustains that role. Ineffectual performance or reception can result in *losing* face, at which point one's identity in a social interaction becomes threatened, potentially producing affects typically labelled as "bad" such as shame, embarrassment, or anxiety (Goldsmith, 2007). The role of advice in the production of "bad" affects can be understood through the notions of face-threatening acts (FTAs), as described in Brown and Levinson's (1987) politeness theory.

Brown and Levinson (1987) propose that the desire to honor and maintain face is a key reason behind the use of politeness or linguistic softening strategies in social encounters. The use of politeness is crucial to maintain face, as many social interactions can threaten face, and thus be classified as FTAs, including orders, requests, warnings, and *advice* (Goldsmith, 2007). In order to explore exactly how face is threatened in these social encounters, Brown and Levinson (1987) further categorize face as being either positive or negative. Positive face refers to the desire to have one's image be recognized, accepted, and approved of by others. Negative face refers to the desire to have one's autonomy respected, independence permitted, and to not be imposed upon by others. As an FTA, advice can be seen as jeopardizing both positive and negative face.

Advice giving as a practice “suggests that the advice recipient lacks knowledge or competence concerning the issue at hand or is unable to cope with a problem without external aid” (Feng and Magen, 2016, p. 752). By suggesting that the advisee is unable to act wisely on their own, notions of competence, value, and acceptability are challenged, threatening positive face (Goldsmith and MacGeorge, 2000). Similarly, advice giving by definition implies that the advice-giver has insight that the recipient lacks, “positioning the interactant asymmetrically” and potentially inducing notions of hierarchal valuation of both knowledge and self into the interaction (Feng and Magen, 2016).

Not only does advice giving threaten the recipient’s positive face, advice rejection is an FTA that can impact the positive face of the advice-giver. Advice rejection can be seen as a form of overt social rejection wherein not only is the advice rejected but, by extension, so too is the knowledge, value, and face of the advice-giver. Advice rejection can therefore be seen as symbolic of “an advisee’s devaluation of an advisor,” threatening their own understandings of their competence (Belkin and Kong, 2018, p. 181). Understanding the rejection of advice as a threatening of positive face and competence of the advice-giver is crucial, as Peluso et al. (2017, p. 501) suggest that giving advice “is one means to restore a sense of control” in one’s life and that it offers a means to restore that control because “it provides a signal of competence to an individual.” In a neoliberal western society, where the potential of disability itself is viewed as a deep threat to capitalism and control, giving advice to others operates as a means to assuage one’s own fears and reclaim perceived control over one’s own body. As such, a rejection of this advice is severe FTA, as the act of giving advice in the first place is means of claiming positive face in the form of competence signaling. Resultantly, the presence of an FTA on both sides of an interpersonal encounter can lead to heightened affective responses, further threatening face.

2.2 Shame and blame culture

It is important to contextualize the face-threatening nature of unsolicited advice within the broader context of contemporary neoliberal western society and how disabled people are articulated as objects of resentment within it—often acting as scapegoats for perceived societal ills (Hughes, 2015). Hughes argues that disabled people have been constructed under neoliberalism as synonymous with parasitism, fraud, and idle dependency—blameable subjects within what he terms a “blame culture” (Hughes, 2015, p. 993). I argue that within the context of unsolicited advice, disabled people emerge not only as blameable subjects but *shameable* ones. Such a conceptualization is indicated in the observation from Jóhannsdóttir et al. (2021, p. 354) that blame culture is “where shame is clumped and reinforced, and disabled people are even judged responsible for numerous societal problems.”

Theorizing shame sociologically, Scheff (2000, p. 96) asserts that shame is “a large family of emotions that includes many cognates and variants, most notably embarrassment, humiliation, and related feelings such as shyness, that involve reactions to rejection or feelings of failure or inadequacy.” The emphasis on rejection as a cause of shame is crucial in understanding shame sociologically, as it conceptualizes shame as resulting from a loss of social connection or a threat to the bond between oneself and another (Scheff, 2000; Bath, 2019). Understanding shame as always intra- *and* intersubjective, occurring in response to others, positions shame as “perhaps the most intimate of feelings,” as it can only be “brought into being by an intimate proximity to others (Probyn, 2004, pp. 330–331). For this reason, Scheff asserts that shame is “the premier social emotion” (Scheff, 2000, p. 84). Importantly, while shame is brought into being in the presence of others, the calling into being of shame also occurs in specific contexts and spaces and is inflected by historical and political circumstances (Probyn, 2005; Richards, 2019). Shame is a thus a complex entanglement of the personal, the political, and the social which constitutes “powerful material and discursive performances” (Shefer and Munt, 2019, p. 145). These performances of shame are instigated by and felt within the body as a “desire to ‘fit in’ and, at the same time, a feeling of being ‘out of place’” in space, context, and community (Probyn, 2005; Johnston, 2007, p. 30).

In the context of disability, shame as a feeling of “being out of place” is inherently intertwined with neoliberalism and the ways that disabled people’s mere presence can work against societal norms of self-sufficiency, meritocracy, and taken-for-granted independence. Here then, shame emerges from affective practices of shaming or blaming (such as unsolicited advice as an FTA), which themselves emerge from broader societal feelings of resentment toward disabled people. Indeed, Jonas identifies resentment as “an entry point for identifying the norms of advice giving” (2017, p. 815). In identifying the norms of advice giving, much pre-existing literature focuses on how to best give advice in order to minimize negative impact and experiences of rejection of the self (Hepburn and Potter, 2011; Jonas, 2017). Resultantly, the focus is moved away from the experience of the recipient of advice, with their affective response devalued in favor of the advice-giver. In this way, resentment does not end with the advice itself but extends beyond it into the reception of reaction. In contexts of advice with disabled people as the recipient, this may align with the abjectification of their identity, wherein their social worth is devalued and stigmatized, positioning them as “objects of disgust” (Hughes, 2015, p. 996).

This positioning may serve a powerful purpose in neoliberal advice transactions, as affective intensities such as disgust have been identified “as key strategies through which the neoliberal subject becomes engaged in the task of its own self-governance” (Parker and Pausé, 2019, p. 251). Thus, in a neoliberal context, the positioning of disabled people as objects of disgust within a ‘blame culture’ may be crucial to the navigation of unsolicited advice, as the simultaneous abjectification of disability identity and a collective societal resentment serves to devalue disabled individuals’ face. This devaluation of face may serve to minimize the collective responsibility in interactions to save face, decreasing the desire for politeness in navigating FTA and instead positioning such advice as deserved and in fact *necessary* for the restoration of the collective neoliberal order and individual notions of merit.

2.3 Against the shame/pride binary

While shame, blame, and resentment are often binarily constructed as purely “negative”—the antitheses to disability joy and pride—it is important to consider how these affects indicate an attunement to environment and connection and the ways that they are engaged and/or resisted. Literature on shame resistance as it relates to disability is typically articulated through the language of a journey *from* shame *to* pride, in overcoming, in passing through phases and acceptance processes, and ultimately in “arriving” at pride and self-recognition (Morris, 1991; Brown, 2003; Manessis, 2014; Richards, 2019). The language of the journey is present in articles and memoirs navigating disability shame/pride, with the beginning exploring the feelings of denial and shame that accompany the onset of or recognition of disability and concluding with a triumphant declaration of pride, shame long forgotten. While these narratives bring important first-person perspectives and explorations of shame/pride to the fore and articulate the experience of disabled pride in a critical way, the neat acceptance narrative that resolves with a triumphant overcoming comes with affective implications and material effects.

The linear trajectory of shame to pride in many ways mirrors linear notions of healing and development that reinscribe disabled people as deficient and continue to position a whole and normative self just out of reach. Such framings of pride as the natural endpoint of a disabled affective identity and experience create parallels of overcoming: one must overcome their impairment and shame for acceptance in the general population, personal life, and disabled community. The parallels of overcoming are reinforced by the medicalization of shame in disabled narratives and the move toward bio-psycho-social interventions into disabled lives to promote pride as a "protective factor for self-esteem" (Bogart et al., 2018, p. 155). The medicalization of shame thus works to discursively construct pride not as a radical or resistant act of self-reclamation but as an affect indicative of better psychological outcomes and alliance with normative mental well-being. While positive self-esteem is no doubt important, the construction of pride as a medical outcome that works to deny or mitigate shame positions it as another aspect of the self for disabled people to control. Thus, pride becomes another tool of medical responsibilization.

Pride, and in many cases joy, therefore become for disabled people an element of what Frye (1983) terms the affective double bind—wherein the oppressed are required to perform a degree of happiness and cheer. To be oppressed is therefore to also be expected to engage in an affective performance that upholds the fantasy of happiness and, in the case of disability, meritocracy and neoliberalism that the broader population is oriented to. Resultantly "anything but the sunniest countenance exposes [marginalized peoples] to being perceived as mean, bitter, angry or dangerous" (Frye, 1983, p. 2).

It is from this understanding of the double-bind of oppression, and potentially harmful implications of seemingly solely "positive" emotions such as pride, that an exploration of the positive or generative potentials of shame become clear. Ahmed (2010b, p. 67) identifies what she terms 'affect aliens' as those who are "affected in the wrong way by the right things" or who "affect others in the wrong way." In the first sense, one may be affectively alien not necessarily due to responding to the same events or objects as others with the wrong affect (e.g., feeling joy when others are sad) but rather by experiencing an affect in relation to the what others deem "the wrong objects" or events (Ahmed, 2010b, p. 171). In the instance of disability, which is broadly recognized as an object of tragedy that should invoke affects of pity and sadness (Goodley et al., 2018), experiencing joy, pride, ambivalence, or any other affect thus results in a disorientation to the expected collective affect and renders one an affect alien. While this alienation can be isolating, Ahmed also indicates that affective alienation can work to expose the origins of violence and act as a form of consciousness raising (2010). Indeed, Ahmed asserts that "the act of noticing limitations can actually make life seem more rather than less limited" (Ahmed, 2010a, p. 584). In this way, seemingly negative emotions such as shame can in fact open up new ways of being in the world that acknowledge the role of oppression and move toward collective liberation. Some disability scholars and artists, including Clare (1999), Chandler (2009), and Chandler (2014) have spoken to the impossibility of the shame/pride binary, particularly as it relates to desire and belongingness in disability and queer communities. The explorations of these scholars form the foundation on which explorations of unsolicited advice and affect can be built. This includes the intertwined desirability of politicized identities, the pride with which we relate to them, and the shame that they can generate in simultaneity.

Thus, it is from these academic explorations, affective frictions, potentials, and sociopolitical contexts that this study and its guiding research questions arise. Very little literature on the reason for and the experiences of unsolicited advice for disabled people exists (For an example see Vayreda and Antaki, 2009); however, the prevalence of this social issue is indicated by the amount of non-academic articles, memes, art shows, and disabled cultural productions that speak to disabled people's experiences of unsolicited advice (For an example see @unsolicited_advice_projects on Instagram). Using this conceptual framework built from a constellation of critical disability studies, affect theory, and extant literature on unsolicited advice, this research seeks to qualitatively explore the affective experiences and political implications of unsolicited advice.

3 Methods

I approach this work from my position as a white, queer, multiply disabled person who was raised by a disabled mother. This coalescing of identities critically informs the way that I have approached this research, its participants, and my engagement with the role of 'researcher.' I informed participants from the outset of my positionality, and it often further emerged in conversation throughout interviews. As such, I cannot lay claim to the role of the detached or 'objective' researcher but instead locate myself as deeply embedded in this process. I note this in order to account for and engage with reflexivity, both in the data collection process and in the restorying of my participants narratives. However, I do not wish to imply that my disability here is a disadvantage or threat to the integrity of the study; rather, I see it as my greatest strength. In recognizing qualitative interview spaces "as intersubjective emotional encounters" (Hoggart, 2021, p. 582) inherently imbued with personal values, I am able to utilize my own lived experience as a disabled person in navigating the *emotional* rapport of the research space in a way that is both informed by, and informs my use of, affect theory and narrative inquiry.

3.1 Participants and sampling

This research draws from interviews conducted with 15 disabled participants residing in Ontario, Canada. Due to the ongoing COVID-19 pandemic, as well as in an effort to increase access for potential participants, all recruitment and data collection for this study was conducted through online means. A non-probability convenience sample was initially collected via social media recruitment, with additional snowball sampling occurring as participants recruited their own social networks in response to their own interview experience. All participants for the study were required to meet the following sample criteria: (1) be 18 years of age or older; (2) reside in Ontario, Canada; (3) be able to communicate in either English or ASL; (4) identify as disabled; and (5) have received unsolicited advice about their disability or health more broadly.

Recruitment was undertaken with a goal of recruiting 12–15 participants for the study—a number that aligns with extant literature indicating that in-depth qualitative interview data typically reaches saturation within the first 12 interviews (Guest et al., 2006; Brian and Clarke, 2013). Between social media recruitment and participant referrals, a total of 24 individuals responded to the call for participation. Out of this initial sample, three participants were deemed ineligible as they did not meet sample criteria, and a further attrition of six participants occurred due to either a lack of monetary compensation or fluctuating capacity due to health considerations. As a result, the final sample of this study consists of 15 participants ($n = 15$). Demographic information along with pseudonyms chosen by each participant are outlined below[2,3]:

Pseudonym	Age	Pronouns	Racial identity	Disability type
Adrian	30–39	He/Him	White	Neurological / chronic illness
Alexis	40–49	She/Her	White	Chronic illness / neurodivergence
Ayla	19–29	They/She	White	Cancer / chronic illness
Brooke	30–39	She/Her	White	Physical / Full-time wheelchair user
Eljay	60–69	He/Him	White	Physical
Helen	50–59	She/Her	Asian	Neurodivergence
Honey	19–29	He/They	White	Physical / neurodivergence / neuroqueer
Lily	19–29	She/Her	White	Neurodegenerative / autoimmune / physical and cognitive
Miki	60–69	She/Her	White	Cognitive
Reese	19–29	She/They	South Asian	Physical
Robin	19–29	They/Them	White	Chronic illness / neurodivergence / wheelchair user
Saff	30–39	They/Them	Mixed-race	Neurodivergence / chronic pain / developmental / mobility
Sam	19–29	They/Them	White	Neurodivergence / chronic illness / physical / mobility
Sara	40–49	She/Her	White	Neurological / mobility / neurodivergence
Toni	30–39	She/They	White	Physical / chronic pain / neurodivergence

3.2 Data collection and analysis

Data collection took the form of in-depth semi-structured qualitative interviews that took a narrative inquiry approach. Narrative inquiry, which approaches interviews and research with a deep and rich investment in participant stories, was selected due to its potential to intertwine storytelling, emotion, and theoretical inquiry such that it produces *lived theory*, connecting the "daily life of the protagonist" (participant) with broader social issues (Kim, 2008). Interviews were conducted over Zoom and ranged in length from 45 to 80 min. Participants provided written consent prior to booking an interview and verbal consent the day of the interview to ensure ongoing consent and mutual understanding. All interviews were transcribed verbatim to maintain the unique ways that participants spoke, in part due to their disabilities. As such, stuttering, stammering, and tangents were included in the final transcripts as data relevant to the participants at hand. In line with a grounded theory approach, data analysis was conducted through two rounds of inductive emergent coding using NVIVO. This grounded approach, which allows inductive theories and themes to be generated inductively *from* the data, was chosen due to its alignment with the inductive sensibilities of narrative inquiry. Further, due to the permeable and slippery nature of emotions, coming up with fully discrete categories of overarching affective response was avoided in favor of larger umbrella categories of an overarching affective 'stem' (e.g., anger, fear) with more specific terms and experiences articulated by participants used as subcodes.

Categories of affective response were grouped using Willcox's (1982) model of the 'feeling wheel', in which language to describe emotive responses are grouped by "primary feeling," those typically considered "primarily pleasant emotions" (peaceful, powerful, and joyful) and "those which are usually unpleasant" (sad, mad, and scared) (274). The feeling wheel model is useful for an affective examination of unsolicited advice over time, as the layout of the wheel includes the opposite correlate of an emotion where the supposed binary inverse of an emotion is included directly across the wheel. This, Willcox (1982) asserts, allows for a conceptualization of "the process of converting feelings" and the affective bridges that exist through coping mechanisms. This model therefore allows for an understanding of how the affective response to unsolicited advice may be converted over time. Using this list of thematic codes and the narrative arc that emerged through analysis, I then set about re-storying the collective participant narrative, slotting thematic codes into the narrative sections that they aligned with and generating a tentative timeline of affective experience. This timeline begins with initial affective responses such as fear, hope, anger, and shame. It then traces how these initial affective responses shift over time toward sadness, loneliness, and apathy in potentially empowering and resistant ways. This narrative and thematic list forms the outline of the following results section.

Ethics approval for this project was sought and received from the Queen's University General Research Ethics Board (GREB).

4 Results

Throughout participant's stories about their experience with unsolicited advice, a clear narrative chronology emerged that coincided with several key themes. Participants articulated the way that their internal affective response and outward social performance

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[2] Pronouns are used in lieu of sex or gender categories based on the desire of several participants to have their specific gender identity or sex assigned at birth remain unclear to the reader in the write-up of the research. However, to respect the co-existing desire of some participants to speak to their experience as trans folks or as "women, femmes, or coercively feminized people" (Kayn, as cited in Ratchford, 2019), data about specific participants' self-identification is provided as relevant throughout this article.

[3] Disability "Type" does not suggest an official typology but rather reflects the language chosen by participants specifically to self-describe their experiences in and with their bodies. This choice to opt for self-description is grounded in a desire to restore autonomy to disabled people in the research process and a refusal to collapse disabled experience into researcher-selected discrete categories. As the *affective* experience of disability is what is at stake in this research, the terms that brought participants the most *comfort* were prioritized.

to unsolicited advice had changed over time. This varied based on disability onset and age, but overwhelmingly there was an articulation of a trajectory from initial experiences of unsolicited advice in adolescence or adulthood (upon disability onset) toward different ways of knowing and being in those interactions. This entailed a move from initial affective responses of *fear, hope*, *anger*, and *shame* in reaction to unsolicited advice toward *apathy,* which allowed for the negotiation and embrace of seemingly negative emotions such as shame and sadness. However, it is important to note that while this narrative arc was evident across all participant narratives, it is far from a linear trajectory. Even as participants described the onset of different emotions over time, others persisted or existed in tandem with those experienced initially. Thus, while a chronology of emotions is clear in the data, and is used to structure the following results, it is inherently complicated by the cyclicity and simultaneity of human affect.

4.1 Initial affective response

In telling their stories, participants indicated that their response to unsolicited advice initially, both in adolescence and upon disability onset, was a strong internal affective reaction. Importantly, however, this internal emotional response did not seem to align with an external performance in the social interaction, with participants instead indicating that they were less likely to "stand [their] ground" (Brooke), due to a more limited understanding of themselves as disabled people and what worked for their symptoms. This more limited understanding of themselves, as well as the newness of disability, meant that participants were experimenting with what felt okay to them. Toni discussed this experience in the first few years after disability onset:

> I kind of had to go through this period of time where I was trying to figure out what my boundaries were, particularly around advice and suggestions and care. And I think a lot of people go through that because, initially, if it's something you have never experienced, it's scary, and you want it to stop, or you want to find solutions. You believe there might be solutions and you believe that those solutions would take the form of the health condition not existing. So, I think in that time I was a lot more vulnerable to the input of others and more open to it.

As participants discussed their perceptions of unsolicited advice, their affective response, too, shifted. Ayla noted that "your initial emotional response, adolescent emotional response is typically not very articulated" and therefore came with some strong emotions—emotions that Reese spoke to in their assertion that.

> when I was first diagnosed, I kind of did feel some resentment. I thought like, look, I tried all of these things and they did not work. And I still have this like issue that I now have a name for… but none of these things actually helped. And you know, just being like an angsty sort of 20-year-old, I just like, I would kind of want to go off on these people and be like these things aren't helping!

Beyond change over time, participants described their affective response to unsolicited advice in expansive and varying terms. While Willcox's (1982) model of the feeling wheel, which guided the initial categorization of affective categories (see Methods), labels shame as a secondary feeling of sadness and hope as a secondary feeling of power, I have chosen here to explicitly name them as their own categories due to the prominence of both of them and their inverse correlate in participant narratives. Therefore, the most prominent initial affective responses to unsolicited advice can be described as *fear*, *hope*, *anger*, and *shame*.

4.1.1 Fear

Fear was a prominent affective response animating participants' discussions of unsolicited advice and disability. Participants used words such as unsafe, insecure, uncomfortable, triggered, dread, doubt, insecurity, anxiety, concern, confusion, helplessness, and rejection to describe the emotional response that unsolicited advice evoked. As previously discussed, the newness of disability, or of disability in adulthood, meant that participants described feeling confusion, anxiety, and fear about the progression of their disability as well as the social interactions they were now confronted with. For some, this fear and discomfort emerged from a lack of words to describe their experience. Lily described this, stating "when I first received that piece of advice, it made me uncomfortable inside, but I did not know how to verbalize how it made me uncomfortable, and so I kind of just took it." For others, the fear came from a place of feeling like they were unable to "communicate to other people safely."

This fear of being unable to safely communicate was grounded in unsolicited advice being perceived as (and sometimes explicitly working as) accusations of malingering, leading participants to question whether their actions and behaviors in relation to their disability were the "correct" ones. This self-doubt and anxiety were described by Toni and Honey:

> Yeah, there was a time where I would leave those conversations [around unsolicited advice] feeling like maybe I'm not doing enough. Maybe I am making the wrong choices. Maybe I would be in better shape if I were doing things differently (Toni).
>
> I do still have that experience of like, am I over exaggerating? […] I feel like a lot of the unsolicited advice, at least that I receive, stems a lot from like "you are overexaggerating" and like "things are not this bad," and "you are just imagining it" (Honey).

Accusations of malingering, both explicitly made and implied by experiences of unsolicited advice, produced self-doubt, anxiety, and fear in participants who were made to question if they were doing enough. This impact of unsolicited advice was summed up by Reese as "very triggering for me, and makes me really like anxious… and I do not know it's just… it feels overwhelming." Ultimately, through lack of vocabulary and knowledge about disability, and a lack of safe space to communicate due to accusations of malingering, unsolicited advice worked to produce initially fearful and anxious reactions in participants.

4.1.2 Hope

The uncertainty and fear that participants felt around their disability and unsolicited advice also lent itself to the potential onset of hope at the advice and opportunities being offered. Toni and Lily discussed the increased openness they felt to advice at the beginning of disability onset, due to fear with a desire to grasp "at anything that could possibly help" (Lily) because "it's scary, and you want it to stop, or you want to find solutions" (Toni). Reese described their experience with the hope that unsolicited advice inspired in this context, saying "toward the beginning of my disability journey when these elders would kind of give this unsolicited advice it would kinda like, raise my hope a bit." Honey spoke extensively to this idea of hope, recognizing that as someone who is newly diagnosed and therefore "recently new to disability" that unsolicited advice still gives them a sense of hope and excitement. He explained:

> So, when I receive this unsolicited advice I get excited because I'm like this will finally work and like, especially when it's newer unsolicited advice […] it's like, it's excitement! It's like, oh, my gosh! I finally found something that might work.

However, this hope was complicated by cyclical feelings of disappointment that emerged when advice did not work, a disappointment that was heightened by the repetition of the hope cycle:

> And then it loops back into when it does not work, then there's something even worse. So, it's kind of this, and this loop of like I feel really excited when I receive unsolicited advice that's brand new, and then when it does not work and I hear it again, it turns into like this disappointment, and like it, kind of reminds me of that… like something… it feels like something is even worse than it was originally whenever I hear advice that's been repeated over and over, just because, like, if I've tried it, and other people are recommending it, that means that it must have worked for them (Honey).

Through the affective cycle by which unsolicited advice inspired hope and then disappointment, this disappointment was slowly converted or 'bridged' (Willcox, 1982) into frustration. Honey articulates this in his discussion of frustration and hope coexisting: "I think I think there's still that frustration there, but I think it comes across as this hope of like this, fresh like "Oh, my gosh, I gotta do this again." But also, there's this obviously new opportunity. Through this affective conversion articulated by the participants who experienced hope, the theme of frustration, or anger, emerges.

4.1.3 Anger

Much like fear, anger was a dominant primary emotion in the affective narration of people's experience with unsolicited advice. Participants described their anger using words like anger, ire, hostility, irritation, frustration, aggravation, annoyance, resentment, and betrayal. When asked what emotions unsolicited advice brought up in them, Brooke responded saying "that is pure frustration for me" or "sometimes, depending on the circumstance it could be a little anger too" while similarly others articulated unsolicited advice as producing "indignance, frustration, aggravation" (Miki), and largely making participants "fucking mad. It's just sort of like, really?" (Sara). Much like the impetus for fear, experiences of anger too emerged from the accusations of malingering, lack of self-knowledge, and incompetence implied by unsolicited advice. Participants identified frustration, irritation, and anger as coming from "sort of like a feeling of being condescended to" (Ayla) and as triggered by assumptions that participants were faking "to avoid working, to you know, sponge off of society, you know? That stuff can be very angering" (Eljay). Robin discussed the implications of these assumptions more, saying.

> like because I already feel like I am not good at like doing things, I do not feel like a capable person, it like triggers me to think that they are just being judgmental. You know what I mean? So, it instantly like pisses me off because I'm like you are just assuming, you know?

For Honey, unsolicited advice and its attendant assumptions were even more frustrating when they did not "come from like a place of care, and it just comes from like a place of fixing." Conversely, in a medical setting, Saff highlighted the feeling of frustration and betrayal that can emerge when one is actively trying to find a solution and instead gets advice on an unrelated matter (for example, advice on weight loss when seeking help for chronic migraines). Saff stated that unsolicited advice "when it's from a medical professional, it's betrayal. Yeah, because these are the people that we go to for help, because hey, I'm in pain." Here, non-disabled people's self-assigned expertise in disabled persons' wellbeing and the role of the "cloak of incompetence" are highlighted across both non-medical and medical settings.

Unlike fear but similarly to hope, repetition of unsolicited advice played a role in the affective response of anger, often articulated as frustration or annoyance. Participants described being aggravated by the repetition of advice that further assumed their incompetence and pulled them back into an unwanted social interaction.

4.1.4 Shame

Participants also consistently highlighted the role of unsolicited advice in producing shame. Participants both explicitly named shame and alluded to it through continually identifying self-consciousness, self-loathing, embarrassment, rejection, and inadequacy. This aligns with Scheff's (2000) sociological theory of shame that aligns shame with embarrassment, humiliation, rejection, and feelings of inadequacy. In describing their own emotional response of shame, participants also pointed to unsolicited advice as "a moral shaming" (Alexis) that was felt most deeply "at the beginning" (Sara) of one's disability journey. This presence of feelings of inadequacy in initial experiences was articulated both by participants with adult-onset disabilities, like Sara, and in adolescence. Ayla spoke to this, saying that in their adolescence "there was a very strong sense of like self-loathing."

Participants named that unsolicited advice caused "all those thoughts of self-doubt and inadequacy" (Reese) that "hurt because it's like oh, well, I'm never going to be enough" (Saff). That shame is felt within the body as a "desire to 'fit in' and at the same time as a feeling of being 'out of place'" (Johnston, 2007, p. 30); this was described by participants who discussed shifting their behaviors in an attempt to mitigate shame. Helen offered one such example:

> And so something [embarrassing] like [an awkward interaction in the hallway] happens, and people start thinking you are weird. And then, because, you know, people think you are weird, you start being really self-conscious, and maybe behaving weird, or you know, behaving differently, like avoiding people, going down different hallways and things, and it just sort of built to a point where people may get burnt out, or they might have a meltdown, or, you know, be in some kind of real distress.

Here, Helen points to the experience of shame pushing her to shift her behavior in order to avoid other shameful experiences. This reflects Probyn's (2004) assertion that shame is incorporated into how one moves in the world. This further aligns with Tabin et al. (2019), who asserted that shame emerges through loss of connection and rejection by others. While Helen here highlights that loss of connection and subsequent avoidance, Sam spoke at length to the role of unsolicited advice in causing feelings of rejection:

> Yeah, again, I think rejection. Is that an emotion, that sense of rejection? […] I think that for a lot of people, and probably myself included unsolicited advice, I think, triggers rejection sensitivity in that people immediately feel or can feel that the advice, because again, the perception of what advice is going to vary. But people perceive it as an attack on them, their character, their experience, whatever and then, in response, become defensive.

The rejection, shame, and sense of being attacked that Sam identifies here in the action of unsolicited advice connects to the idea of shaming as an affective practice that works to produce shame as not only an emotion but "a moral tool" (Tabin et al., 2019:90). While participants were encouraged to think broadly about who gave them advice, and no parameters on the kind of advice-givers they could talk about were given, participants exclusively gave examples of advice from non-disabled advice-givers, suggesting the weaponization of shame as a moral tool by the non-disabled populus specifically.

This was just one way that unsolicited advice as an affective practice produced shame, with other participants identifying interlinked practices of mockery, labelling of burden, and assignation of moral blame. Lily spoke at length to the ways that unsolicited advice worked to produce shame:

> Anyways… burden, shame, of course. How could it not? If someone says, hide exactly this thing from me, how could that not make me feel shame about it? You know it like so blatantly communicates that they do not want to see that part of me, or that they do not want that particular thing to happen to me […] Yeah, for sure, it definitely makes me feel like they, they interpret me not following their advice as an opportunity for me to become more burdensome. And then that it is shameful that I would not take their advice, because you know, they are giving me a nugget of wisdom that will allow me to, you know, maintain goodness in their eyes, you know?

This idea of needing to take on and comply with unsolicited advice as a way to mitigate symptoms or reduce burden on others—a burden that is identified as a moral failing—was highlighted throughout other participants' stories too. Miki highlighted that unsolicited advice sometimes worked to establish her as having caused her disability herself, saying "it's that whole fatalistic, either I invited it, or some force intended it to happen to me. But what they mean when they say that, like if I were really to absorb that I would be living with guilt, with the idea that I've done myself damage." Ayla too identified that with unsolicited advice "if you fail to like, do any of these things that people are suggesting it's sort of like bringing your death upon yourself," further asserting that it is a way to create a moral blame or find a fault as to why a condition occurs. The notion of fault was echoed by Brooke, who spoke to an intertwined experience of disablist and fatphobic shaming at a medical clinic:

> That nurse that that shamed me at that clinic… it did feel like shaming. It did feel like fat shaming. It was like my fault I was obese, and like one, I'm a wheelchair-user I have no mobility in my legs at all and so like exercise is difficult. You're not going to find me at the gym six days a week [Laughing].

Ultimately, participants' stories pointed to the ways that unsolicited advice operated as an affective practice that worked to position disabled people as responsible for risk mitigation of their disability and to shame them into what advice-givers deemed morally "good" behavior. This aligns with the conceptualization of the moral economy, which a participant, Saff, further identified in their discussion that "we do live in that culture of shame." Here, unsolicited advice thus operated as a tool to maintain belief in "a just world" where "good things happen to good people" and bad things happened to bad or irresponsible people who "deserve it" (Saff).

4.2 Affective response to advice over time

In narrating their experiences with unsolicited advice, participants described the shift that happened over time as they came to develop response scripts, coping mechanisms, and simply trust themselves and the communities that they found through taking their identities and disabilities seriously. Continuing with Willcox's (1982) feeling wheel, this section explores how the experiences of participants with unsolicited advice—while in some ways co-existing with the four initial affective responses—largely shifted through sadness and loneliness toward apathy. While Willcox identifies *sadness* as a primary emotion, I pull out two of the secondary and tertiary emotions identified in more depth: *loneliness* and *apathy*. These affects were also held in tension with others, bridged or converted, and navigated through as varying resistance strategies.

Participants consistently described their reaction to unsolicited advice as shifting over the years, a process that was highlighted in particular by participants who had been living with their disabilities for a decade or more, as well as participants in their thirties and older. While all participants indicated a shift in response over time through their narrativization and anecdotes, these participants with decades of experience were quick to explicitly name the way that their experience had shifted over time and reflect on it. Toni asserted that their "reaction to [unsolicited advice] has changed a lot over the years," a process that other participants described as consisting of both shifting internal affective reactions and development of external responses. Brooke spoke to this, explaining.

> I had to learn over the years kind of how to stand my ground, and you know kind of navigate… and it has not always been successful. There have been, you know upset providers or upset people. I've been upset. It depends, you know, depending on the circumstances, but I do find that I'm getting… because it unfortunately repeatedly happens, I'm getting better at the response. I've kind of dialed in on how to respond.

The emotional element described by Brooke here was echoed by Eljay, who described how over his years of experience he has "been more inclined to react one way then another, more inclined to take it in stride and try to understand." He further explained how around 5 years after disability onset, he was more prone to react with anger, but as time has gone his emotional reaction varies with mood, but he is more likely to "just let it flow […] like water off a duck's back."

Participants also echoed Brooke's sentiment of dialing "in on how to respond." Miki explained that "after 18 years you learn how to respond like you… you get the phrases, and if they dismiss you, you are willing, I guess, to dismiss them. Not them, but the comment." This move toward internal dismissal of unsolicited advice was a prominent theme across participant narratives; however, it was not always reflected in the outward response within the social interactions. In addition to shifting affective response, these themes of dismissal of unsolicited advice and outward performances are discussed further below.

4.2.1 Sadness: "at this point it's more like existential crisis sadness"

Experiences of sadness and alienation dominated the continued affective narratives of participants, alternately described using words such as sadness, grief, hopelessness, depression, collapse, loneliness, disconnection, alienation, isolation, exhaustion, tiredness, and resignation. While this affective predomination of sadness guides the narrativization of this section, sadness continued to exist in tension with the other affective responses previously described. In particular, anger, most frequently described in the form of frustration and annoyance, continued to make an ongoing appearance; however, these affective responses of frustration also seemed to affectively bridge toward resignation and apathy, with the ongoing repetition of unsolicited advice providing the fuel for this emotional conversion. Frustration also emerged continuously as the trajectory from those who had initially experienced its inverse correlate, hope, and which eventually transformed into disappointment through storytelling. Therefore, while I take sadness as the primary emotion of interest here due to its narrative dominance, I do not wish to suggest that this dominance precludes other affective responses to unsolicited advice, nor that it exists without tension being held between it and other coexisting emotions.

Participants described how sadness emerged in their ongoing experiences with unsolicited advice as they came to realize, over repeated interactions, the critical ideological and social disconnection between them and the disablist society at large. Saff described how this impacted them, saying that the "knowledge that we could die and no one would really care, we are entirely disposable… that weighs on you." For participants, this conceptualization of their disposability was manifest in unsolicited advice with the suggestions of ways to mitigate or "fix" their disability, representing a fundamental devaluation of them as people. Toni explained this, saying.

> [disability] is beyond a specific bodily concern, it is your whole world, and I think that that is just so deeply misunderstood. So, it's like they want it to be eliminated. But then it feels like they want you to be eliminated, like that's what it becomes, because there is no separation for so many of us.

This recognition of the devaluation of disabled bodies led to a sadness, not necessarily rooted in shame or self-consciousness at one's own disposability, but a broader sadness at the disablist state of the world and the impacts of oppression on themselves and others. Saff described being "unable to get over the injustice of that […] so, what ends up happening for me a least, is that it sends me into a place of collapse and depression." This was echoed by Toni who described the way that unsolicited advice contributed to a feeling of "existential crisis sadness."

4.2.2 Loneliness: unsolicited advice as disconnection

Participants highlighted the role that unsolicited advice played in producing a sense of disconnection from others in social situations or heightening their awareness of relational disconnections that already existed prior to advice-giving interactions between themselves and others based on the advice-giver's perception of their disability. Unsolicited advice was described as a moment in which the disconnect between the self and the advice-giver became clear, resulting in participants describing feeling disconnected, alienated, isolated, lonely, dismissed, and not seen, heard, or recognized as themselves. This was primarily described in relation to pre-existing relationships, and therefore was a moment in which ableist preconceptions of the participant, or broader experiences of "othering" that facilitated the interaction, became clear. For some participants, this disconnect between themselves and others felt so wide that advice-givers were described as "liv[ing] in another world" (Miki) that separated the two in the interaction. Lily spoke poignantly to this disconnect:

> I think a lot of the time, especially when people are giving me unsolicited advice in the context of disability it highlights the ways that they feel disconnected from me, and that's their way of communicating that. And a lot of the time it kind of like comes out of left field, like you do not really realize that that was a disconnect that you had in that relationship until they verbalize it through advice that they are giving.

This eerie feeling of someone not really knowing who they were was further compounded by participants' description of unsolicited advice as a "dismissive" (Saff) action, which ultimately "bypasses the reality of [their] experience" (Toni). Helen spoke to the way that unsolicited advice worked as a dismissive strategy to produce disconnect:

> But if you say like, "you know, you just need the right planner," then you are sort of shutting that conversation down. You're making them think that, you know, they cannot really confide in you, because you'll just tell them what they should be doing, instead of listening.

In this way, unsolicited advice worked to not just make evident the presence of a disconnect between advice-giver and recipient but to cut off potential futures of connected interaction. This ongoing disconnection was described by participants as resulting in almost scripted behavior from advice-givers that relied on formality and an emotional detachment from the recipient that was seen as indicative of a broader social detachment from disability. Helen spoke to this, saying "people, have gotten to the point where they are dealing so formally with me now, and it's like breaking my heart." Unsolicited advice therefore caused disconnection or made participants aware of a pre-existing disconnection—a disconnection that was not temporary but sustained through ongoing alienation of non-disabled recipients through formal language and the repetition of that advice (discussed further below). Understanding this shift away from the initial highly intense and reactive affective response to unsolicited advice and toward a deeper societally oriented sadness is crucial to understanding how this disconnect produced a sense of exhaustion in participants that oriented them away from the advice-giver and toward apathy, resignation, and indifference.

4.2.3 Apathy: the politics of disconnect

Participants repeatedly described how repetition of unsolicited advice and the resultant cycle of awareness of disconnect played a role in a move toward apathy, as they slowly resigned themselves to the experience of the interaction. Robin described how "it's happened so so much like my entire life. Like anytime someone starts saying "Have you tried…?" I'm like, shut the fuck up, you know? Like do not start, please." Similarly, Reese described how their current "initial reaction is usually like, "oh my God! This again?!" This process of dismissal, wherein participants recognized the cycle of unsolicited advice as an irritant to be dismissed, was described by Brooke who said "for someone whose had a lifelong disability, it's like at this point you are not being helpful, you are just being annoying" and Adrian, who stated that with unsolicited advice "I already know that. Like I do not need to hear it, it gets to be annoying."

To this irritant of unsolicited advice, participants therefore came to resign themselves to the situation. This was described by Adrian who said, "pretty much like there's no point in disagreeing with them" and Helen's statement that "I have to kind of resign myself to the fact that I'm an unwitting participant in the education of people." Through this resignation to the experience of unsolicited advice, participants described how some unsolicited advice, typically the most often cited lifestyle-oriented advice, slowly came to affect them less. For Helen, unsolicited advice became "truly just words, and I'm like… okay?" which was echoed by Reese in their statement that unsolicited advice was "still not exactly welcome, but I do not dread it the same way I used to." As participants came to dismiss unsolicited advice as just unwelcome words, they described a move toward apathy, where the feelings "just roll through [their] body" (Sam) and eventually "one day someone may say something and I just let it, you know, like water off a duck's back" (Eljay).

This move toward viewing unsolicited advice with a degree of apathy was crucial, as it allowed disabled participants to affectively and effectively navigate the interpersonal dynamics around unsolicited advice. This move toward apathy can be seen as a resistant strategy to the harms of unsolicited advice as an FTA. The harm of unsolicited advice relies on the recipient of unsolicited advice buying in to the collaborative nature of the encounter wherein both participants attempt to save face and sustain the other's as well. By becoming aware of the disconnect between themselves and the advice-giver, participants were able to affectively distance themselves from the collaborative nature of the encounter and the emotional impacts of attempting to maintain face in an inherently face-threatening situation. As the repetition of unsolicited advice was frequently contradictory (e.g., 'you should go running', 'you definitely should not go running'), participants were able to dismiss unsolicited advice while simultaneously recognizing that any course of action they took would ultimately cause them to 'lose face' in the eyes of advisors.

This resignation to losing face was ultimately described as liberating by Toni, who offered that "in some ways that realization can be really freeing. Because once you realize that you are never going to get it right, then you do not have to try." This liberation from resignation was compounded by an indifference and apathy to advice as participants came to dull to it through repetition. As the FTA of advice is heightened by any degree of obligation to follow the advice or a sense that taking the advice may constrain autonomy, by dismissing unsolicited advice as "truly just words" (Helen) that they were not obligated to follow, participants preserved their internal sense of negative face. In this way, participants resisted not only the internalization of negative face but also the sense of expectation to provide a smooth social interaction for those threatening their face. This simultaneous internal preservation of negative face and resignation to losing their positive face therefore worked to resist some of the affective modalities of emotions such as shame and fear.

5 Discussion: feeling ashamed and a crip politics of shame

While navigating incredibly different life circumstances, diagnoses, relationships, and contexts, participants collectively told a story of affective changes, wherein initial experiences of unsolicited advice brought about fear, anger, shame, and hope, which was bridged and converted over time toward affects stemming from sadness, notably loneliness and apathy. While there was a distinct shift toward different affective responses over time, it is crucial to note that these emotions continued to coexist, with initial responses not necessarily disappearing but merely becoming less prominent in participant's stories about themselves and the world. This shift toward apathy and resignation as advice repetition caused it to lose its salience and allowed for participants to in some ways detach from the encounter of unsolicited advice as a face-threatening action. This 'bridging' of emotions opened up space for participants to resist the expectations of compliance or gratitude for unsolicited advice that they saw coming from advice-givers in an interaction and to also hold space for multiple emotions at once. Notably, *shame* continually emerged across all narratives as a crucial piece of the affective puzzle—an emotion that participants both continually made space for in themselves and saw as a direct process of *shaming* from some individuals giving advice.

The specifics of how advice operated as an affective shaming practice were deeply influenced by the specifics of relational norms between advice-giver and recipient and whether a disability was hidden or perceivable. Participants with hidden disabilities, such as neurological conditions, neurodiversity, or chronic illness, described most of the advice they received as coming from those who had reason to know their disability status, namely family, friends, coworkers, and medical professionals. Conversely, participants with perceivable disabilities, such as wheelchair users or individuals with other visible mobility aids or assistive devices, spoke more frequently to the role of unsolicited advice from strangers.

While unsolicited advice from all people worked as a moral tool, advice from those that participants were close to, such as family and friends, was often seen as intended with care, even if the impact was not experienced as such. Despite 'good intentions' (a term used frequently by participants) and an ethic of care, this advice was still perceived as a moral tool to restore them to a state of disablist and neoliberal conformity and often to soothe the advice-giver's own discomfort or fear of someone they cared about veering from the path of normativity. Conversely, advice given by coworkers, medical professionals, or strangers was seen more directly as an attempt to "fix" the disabled person or eliminate the "problem" of disability altogether due to a socio-cultural devaluation of disability. Crucially, the relational aspects and perceivability of disability also impacted the perceived motivation for advice, with those with hidden disabilities seemingly more likely to be accused of malingering, whereas those with perceivable disabilities seemed more likely to be labelled as a burden.

Ultimately, in describing their initial affective experiences, participants identified unsolicited advice as an affective shaming practice that worked to reaffirm the moral economy in which disabled people were both "good to mistreat and good to be good to" (Hughes, 2012, p. 832). Here, unsolicited advice emerges out of what Saff identified as a "culture of shame" and what extant literature labels as "blame culture" (Hughes, 2015) where disabled people are subject to shaming due to the misdirected ideological rancor of resentment experienced by the non-disabled population for disabled people's perceived production of burden. Importantly here, resentment and shame do not just appear but are institutionalized within a sociopolitical context (Mulligan and Brunson, 2020) that accounts for unsolicited advice's presence across various interpersonal encounters, including clinical ones. Crucially, while unsolicited advice operates as a shaming practice, not all participants indicated that they had been a/shamed (Kolarova, 2012), pointing toward an uneven distribution of affective responses to shaming practices and the potential of resistance.

Beyond the uneven distribution and experience of shame in relation to shaming practices, the politics of affect here emerge in that, while non-disabled advice-givers are permitted to engage in shaming practices, disabled recipients of advice are expected to signal their docility and cheerfulness in the face of oppression (Frye, 1983). This is described in Reese's prior assertion that the most frustrating element of unsolicited advice "is that you cannot really voice discontent about that, because people take it personally." Here, disabled people are expected to be docile and tolerant despite Scheff's (2000) assertion that a shaming practice does not need to be very strong to produce shame and Kolarova's (2012) assertion that processes of shaming induce strong affective reactions. Thus, despite the likelihood of experiencing a stronger affective reaction than the potential discomfort being expressed through advice giving, disabled people must control their emotions or risk "being perceived as mean, bitter, angry or dangerous" (Frye, 1983, p. 2). This again represented a devaluation of disabled peoples 'face' needs in interactions, justifying FTAs such as unsolicited advice. The need to maintain docility is further exacerbated by intersections with other identities such as one's gender, race, or class. Saff, a mixed-race AFAB non-binary person with a history of being coercively feminized, spoke to this, saying.

> you cannot really have that emotional reaction because then you are going to be labelled as "crazy" in air quotes, more reactive, and that'll be used against you. Oh, classic. And of course, they'll rely on your intersections, so you are just an angry woman, you are just an angry like insert racial slur here.

Here, unsolicited advice works as a moral tool to maintain the colonial racist, sexist, disablist and cisheteronormative neoliberal status quo that relies on the production of the self as the "right" kind of person in order to achieve respect and be seen as morally "good."

Beyond the obvious social and psychological impacts of unsolicited advice on recipients as described through these affective responses, unsolicited advice was also articulated by participants as causing direct material harm through access to resources and medical treatment. Participants identified that advice-givers operated under the assumptions that "well, this might help and if not, you know, it cannot hurt" but articulated that unsolicited advice, especially in the form of inaccurate medical information from doctors and others, "can hurt!" (Alexis). For this reason, unsolicited advice was sometimes "problematic, sometimes even dangerous" (Toni) as it impacted how and when participants accessed medical care (Alexis, Ayla, Brooke, Honey, Miki), increased their mental burden (Ayla, Helen, Reese), impacted career decisions and their initial capacity to identify with disability (Lily, Toni), and, in the case of participants such as Alexis, Lily, Miki, Saff, Sam, and Miki, actively impacted their disability symptoms and diagnostic experiences. Unsolicited advice can therefore be understood as acting as an affective moral tool with very real emotional, social, psychological, and material consequences. Resultantly, as outlined, participants described varying resistant strategies to mitigate these harms that resulted in affective changes over time, including resigning themselves to situations, joking around, dismissal, or setting explicit boundaries. Resistant strategies can be understood as any behavior, internal or external, that allows an individual to mitigate the potential harm of an affective shaming or blaming practice and/or which expands their feelings of agency and self-trust in social interactions, despite negative impacts.

Importantly, though I have outlined unsolicited advice as an affective practice and a shaming tool with incredible emotional and material consequences, participants did not describe in their narratives a full rejection of shame nor a complete embrace of disability pride at all times. Rather, participants were intentional in their narration, maintaining that both seemingly "bad" and "good" emotions coexisted across social encounters. This coexistence is crucial to acknowledge, as extant literature on shame and shaming practices has largely outlined resistant strategies as relying on an utter refusal of shame and a linear trajectory toward pride. However, this goal of pride as the telos of affective achievement and the linked refusal of shame does not just require cutting off shame itself but also requires cutting off interest. Shame as a relational affective practice is "reliant on the investment, interest, and attachment of the person being shamed" (Parker and Pausé, 2019, p. 255). Without interest, "there cannot be shame" and thus you cannot be ashamed of something you do not care about (Probyn, 2004, p. 329). To fully reject or transcend shame to pride, then, requires cutting off connection: to people, to worlds, and to futures. While such connections, or interests, open one up to shame, such connections and their attendant are part of an attunement to the social environment and others that are implicated in ways of being in the world and the productive potentials that can result from connection. Indeed, shame can be an indicator of a fraying or severed connection, helping to establish where and with whom we should invest time, interest, and care in rebuilding (Shefer and Munt, 2019).

It is here that one can connect the initial affective response of fear and shame to unsolicited advice with the disconnection that participants identified as they came to live with disability and unsolicited advice. Participants, rather than navigating a linear trajectory from this initial affective response toward pride, cutting off connection, instead spoke continually of an orientation toward connection that required sitting with their feelings, even "bad" affects, and allowing those emotions to guide them toward other people and other futures. In this orientation toward connection, participants therefore moved not from shame, fear, and anger toward pride but instead apathy and sadness. These affects, while typically considered "bad" or entirely negative, in the case of participant experiences of unsolicited advice therefore indicated an ongoing strength, determination, and choice to orient toward connection and community despite the double bind of oppression. They represented a choice that produced self-competence, community identification, and moments of connection and understanding that may have otherwise been lost. Thus, while unsolicited advice undoubtedly caused negative affective experiences, harm, and oppression, this did not exist in a vacuum and coexisted with resilience, resistance, and a desire for otherwise.

It is these open potentials that Tabin et al. (2019, p. 100) articulate in their discussion of shame being "not merely a negative emotion, the antonym of which would be pride," but an emotion that both makes and is made of us, such that it "actively participates in the creation of the social world" (Despret, 2005, p. 246 translation cited in Tabin et al., 2019, p. 100). While shame was only one of many affects described by participants, shame, and the majority of other emotions discussed in this research, fall under the broader category of sadness on Willcox's (1982) feeling wheel. These so-called "negative" affects can therefore also be understood as participating in the creation of the social world. Further, as unsolicited advice works as a tool of shame, regardless of whether shame may be felt, the social interactions that are induced by the potentialities of shame deserve attending to.

Understandings of shame as holding positive or productive potentials are well articulated by feminist scholars, who have articulated a feminist shame theory and feminist politics of shame (Fischer, 2018; Shefer and Munt, 2019). Probyn conceptualizes shame as politically productive and as useful to the project of social justice in its capacity to advance a "project of everyday ethics" (Probyn, 2004, p. 329) and "develop a wider notion of the everyday - of what is personal and what is social" (Probyn, 2004, p. 336). Shame's capacity to add intensity and interest to experience is also argued to hold productive potentials through its incitement to re-evaluate behaviors, perceptions, or connections (Probyn, 2005; Richards, 2019). Shame thus offers a "powerful resource for social critique" in its embodied relationality, forcing one to consider their connections with others and what interest, what frayed connection, the shame derives from (Shefer and Munt, 2019, p. 152). This role of shame in social critique was articulated by Toni:

> there maybe was a time where it was my shame. But at this point it's [advice-givers'] shame, and that's what makes it particularly foul to me in my life now so I do not feel as threatened by it, but I just feel like… why are you putting that on me? Like you have tons of work to do go, do your work over there.

The power of shame to compel inspection of daily lives and what lives are made available and to whom thus acts as a catalyst for "an ethics of the everyday (Shefer and Munt, 2019, p. 151).

Shame's "call to action" (Richards, 2019, p. 271) has been taken up by queer theorists such as Munt (2007) in their exploration of the shame/pride divide, with the emerging question being not 'how do we resist shame?' but rather "what will we do with our shame?" (Johnston, 2007, p. 37) The question of what shame might become, or the potentialities of affects so reliant on mutual investment, point to the ways that so-called "bad" affects might instead move us toward alternative futures. By entangling affects, temporalities, and narratives and challenging the notion of a linear trajectory away from "bad" affects and toward "good" ones, I argue that this research plays a role in cripping the politics of emotion. Just as queer theorists have articulated both queerness and affect as things to be queered, crip theorists, such as Kafer (2013), gesture toward crip as a way to destabilize conceptualizations of disability and disabled identity. With unsettling affinities "[c]rip and queer mark out, and indeed, flaunt the failures of normativity" and work to embrace "the possibility of an outside or more-than-one" (Fritsch and McGuire, 2018, p. i). It is this notion of crip as embracing the more-than-one that indicates a need to move beyond the binaries of shame/pride, good/bad emotion, and hope/apathy and toward an understanding of these emotions as affectively entangled and immersed in a broader blame culture.

A crip politics of emotion sees shame and other "bad" emotions not only as holding productive potentialities through its appeal to socio-emotional connection but as inherently entangled in the politics of pride, hope, apathy, and resentment, amongst others. As the linear notion of the shame-to-pride journey requires the refusal of shame and the positioning of oneself as the privileged exception within blame culture, pride, as it is usually conceived of, mirrors "disability shame: a shame construed by the very logic of conditionally tolerated exception" (Kolarova, 2012, p. 266). As such, a simplistic understanding of pride, or other "good" emotions, as resistance to shaming practices does not offer the keys to disabled liberation. Pride here is a closed future, limited in its potentiality. A crip politics of shame understands shame and pride, joy, hope, apathy, etc. as always co-existing, dynamic, and in tension. While the affective intensities of all may vary, these coexisting emotions work to map out the political horizon—"political imaginaries and their conditions of possibility" (Gould, 2009, p. 262). The affective intensities and practices of shame and pride work together to map out relationalities, indicating which connections are strong and which are frayed. A crip politics of shame understands shame, and the strategic performance of shame itself, as part of the survival kit of disabled people, with the persistent attunement to the environment indicating which connectivities are safe and which are not.

Beyond indicating what connectivities are available and safe, a crip politics of emotions understands affects such as shame as occurring not from an inability to 'fit in' to a societal mold or overcoming of said mold but from resentment structures such as unsolicited advice that construct the disabled subject as a/shamed. Affects thus cannot be transgressed by an individual in a linear path toward other ones, as the process of becoming a/shamed, and the experience of encounters such as unsolicited advice, are triggered by one's existence within the broader label of disabled. Moving toward a crip politics of emotion means accounting for the varied affective intensities of both "good" and "bad" emotions, understanding that affects indicate political horizons and, indeed, the crip horizon. Not only do the affective practices of resentment, blame, and neoliberal shame structure worlds, but the coexistence of affective experiences respond in a structuring way. By accounting for the political capacity of "bad" affects in disabled experience, there opens up potential to understand disabled experience beyond linear narratives. Such potentials have the capacity to disrupt affective understandings of disability and resist the structures of resentment. Through embracing "bad" emotions and taking "good" emotions off their pedestal, the structures of resentment, while affectively intense, lose their assimilatory powers of "cultivating subjects "in the right way"" (Ahmed, 2010b, p. 32). Ultimately, by embracing the coexistence of affects, of narratives, and of resistant, reproductive, and shaming practices, ways of being otherwise are made clear.

6 Conclusion

This research sought to understand the affective impacts of unsolicited advice on disabled people and how they may negotiate and resist the emotional impact of these experiences. Despite varied experiences, backgrounds, and disabilities, participants articulated similar, though not linear, affective arcs in their narration. They spoke to the ways that, while unsolicited advice acted as an affective shaming practice and moral tool that caused direct psychological, emotional, and material harms, that their emotional response resisted easy categorization into shame or transcendence of so-called "bad affects" toward pride and happiness. Instead, participants described an enduring relationship with shame and other seemingly "bad affects" in a way that allowed them to move toward apathy and an engagement with a broad spectrum of emotions. In this way, participants not only resisted the shaming practice of unsolicited advice but also resisted the individualizing narrative of overcoming, so often present in disability narratives, that argues for a linear trajectory from disability shame to disability pride. Participants thus engaged in a crip politics of emotion, and specifically a *crip politics of shame*, that allowed new ways of being in the world that refused both narratives of vulnerability and of overcoming, inspiration, and pride, allowing them to instead just *be*. Here, a *crip politics of apathy* becomes crucial to understanding and reimagining shame, and crip shame, as an affect that can exist in the grey zone of affective intensity, compelling one neither to pure shame nor pure pride. Crip apathy allows for a rejection of *shaming* without a rejection of shame itself, moving beyond the binary of shame/pride, good/bad affects, and shame/shaming. Thus, to understand crip shame, one must understand crip apathy, against the backdrop of other "bad" affects, as decreasing the usefulness of the "tool" of non-disabled shaming itself.

In doing this research I wish to reiterate that participant's narratives at times disagreed with each other, indicated different ways of knowing and being in the world, and are informed by my own affective experience and narration of their stories. I attend here to the ways that this qualitative research inherently relies on complex personhood wherein "the stories people tell about themselves, about their troubles, about their social worlds, and about their societies' problems are entangled and weave between what is immediately available as a story and what their imaginations are reaching toward" (Gordon, 1997, p. 4). Thus, the stories that are told here do not represent a homogenous story of disabled life or experience and, while at times explicitly reach for the desired futures and interactions otherwise, are also at their core informed by what participant's desires and imaginations, apathy, and resistance are gesturing toward. These desires coexist with the oppression articulated by participants in their narratives and across the page. This coexistence is crucial as, as a theoretical concept, "desire interrupts the binary of reproduction versus resistance" wherein it is believed that "people are bound to reproduce or replicate social inequity or, on the flip side, that they can resist unequal social conditions" (Tuck, 2009, p. 11). Rather, this research seeks to demonstrate that resistance can look like the reproduction of social inequality in the double bind of oppression and, conversely, that apparently resistant actions can instead work to individuate the resistor as a privileged exception and reaffirm oppressive ideals. As I have argued throughout this work, there is a need therefore to not only allow desire and damage to coexist in narrative space but to move away from the binary and linear assumptions of emotional trajectories.

Data availability statement

The datasets presented in this article are not readily available because ethics approval and participant consent forms both indicated that only the researcher would have access to the raw data. Requests to access the datasets should be directed to Megan Ingram, megan.ingram@queensu.ca.

Ethics statement

The studies involving humans were approved by Queen's University General Ethics Review Board (GREB). The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

MI: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Validation, Visualization, Writing – original draft, Writing – review & editing.

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Conflict of interest

The author declares that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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Emotionally entwined narratives: a polyphonic trialogue on learning disability history research

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This paper offers a critical analysis of the concept of "emotional community" in the context of our research into histories of learning disability. Emotional communities are places where people feel, express and make sense of emotions. They help us to understand that emotions are something we experience socially and not just individually. The paper is presented in the form of a conversation between many researchers. This is what we mean by "polyphonic," which translates as "many voices." Some of us have learning disabilities, and some of us do not. Although there are many voices, the authors belong to teams who worked on three learning disability history projects. Each team comprises researchers and self-advocates with learning disabilities and academics without. We use the word "trialogue" to mean discussion involving the three teams. In the discussion, we first talk about what we mean by "emotional community." Then we talk about the purpose of emotional communities, and their "light" (good) and "dark" (bad) aspects. We also talk about a process called "commoning," which is working to understand what we have in common. This leads into a discussion of the ethics of emotional communities. We conclude by reflecting on some of the possibilities and problems we see with emotional communities.

KEYWORDS

emotions, emotional community, learning disability studies, critical disability studies, inclusive research, autobiography, polyphonic conversation, activism

1 Introduction

We start this trialogue in the middle, on a day in July 2023. By a trialogue, we simply mean an extended conversation between three teams of learning disability history researchers. On that day in July 2023, three teams of researchers who had been independently researching histories of learning disability[1] met for the first time at a seminar to explore

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[1] 'Intellectual' and 'Cognitive' Disability are terms referring to impairment of intellectual ability causing difficulty with learning and everyday activities. In the United Kingdom, this term is interchangeable with

history and activism. We met at the Social History of Learning Disability (SHLD) Conference at The Open University, which has a 30-year history of showcasing research done by and with people with learning disabilities. One of the three teams was from The Open University's SHLD group, which had been exploring the role of life stories in both illuminating and facilitating experiences of belonging, primarily through the story of SHLD co-chair Ian Davies. The second team had worked on a project officially called *Inside the History of Learning Disability*, although it came to be known affectionately as *The Antonia Project* because it centred on the life history of one woman with a learning disability, called Antonia Grandoni. This team included members from the Centre for Culture and Disability Studies (CCDS) at Liverpool Hope University, The Brain Charity in Liverpool, and the Teaching and Research Advisory Committee (TRAC) at the University of South Wales. The team researched Antonia's life history after finding it in a book published in 1877 by Dr. William Ireland, who was considered at the time to be one of Britain's foremost experts on what we now call learning disabilities. The third team were from the University of Iceland. Their project was called *Bibi in Berlin*, and was about the life history of one woman with a learning disability, called Bibi, who was brought up on an isolated farm in Iceland called Berlin. All three teams comprised researchers and self-advocates with learning disabilities and academics without. The seminar was organised as part of international network and engagement activities built into the *Bibi in Berlin* project. The Icelandic team has a long association with The Open University's SHLD group, and members of the SHLD group acted as academic advisors on the Bibi project. The Icelandic team had also been greatly influenced by *The Antonia Project*'s approach and methodology, resulting in some similar findings. As such, we all stayed behind for a day after the main conference was over, and spent a morning together with the aim of sharing details of our respective projects, exploring synergies and connections, and directions for future research.

The contribution our article makes is twofold: conceptual and epistemological. The conceptual contribution comes from our exploration of one emotional community and consideration of its potential for learning disability activism. The epistemological contribution comes from bringing together and giving equal weight to our diverse etic and emic ways of knowing about learning disability. The article thus brings together experiences, insights and theory from disability studies and the sociology of emotions in a novel way. In making this contribution we submit that our disability studies orientation offers a useful lens for understanding the power and potential of emotional communities. This power and purpose relate not only to feeling and expressing emotions within our community, but also harnessing them in activism. As an emotional community, we are activists, involved in learning disability self-advocacy organisations including The Brain Charity, People First, and Throskahjálp. This, of course, returns us fittingly to the origins of disability studies and disability rights, which are rooted in activism: activism motivated by emotions such as anger, injustice, and hope. We think this rehabilitation of emotions is worthwhile (Barbalet, 2008) when the emotions of people with learning disabilities have long histories of being proscribed, monitored, regulated and pathologised.

1.1 The three stories

Ian Davies was born in England in 1955. He was sent to a residential special school as a young boy and then spent many years in learning disability day care services, interspersed with periods of employment and volunteering. In the early 1990s, Ian became a founding member of Northamptonshire People First, and subsequently gained a national and international profile as a leading self-advocate. In 2019 he collaborated with Liz Tilley to record his life story, which explored experiences of loss, relationships, challenges and achievements. Ian's first experience of sharing his life story publicly in 2019 at an SHLD conference was an unexpectedly emotional experience—both for Ian, and for members of the audience. Later that year, Ian shared his life story in Japan as part of an international project to explore experiences of belonging for people with learning disabilities (Tilley, 2020). This included presenting to Japanese social work students who reported feeling very moved by his story. The project resulted in a manga version of Ian's life story which he shared at our seminar in July 2023.

Both Antonia and Bibi spent much of their lives in institutions: Antonia in a hospital in Milan, between approximately 1840 and 1870, where she was subject to frequent visits and examinations by professors and doctors, which continued even after her death. Dr. Ireland compiled the various 'expert' reports into a case history to include in his book *On Idiocy and Imbecility* (Ireland, 1877). Bibi was institutionalised in a home for older people in Blönduós in 1958, following the death of her mother. This was not an uncommon experience for people with learning disabilities in the mid twentieth century. Bibi was only 31 at the time of her admission, and lived in the home for 17 years until she was supported to move into the community. After her death, the Icelandic researchers were gifted Bibi's 145,000-word handwritten autobiography to review, and subsequently discovered Bibi's diary and numerous poems that she had written. These texts, alongside other artefacts such as Bibi's extensive doll collection, revealed a complex and insightful interior emotional life (Stefánsdóttir et al., 2025). Like Antonia, Bibi often seemed to crave emotional connections and caring human relationships. Analysis of Bibi's autobiography led the team to theorise Bibi's life in terms of the "emotional communities" she belonged to (Rosenwein, 2006).

1.2 How we have worked together

The concept of emotional community was a new one to the rest of us, and immediately of great interest. The call for papers for this special issue had come out just before we met, and as our conversations on that day came to a close, we agreed to co-author a paper on emotional communities and learning disability history as a way of continuing the work. This is why we say we are starting in the middle: the day we met represents a kind of starting point, but our trialogue reaches back into the past as we discuss the research projects that led

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the term 'Learning Disability'. A 'Learning Disability' in other parts of the world, such as the United States, refers to what is termed in the United Kingdom 'Specific Learning Difficulty' which instead refers to diagnostic labels such as Dyslexia and Dyscalculia.

up to the meeting, and forwards as we continued it in a series of meetings set up to facilitate the writing of this paper, and on into the future as we close the paper by considering some implications of our theorising of emotional communities in the context of international learning disability history research.

Previous work we have published has argued the case and paved the way for the contributions of co-researchers with learning disabilities to be rightfully accredited by publishers and the academy in the form of joint authorship (Barden et al., 2022; Tilley et al., 2021). Equality of authorship in this article reflects the collaborative and co-produced nature of our work, building on a growing movement that seeks to privilege 'pluralistic ways of knowing' (Durose et al., 2022). It also exemplifies our ongoing commitment to critique and challenge the ableist forms (and norms) of knowledge production and dissemination within academic publishing that threaten to both stifle and render invisible the critical contributions made by disabled colleagues. Inclusive research prioritizes co-creation, seeking to ensure that the voices and perspectives of people with learning disabilities are not only represented but actively shape the research process and its outcomes (Walmsley et al., 2018). Flexibility, responsiveness and acknowledgement of each person's capabilities is key. In our field of research, authorship can never simply be about who physically writes the text, or who reads and comments on iterative drafts of an article. This version of authorship would soon become highly exclusionary. Instead, we argue that authorship can and should be a politicised (if contested) space in which we work carefully to identify alternative and creative mechanisms to facilitate people's involvement in the publication process. It also involves articulation of the diverse and meaningful contributions (intellectual and experiential) made by authors with range of personal and professional backgrounds, and differing communication needs and preferences. Through listening to the voices of authorship in different ways that allowed those voices to be fully heard, we formulated our adaptive dialogic interpretative methodology.

In practical terms, this meant that our article came about primarily through a series of meetings in which personal and collective insights were generated, reflected upon and further interpreted, and ultimately written down. Some of these meetings involved representatives from each team sharing and reflecting on the emotions associated with learning disability history research and the nature of our own emotional community; these meetings were audio-recorded and transcribed. Other meetings involved each team reflecting separately on these issues at times and in places that worked well for them. These team reflections were then fed back to the wider group on Zoom calls and by email and subsequently embedded into this article as we commenced the writing process. Although the academic participants took on the bulk of 'writing' task (typing words onto the screen and providing some contextual content), we would have had little to write about were it not for those shared conversations. The result was described by one author as a kind of 'inclusive and reflexive narrative'. Everybody who contributed to these discussions, and who wanted to be, is therefore named as an author on the paper.

The trialogue we present below is woven together into what we are calling an *emotionally entwined narrative* of learning disability history research. Quotations from our meetings and email conversations are presented in italics throughout the article to help distinguish individual reflections from our collective interpretations. Our meetings, and the writing of this article, have been something of an experiment in sharing memories and building an understanding of what we witnessed, and crucially *felt* on that day in July 2023. In doing so we attempted to activate 'emotionally engaged' methods for group analysis and interpretation (Thomson et al., 2023), working collaboratively and intuitively to unpack the emotional community that had been rendered visible during our seminar. Specifically, we were interested in which emotions were in play on that day, and why; how these emotions might point to areas of commonality between us; and the potential impacts of these emotions on future learning disability history research, particularly research which is animated by activist principles. In keeping with our inclusive ethos, we have tried to write the bulk of the article in the most accessible language we can, ensuring that the voices of all co-authors were captured and thus heard within that writing while maintaining the degree of criticality and rigour appropriate to an academic journal.

This paper therefore contributes a theorisation of the role and nature of emotions and emotional communities in learning disability history research. It sits at the intersection of history, sociology, disability studies and narrative research, although reviewing these bodies of work is beyond the scope of this paper. Although there is a growing literature on learning disability history, explicit discussions about the place of emotion within that history are rare—but see Rolph and Atkinson (2010) for a unique and important contribution. This is a branch of social history that has evolved since the 1990s in highly inclusive ways, developing research methods to proactively address archival silences and distortions, and to foreground the experiences of people with learning disabilities and their families (Atkinson and Walmsley, 2010). More recently we have seen a growing number of self-advocate historian activists leading their own heritage projects, exploring ways to use history for social change (Jarrett and Tilley, 2022). As such, it seems to us that this is an important moment in which to take stock of the emotional dimensions inherent in a field of scholarly inquiry that is both highly inclusive and often political and politicised.

It is well known that people with learning disabilities tend to have smaller social networks than the general population, often restricted to family, members of staff and friends/acquaintances made through services (Harrison et al., 2021). While social media has opened up opportunities for many disabled people to develop social connections across geographic boundaries (national and international), there are ongoing challenges regarding digital inclusion for people with learning disabilities (Chadwick et al., 2023). Opportunities for international travel appear to be limited for many people with learning disabilities (Sánchez-Padilla et al., 2024), and so our emotional community offered a unique space in which people could both expand their social networks through research endeavours, while sharing experiences that were intergenerational and geographically distinct. The day we met was itself very emotional. We talked a lot about the emotions we felt when doing research about the history of learning disability. These run the whole gamut from shock, disgust and outrage at the way people with learning disabilities have been, and continue to be treated; to defiance and pride; to taking delight in sharing stories and producing creative works to show what we have found and what we feel about it; to devotion to the cause of advocacy. Perhaps most affecting were shared moments of empathy couched in a developing sense of solidarity; a knowing glance was often enough to convey mutual understanding born of personal resonances with what was being discussed. A distinctive paradox of doing this kind of participatory research is how harrowing moments are juxtaposed with moments of laughter and joy. However, we seek to move the discussion beyond merely reporting the emotions people feel as they undertake this kind of research, to theorising both how research can bring us together as an emotional community, and how that emotional community might be harnessed in advocacy work. The article begins by defining the concept of emotional community, and critiquing it in the context of our learning disability history research. We then explore the emotions associated with our work, using metaphors of dark, light, dusk and dawn to describe how we are constantly moving between emotional states. The trialogue closes with some suggestions for how this theorisation might be developed in future work.

2 Emotional community

The concept of *emotional community* comes from Barbara Rosenwein, professor of mediaeval history at Loyola University, Chicago. In 2002, Rosenwein wrote a landmark article in the *American Historical Review* entitled "Worrying about Emotions in History" (Rosenwein, 2002). In it, she critiques grand historical narratives and scholars who argue that the emotional lives of people in mediaeval Europe were somehow more childish, simplistic, and coarse compared to later centuries. Now, it is fair to say that there is evidence to suggest that the expression of emotions—and the effects those expressions have—vary across cultures (Tarlow, 2012). Following from this, it is reasonable to assume the expression of emotions, and the effects of those expressions, will also vary across time. History, as the renowned learning disability scholar C.F. Goodey reminds us, is anthropology with time rather than place as the variable (Goodey, 2011). So, just as we cannot assume that labels like 'idiot' and 'imbecile' directly correspond with contemporary diagnostic labels like 'moderate learning disability', we cannot assume that historical emotions correspond exactly with emotions as we label and experience them today. Despite this caveat, we believe that the emotional community is a useful way of framing our learning disability history research, because it helps us make sense of what we do, how we do it and why we do it.

Rosenwein asserted that although we all possess an inherent, biological capacity to experience what we call emotions, how we label, express and react to emotions is not simply a personal matter, but shaped by culture and context. These cultures and contexts form emotional communities. Emotional communities are what give emotions names, values and respect; they are where we make sense of the emotions we feel, by sharing them with people who experience and evaluate them in similar ways. They are somewhat similar to speech communities, where people use language in specific ways in specific contexts (Matsumoto, 2013; Stefánsdóttir and Ólafsdóttir, 2021). Emotional communities therefore embody systems, cultures or conventions of feeling (Hochschild, 2008). A person can belong to multiple emotional communities simultaneously. Sola, who introduced us to this concept, uses the analogy of the public baths:

> *Sola: I always use the analogy of going into an Icelandic swimming pool. You go to the showers, and you meet someone there and you're all naked and then you go out and you go to the hot tub and there's a political debate and then you go into the steam bath and everyone is just trying to survive the heat and then you go to the sauna, where you have very relaxed conversation, if you know someone there. And then you go for a swim. So you are in the same place the whole time, but you are in three or four different emotional communities while you are there. If you meet a best friend and you are going to have a very emotional talk, you go to some private area of the baths; in the political debate, you can choose from one hot tub or another by a political point of view.*
>
> *Liz: That's really helpful. I like that analogy. Has anyone written about this from a disability studies perspective, or about how it might work across international contexts, as far as we know?*
>
> *Sola: I don't know of anyone writing about this.*
>
> *Owen: So Liz, were you thinking that this is how we might frame the contribution of this paper?*
>
> *Liz: That's exactly what I had in mind. How we might expand the concept of emotional communities in some way to make it more inclusive, and to address that the literature to date has not necessarily attended to those issues around international context, different languages, but particularly, I think, issues around learning disability, and where some people may not use words to communicate.*

This, then, is the premise for the rest of the article. On the day we all met at the SHLD seminar, Sola defined emotional community and we came to realise that perhaps we were one, and had been one for some time, without knowing it. There was a sense that maybe coming together in the same room had somehow made our hitherto hidden emotional community manifest. But we could not be sure; we needed to think it through and doing so would involve reflecting on, critiquing, and elaborating on Rosenwein's original concept. Our analysis of her concept forms the rest of the trialogue.

3 Emotions at play: the light, the dark and the liminal

Throughout our discussions we talked about what was emoted during our seminar and our reflections on those emotions in the months since. Our emotional responses were varied and specific, but there were commonalities too. Certain moments stood out as having prompted strong emotional reactions. One example was when Ian recounted to us all the first time he had told his life story to an audience, an event which he explained had been surprisingly challenging and which caused him to cry in the moment of telling of it. Afterwards, in meetings of the respective groups, some of the other researchers with learning disabilities told of how they had been particularly moved by Ian's talk, because they felt they could empathise with him and his experiences, despite generational differences:

> *Steve: Yeah, I've already had the first conversation, with Sam and Rhiannon from TRAC. And they brought up that they were quite emotionally affected by listening to Ian's experience because that was something that as younger people they haven't lived. But to*

> *listen to somebody who had been through it that really got to them, they said as much.*
>
> *Helena: I was also thinking about that, because Ian's story impacted my group the most, because it was so accessible. And I think that was a key element.*
>
> *Katrin: It has been really interesting but also sad. I have realized that things have changed even though it could be better. I felt it was sad and difficult to listen to Ian's story but I have also learned that I have in many ways a good life compared to Ian, Bíbí and Antonia. I think we got more understanding of each other and that we are strong and can do a lot of important things.*
>
> *Jónina: I agree and I think also it is difficult to listen to people tell about difficult things in their life and I remember people with intellectual disabilities when I was growing up out in the country who were sent to Kópavogshæli (biggest institution in Iceland). I realise I was lucky, I was not sent to any institution. I have a family who cares for me and looks after me. I would like to know more about Antonia's life.*

This dawning realisation that through empathising with Antonia, Bibi, Ian and others we perhaps seemed to experience and express similar emotions about similar things when co-producing research on the history of learning disability was an early indicator that we might be an emotional community. Of course, membership is not as straightforward as everybody feeling identical emotions about the same time about the same things, because humans are complex beings who do not respond to things in identical ways. But what did seem to be important was how the emotional atmosphere promoted the experiencing and expressing of important emotions (de Rivera, 1992). There was a sense that we were in a safe space for showing and sharing these emotions. The importance of atmosphere and safe spaces was something that came through in the subsequent meetings we had in our teams:

> *Helena: I talked to someone else from the Bibi project, and she is not used to talking about her feelings. She is afraid of talking about her feelings, because they are difficult. She remembered very hard feelings and complicated emotions, since she was a child. She also said that, during the Bibi project, she was able to talk about her feelings for the first time in her life. And to be able to sit with people who are also remembering complicated things, and, you know, sharing all these feelings that just brought up so many emotions for her. And I think maybe some of the others in the team.*
>
> *Nathaniel: How incredible!*

This does indeed seem incredible—to become able for the first time in your life, when in your early 20s, to speak about the powerful and complicated emotions you feel. Clare and Christine are a mother and daughter who were part of The Brain Charity team on the Antonia Project, and described a similar liberating experience, this time not just about expressing emotions for the first time, but empathising for the first time and beginning to understand other people's emotions. This is equally remarkable:

> *Clare: It was the first time you opened up about your disability.*
>
> *Christine: This is where I was going to check in. I wasn't able to speak much, because my epilepsy affected everything. However, I have always found it hard to appreciate emotions. I can't really read emotions at all. Therefore, to me, I became Antonia. Does that make sense?*
>
> *Clare: Because she's had brain surgery - they removed the temporal lobe, the part responsible for emotion - she's sometimes not able to even show emotion or recognize other people's. But through the work that we did, she certainly did. Yeah, and could talk about it in a way that she's just never really talked about emotions before.*
>
> *Owen: Oh, wow. That's pretty amazing. What do you think it was about that situation that helped that to happen? Was it reading Antonia story? Was it the people in the room? What?*
>
> *Christine: First of all, reading her story, taking that it would have been me in that locked away situation. And sort of talking to this person I've never met before [Antonia], and saying what's your story? And so through that I sort of became Antonia but thought, I don't know if I'd like to be locked away. I am happy where I am now.*

Everyone seemed to agree that the positive atmosphere of a safe space with people with similar interests seemed to help people feel and express their emotions, contributing to these liberating and in some cases even revelatory experiences. Something important these discussions suggest to us—and there are many quotes we could use in addition to the ones above—is that within the safe space of our emotional community, people often felt able to think about and express complex and difficult emotions, and that in at least some cases this could be empowering. Feeling and expressing emotions within this safe space helped us to integrate as a community (Kemper, 2008). To extend our meteorological metaphor of light and dark, this integration helped foster a climate of solidarity and hope within our community, a climate reciprocally constituted by the emotional atmosphere of the day we met. Climates of solidarity—solidarity being a word which featured regularly in our trialogue—exist where people share a common cause and set of ideals (de Rivera, 1992). In our case, a belief in and commitment to disability justice. Climates of hope relate to people's past and present levels of satisfaction and how satisfied they anticipate being in the future (op.cit). In our case, we may be less than satisfied with the present and the past, but we have hope that through our research and activism, we can change things for the better in the future, by changing the way people think about and respond to learning disability. We remember that disabled people came together in a movement to fight for social change not only because they were sad and angry, but because they had hope for a better future (Cosier and Ashby, 2016).

It is perhaps tempting to think that many or even most people might react to Ian, Antonia or Bibi's stories in similar ways to us. But this is not necessarily the case. While people in our emotional community feel a sense of solidarity with each other, and respond to issues around learning disability in normative ways—being shocked and horrified by the same things, laughing at the same things, and so on—the long and often dismal histories of learning disability and learning-disabled people demonstrate amply that many people feel very differently about learning disability to us. One only has to think of the Do Not Resuscitate orders placed without consent on many learning disabled people during the Covid-19 pandemic (*People First*, including some of our co-researchers, rightly led vociferous opposition to this injustice in the United Kingdom); the higher mortality rates and poor healthcare in the years leading up to the pandemic; the litany of headline-making abuses in care homes and hospitals; or the moves to eradicate people with learning disabilities in Iceland, Nazi Germany and elsewhere to appreciate that many people are at best indifferent and at worst downright hostile towards people with learning disabilities (Barden, 2020a; Barden, 2020b; Barden et al., 2023).

We also think it is important to note here that emotional communities are not inherently good; that it is perfectly possible for people to belong to harmful emotional communities, where one finds oneself living at the mercy of that community's emotional norms. This seemed to be the case not only for Antonia and Bibi—both of whom seemed to have craved affection and friendship during their lifetimes—but also for some of our learning-disabled researchers.

> *Sola: With Bibi, we found that it's two-way. So you can actually be forced into an emotional community that you don't like. And no, you cannot save yourself from it. That is something that I can feel once Bibi was inside the old people's home. Because she had a learning disability, people had power over her and she was forced into an emotional community that was not very good for her.*
>
> *Owen: That hadn't even crossed my mind. I thought that emotional communities were things that you wanted to be involved in. I hadn't thought about people being part of emotional communities that they I didn't want to be in or that were, if you like, bad.*

Nathaniel, a researcher from the SHLD group who has autism,[2] captured the range of emotions he experienced during our seminar, how they related to prior experiences within a harmful emotional community, and how he moved between these emotions, using metaphors of dark and light, rather than positive and negative or good and bad:

> *Nathaniel: I find that my emotions on the whole seem to have a repeating narrative given meaning by lived experience and the order these emotions come in: shock and fear - being too young to experience institutions and scared of a repeat of history. Anger - people should be treated as people. Defiance - against this injustice. Pride - reflecting at the many things people have accomplished and the intrinsic worth of the human self. Devotion - a deep desire and a promise to serve humanity and prevent a repeat of history ever occurring again. I have found this narrative of emotion to be present within not just myself but many self-advocates and the researchers I have spoken with.*
>
> *It is, I think, undeniably good to feel 'bad' emotions, for bad things have occurred which in an empathetic and emotionally intelligent community will inevitably bring up feelings that could be termed 'bad' or as I put it 'dark emotions'. I think though a matter which is more complex and alluded to in this question, is by what metric do we state whether an emotion is 'bad' or 'dark'? Do we need more explicit focus on the 'good' or 'light' emotions? And how do cultural norms and values affect our framework of emotions? To kick start this conversation off I will share how I measure whether an emotion is light or dark.*
>
> *Light emotions are least likely to cause the individual to have a desire to cause physical injury to another individual. For example, happiness, joy, love are unlikely to be the direct instigators of aggressive action. Of course, these same emotions can be taken advantage of, and the person does not become invulnerable to doing harm when feeling these emotions. But the definition is not about protecting oneself from being taken advantage of, but rather protecting others from one's own capacity for violence, and the possibility of that capacity being used with intent. Dark emotions are most likely to cause the individual to have a desire to cause physical injury to another individual. Note this does not mean that the results are bad but the emotion of itself is. For example, feeling anger at a carer abusing those they are meant to support could make one lash out with anger or fear, which potentially could stop the abuse from continuing. However, the intent was still to make another suffer and is therefore harmful. But we live in an imperfect world so it is a sad truth these moral compromises are sometimes necessary, but still constitute a failing in the ethical sense even if tactically there was little or no choice.*

Several other researchers within the group also commented on the importance of experiencing 'dark' emotions. What all this seems to suggest to us is that within our emotional community, as we move towards a common understanding of the histories and of each other, we are constantly cycling between the light and the dark (Edensor, 2015). We frequently find ourselves in the liminal spaces of dawn and dusk, not just in the overwhelming brightness of midday or the total blackness of midnight. It is this coming together to experience and make sense of a range of emotions through storytelling that defines us as an emotional community (Lemmelijn, 2012; Prendergast, 2022). And it is the emotions that make learning disability history research what it is.

4 Commoning

Our sense was thus that we did belong to an emotional community, one which allowed us to experience a wide range of emotions, and through doing so a sense of solidarity. Yet we wanted to test this hypothesis:

> *Liz: Is it possible that we could have all of our conversations and conclude that perhaps we didn't form an emotional community? Given what we've said about people responding differently to events, like the day we all met, how can we be sure we belong to the same emotional community?*
>
> *Owen: I think it's a fair question, Liz - how do we know that we're part of an emotional community, other than just asserting that we are? How would we know if we weren't? This has got me thinking about what community is in general. If you set aside the emotional bit, I think it's a group of people having a common purpose. People*

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[2] This is Nathaniel's preferred phrasing; we acknowledge that some people prefer alternatives.

> *have different roles and responsibilities within a community, but I think we have a shared purpose in the kind of research that we're undertaking and why we do it. And that brings me to one thing that has popped into my head while we've been talking. I've been using the work of Tim Ingold recently to think about learning disability. He's an anthropologist. He talks about the etymology of community. So, the 'com-' part is coming together. But the '-munity' is munificence, like gifts. In other words, a community is where everyone has their gifts to give. That's what makes a community, the idea that everyone's got their gifts to give. But what happens when people struggle to give their gifts, because of the language barrier, or what have you?*
>
> *Liz: That's really interesting. I really love that idea of communities as the giving of gifts, and then thinking about how people can be enabled to give their gifts, to be able to participate. That's quite a new concept for me to think of it like that, but it actually goes to the heart of so much of our thinking in disability studies, doesn't it, that people are prevented at every turn from being able to give the gifts they have.*
>
> *Owen: Another thing Tim Ingold talks about is 'the commons'. Having something in common. But he actually talks about the process of commoning. This means continually creating things that you have in common rather than trying to assume that everyone's the same to begin with. So commoning is a process that we all undergo together. And it's toward creating a new sense of commonality rather than trying to work out what we had in common before we all started. And I think this notion of commoning might help define us as a community.*
>
> *Liz: I wonder whether that process of commoning is enhanced by the display of emotions. Does expressing emotions enhance people acknowledging or realising that they have things in common? Because there was that realisation that all of our lives are so different … Different cultures, men, women, different ages, disabilities, but actually there are things that we share, whether it's values or experiences. Or is it the other way around - did we sense that day that we were a group moving towards commonality, and that is what provoked strong emotional responses?*
>
> *Steve: It could be a reciprocal driver. It could be a case of emotional connection driving commoning, and commoning driving emotional connection. Maybe that intersection can't be broken. Maybe it shouldn't be.*

Our sense, then, is that our emotional community is a place where commoning happens (Ingold, 2018). Through commoning, we constantly enhance our understanding of each other, the gifts each of us can offer, and what we have in common. Our commoning is thus an expression of the appreciation of diversity that is characteristic of climates of solidarity (de Rivera, 1992). This process of commoning within an emotional community feels as though it is reciprocally driven by experiencing and expressing strong emotions (Collins, 2008).

5 Emotional community and ethics

Something important that we felt emerged from the day we met at the SHLD seminar was our sense of moral obligations to attend to, engage with and negotiate our own emotions, and to help others do the same (Shanks, 2022), because learning disability history, policies and practices can weigh heavily on all of us at times. As our discussions after the seminar progressed, we recognised that some emotions are generated by the ethical obligations that drive many of our shared research endeavours:

> *Sola: You are going to have more cultural capital. And that is something I think it's something that I am a little bit afraid of, because bringing people into the community brings responsibilities with it.*
>
> *Steve: That really resonates with me, because I've literally got that happening now, this week. I'll be seeing Owen on Wednesday because we're coming up to Liverpool for a conference. Samantha and B*[3] *are coming with me. Samantha has been working with us for quite some time on a number of research projects. So she's used to this. But B, who is her partner, is new to it. But there's been this transfer of cultural capital, he got interested by being Sam's partner, and became more interested and decided to be part of this. So he's coming up just to see how this works. And moving more towards being a participant in research. But he's been chatting to me as well. And I'm feeling that same weight of responsibility.*
>
> *Liz: That is a really interesting dilemma. And it connects, I think, to the discussions we were having last time around the ethics around a lot of this work, because I think there is a sense of responsibility amongst all of us. There is a sense I think when you've had an experience that was quite heightened emotionally, you do want to find ways that you can sustain that, it genuinely does feel like an ethical obligation, actually. But we're also dealing with the imperfect nature of the institutions in which we work. And that is not always that easy to do. I did feel that responsibility after our meeting last July, it provoked excitement but also anxiety, which is one reason why I'm so pleased we're able to do this paper because it gives us a mechanism to carry these conversations on.*

What this conversation highlights to us is the ethical obligations we feel in belonging to our emotional community; the need to continue the work in order to honour the gifts that people give to the community, and to carry the work of the community through to our activism. We conclude our analysis by discussing problems and possibilities we see for our emotional community, beginning with a consideration of potential purposes.

6 Discussion: possibilities and problems

We have started to ponder what our emotional community might *do*, beyond offering a closed space for commoning and mutual respect (Helm, 2014). One possibility is to harness it in advocacy and activism. Much learning disability research is motivated not just by a desire to find things out, but to amplify the voices of learning-disabled people in

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[3] Unlike Samantha, B is not a co-author and so has been anonymised.

arguing for positive change which moves us towards a more inclusive and equitable society. This, as we said at the outset, returns us fittingly to the activist roots of disability studies. This is important when leading lights in the field have criticised much research for straying too far from its original path of enacting meaningful change (Barnes, 2022). One important aspect of such advocacy work is very basic yet also extremely difficult: getting people to care about people with learning disabilities, and learning disability histories. Anecdotal evidence suggests that our emotional community has the power to do just that. For example, Sola can tell a story about how on a visit to Japan, a colleague's recounting of Bibi's life history had such an impact that it reduced one of the host professors to tears. This is perhaps a tentative first step towards positive change; a way to make things happen. If you can get people to care about something so much that they cry, perhaps you have already made an important change that influences them to think and act differently in the future. How we might harness the emotional power of our community is something that we will keep at the forefront of our minds as we carry this work into the future in the United Kingdom and Iceland.

Our community has helped remind us that history is comprised of events that happened to people like us, and not just of things written into books. This understanding appears to translate across borders of both nations and age, and thus points to our common humanity. We argue that it is time for us to become more emotionally curious and to consider how a 'willingness to follow feelings' might 'incite an analytic process that involves connecting individual stories to collective endeavours, social resistance and social research' (Thomson et al., 2023, p. 14). Through the production of this article and the multiple conversations that informed it, we talked ourselves in, and out, and back into an emotional community. Our mutual research interests, underpinned by shared ethical and political concerns and combined with our own subjective and emotionally driven experiences of doing research in this field, persuaded us that we were actively engaged in a process of commoning that was coherent enough to constitute an emotional community. This realisation in many ways raised more questions than it answered. How might the concept of emotional communities, so heavily dependent in its focus on oral and textual capabilities, be further democratised to include people who may not use words to communicate? Given the ineffability of emotions—the challenges of expressing emotions even in your native language—how might emotional communities navigate the complexities that arise when we are commoning cross-culturally, and in different languages (Kahl, 2019)? We, for example, have speakers of English and speakers of Icelandic, but none of the native English-speakers speak Icelandic, and only a few of the Icelanders speak English. How can we be sure that we are talking about the same emotions? That we have found ways for everyone to give—and receive—their gifts (Martinez et al., 2016; Ferrari et al., 2022; Gaya-Morey, 2024)? What is the role of body language and facial expression, which one autistic member in our trialogue suggested some neurodivergent people may find hard to read? Having identified that we are an emotional community, what do we do next? What might this realisation animate in our practices, our priorities and our plans? Our ongoing discussions following the seminar have clarified that we all believe the research we engage in to be inherently emotional. We are all open to further analyses that explicitly foreground the layers of emotion that arise in, between and across different temporal moments in learning disability history and biographical research, and our own positions within those analyses. Perhaps most significantly, we are interested in what these emotions might provoke, and how they can be used productively to address the historic inequalities and slow violence facing people with learning disabilities across our respective contexts (Nixon, 2011; Mills and Pring, 2024; Stefánsdóttir et al., 2025). At our seminar there were tears, laughter, empathy, insight, resonance and solidarity. We look forward to the evolution of our emotional community and the directions in which it may take us.

Author contributions

All authors contributed equally to this work. These contributions took diverse and often non-normative forms, as we discuss in detail in the body of the article. As a matter of epistemic justice we regard it as imperative that the experiential contributions of researchers and self-advocates with learning disabilities are afforded equal recognition with the authors who typed words onto the page.

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Feeling the fear of many: orienting affects in Swedish austerity politics

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This article investigates the emotional consequences of austerity politics targeting services and support for disabled citizens in Sweden, contributing to ongoing debates in disability studies and welfare state governance. Drawing on theories of crip phenomenology, the study focuses on how austerity policies produce affective responses—particularly fear—among disabled individuals. Based on qualitative interviews, the empirical material was collected from disabled citizens navigating the Swedish welfare system under intensified austerity measures. The research examines how these citizens experience the impact of policy reforms and the bureaucratic implementation of support reduction. The results reveal a pervasive sense of fear, disorientation, and existential insecurity, as well as increased instances of bodily harm. These affects are linked to the experience of bureaucratic violence and ableist discourse embedded in the governance of welfare services. Participants describe how these dynamics constrain their capacity to imagine and pursue viable personal futures. The article argues that austerity-driven policy changes have reshaped not only the material conditions of disabled citizens but also their emotional and social lives. It challenges the notion of 'Swedish exceptionalism' by illustrating how bureaucratic violence disrupts disabled individuals' experience of full citizenship. These findings offer new insight into the relationship between affect, power, and policy in a contemporary welfare state context.

KEYWORDS

affect, austerity, welfare state, disability, orientation, crip phenomenology, Sweden

1 Introduction

The past two decades of global austerity have rekindled an academic interest in the relationship between the welfare state as a political and bureaucratic mechanism of economic stratification and the practical and emotional conditions it produces in citizens' everyday lives. This leads us to ask: *How does austerity make a person feel?* Previous research has shown that austerity measures that target services and support for disabled citizens produce a range of emotions, including dread, shame, fear, grief, and anger in disabled individuals (McRuer, 2018; Ryan, 2019; Norberg, 2019). It has also demonstrated that austerity reproduces hegemonic discourses that position disabled citizens as 'counterfeit citizens', 'burdens', and 'parasites' (Hughes, 2015; McRuer, 2018).

Saffer et al. (2018) have shown how feelings of fear and anxiety were central to the experience of disabled citizens who found themselves in need of services and support from the welfare state of the 2010s United Kingdom. Among the range of emotions elicited by austerity politics, *fear* emerges as particularly significant due to its ability to reflect both individual vulnerability and systemic precarity. As Berezin (2002, 37) claims, it is apparent that "some emotions are more relevant to politics than others" and that "some emotions are more likely than others to emerge in the political sphere and have discernible political consequences."

In the material analyzed for this article —consisting of interviews with disabled citizens in Sweden in need of state support and services —fear was the predominant emotion. The interviewees expressed fear in relation to previous experiences of applying for or reassessing support and service, as well as fear for present changes to eligibility criteria and for future changes to the welfare state's support. By focusing on fear, the present study highlights its dual role (i) as an affective response to austerity measures and (ii) as a political tool that shapes and informs disabled citizens' everyday lives and social position. In the interviews, fear not only emerges as a central emotional response but also configures the orientation of disabled citizens, thus determining how they navigate and relate to the welfare state, society, and their personal futures.

The need for studies of affect and disability becomes evident when one examines the effects of austerity politics on disabled citizens. For example, Goodley et al. (2018) argue that affect theory and the study of emotions should be a central component of disability studies since affect is crucial to the stigmatization that forms around disabled bodies. Consequently, studies of affect are not merely investigations into individual psycho-emotional reactions but constitute analyses of how these emotions are produced, how they correspond to economic and cultural structures, and how they are distributed across society.

1.1 Aim

This study contributes to and develops research on affect and disability in sociology by analyzing accounts of fear provided by disabled citizens who require welfare state support in Sweden. Drawing on material collected between 2017 and 2019, and focusing on fear as an affect produced by austerity politics—as well as a political emotion with both individual and collective consequences—this study investigates how austerity measures shape and inform the emotional experiences of disabled citizens.

The central questions addressed by this study are:

- How is fear expressed by disabled citizens who are affected by austerity measures?
- How does fear impact the lives of the interviewees?
- What orientations does this fear produce?

1.2 Background: disability and the changing Swedish welfare state

The Swedish welfare state has been of interest to sociologists for several reasons. Despite, having been characterized as a well-functioning system of stratification (Esping-Andersen, 1996), the Swedish welfare state's standing has also been subject to debate in research that has examined how the early Swedish welfare state was built on a program of highly repressive social engineering influenced by eugenics, race-biology, and social Darwinist motives (Lucassen, 2010; Norberg, 2019).

During the early years of the Swedish welfare state, services and support for disabled citizens were primarily concerned with the provision of pensions for those who acquired their disability whilst working, i.e., a form of worker's compensation. From the 1940s and 1950s, a large-scale institutionalization of (predominantly) disabled children took place. In these state institutions, education and health care were provided, but the surrounding society remained, in the main, inaccessible. Following the introduction of the 'principle of normalcy' (Lewin, 2021; Bylund, 2022) in the late 1960s, arguing that the institutionalization of disabled citizens was immoral, and the Marxist disability rights movement 'Anti-Handikapp', who established that the marginalization that disabled citizens faces is shaped by an inaccessible society, many of the institutions for disabled children and adults were dismantled. In the late 1970s and early 1980s several support systems were implemented, including residential care arrangements outside the state's large-scale institutions. However, support that would grant disabled citizens self-determination was not implemented (cf. Bylund, 2022).

In the late 1980s, mobilization by Swedish disability rights movements resulted in legislation that regulated the provision of support for disabled citizens, often understood as enjoying a peak in 1994 with the implementation of the LSS Act [the Law Regulating Support and Service to Persons with Certain Functional Disabilities]. LSS grants support such as personal assistance and guidance services for disabled citizens with the goal of independent living and inclusion in society (Bylund, 2022; Norberg, 2019; Hultman, 2018). Implementing the LSS Act marked a shift in Swedish disability politics, centering around a social model of disability and framing services and support for disabled citizens as a question of democratic and civil rights. Services and support for disabled citizens were understood as being in line with the provision of a general safety net for citizens provided by a welfare state.

However, the reforms mentioned above faced opposition during their initial years of implementation, as some considered them too costly for the welfare state economy. As a result, in 1996, eligibility for personal assistance under the LSS Act was redefined based on the concept of 'basic needs' (Bylund, 2022; Lewin, 2021). Alongside this definition, a division was introduced between those requiring more than 20 h per week of assistance with basic needs and those requiring less. If a person's needs exceeded this threshold, support was to be funded by the state through the Swedish Social Insurance Agency, Försäkringskassan. If the needs fell below the threshold, the municipality where the person resided was responsible for providing support.

From the late 2000s and onwards, following global austerity measures, a shift towards a neo-liberal focus has taken place that has entailed easing citizens' tax burden (Norberg, 2019; Bylund, 2022). Consequently, debates on the cost of services and support for disabled citizens have resurfaced. Austerity measures, from 2009 and onwards, have been aimed directly at reducing services and support for disabled and chronically ill citizens. These measures have primarily focused on changing the eligibility criteria for sick benefits provided by the social insurance agency Försäkringskassan, and services and support mandated by the LSS Act (Norberg, 2019; Altermark, 2020; Lewin, 2021). Norberg (2019) has shown that politicians do not explicitly announce Swedish austerity measures to the Swedish population. Instead, they result from political pressure that is exerted on various authorities. Austerity measures have been implemented through bureaucratic and legal arrangements, for example, in changes in legal praxis and in the bureaucratic definition of 'basic needs' in the LSS Act (Berggren et al., 2021). A key aspect of these changes has been the 20-h-per-week threshold for basic needs in order to obtain personal assistance from the state, which has played a crucial role in the implementation of austerity policies. The shift in eligibility criteria has progressively narrowed the definition of basic needs—for instance, dressing no longer includes putting on coats or shoes, and eating excludes plating or cutting food. As a result, many individuals who previously qualified for state-funded support through Försäkringskassan have been excluded. These changes have led to thousands of disabled citizens either losing their support and services entirely or facing substantial reductions in the support they receive (Norberg, 2019; Berggren et al., 2021; Lewin, 2021). Furthermore, by the state's use of invasive tools for the assessment and re-assessment of a person's needs that breach their personal integrity, disabled citizens who require support and services are not only put in precarious living conditions but also find themselves under immense emotional pressure. In this article, the term 'contemporary austerity' refers to the ongoing political and bureaucratic transformations that were initiated in 2009 and continue to shape policy and practice in the present.

Norberg (2021, 662–664) has labeled the bureaucratic implementation of these austerity measures as 'bureaucratic violence'. Norberg (2021, 656) states that "[s]ociological attention to bureaucratic violence is important as the technocratic veneer of bureaucracy obscures the structural and material violence enacted and contributes to its mundane appearance." Following Norberg, I claim that more research should be conducted in this area, especially on the emotions and affects that are produced by Swedish austerity, if we are to fully understand the violence enacted on disabled citizens through austerity measures.

1.3 Disposition

The following section presents the theoretical framework of the study. This is followed by a description of the data collection methodology and the data analysis. The study's findings are organized around four central themes, namely: (i) Traded narratives, (ii) Objects of fear, (iii) Wounding affects, and (iv) Disorienting affects. Each of these themes elucidates different aspects of the emotional landscape experienced by disabled citizens amidst the prevailing austerity politics that inform public and private life in Sweden. The study concludes with a discussion section that contextualizes the results within the existing literature on the topic and proposes avenues for future research into the complex dynamics that exist between power, discourse, and emotions in contemporary welfare states.

2 Theoretical framework

The following section outlines the theoretical perspectives that inform the analysis, focusing on the key concepts of 'ableism', 'affect', and 'combat breathing'.

2.1 Ableism as a hegemonic discourse

Discourse is the key mechanism through which power operates within society, shaping our understanding of reality via language, actions, and representation. Discourse not only reflects existing power relations but also reinforces them by constructing oppositional 'others' and influencing how individuals perceive themselves and others (Foucault, 2010). Foucault argues that hegemonic discourse materializes in *biopolitics*—i.e., the regulation of populations and bodies by state institutions—as a central feature of modern governance. Biopolitical mechanisms, such as disciplinary practices and technologies of surveillance, operate through discourse to govern and control populations. In this way, discourse and biopolitics constitute integral components of modern power relations, shaping individual subjectivities and broader socio-political structures (Foucault and Senellart, 2010).

'Ableism', as developed by McRuer (2006, 2018), Campbell (2009), and Kafer (2013), can be understood as a hegemonic discourse that forms a system of discrimination and prejudice by privileging able-bodied individuals while marginalizing and oppressing those understood as 'disabled'. Ableism is deeply ingrained in societal structures, norms, and attitudes, perpetuating the notion that able-bodiedness is inherently superior and desirable. It manifests in various forms—including physical barriers to access, unequal opportunities for employment and education, and harmful stereotypes that perpetuate stigma and exclusion. McRuer (2018) has shown how ableist discourse underpins neoliberal austerity politics by promoting and safeguarding able-bodied citizens' safety and desires. Similarly, Goodley et al. (2018) have explored how ableist discourse interacts with the neoliberal welfare state's emphasis on autonomy, self-sufficiency, and independence. As Goodley et al. (2018, 210) argue, this discourse fosters "the elision of individual and national economic independence with an individual and cultural celebration of autonomy." Although Norberg (2019) applies the term *disablism* to refer to the stigmatizing discourse aimed at disabled people, while *ableism* promotes the hegemony of able-bodiedness, she makes similar claims regarding the idea that the stigmatization of disabled people is a driving force in neoliberal austerity. This stigmatization is produced and based on affect, an observation discussed in the following section.

2.2 Affect

Seyfert (2012, 32) describes an *affect* as something that "defines and ceaselessly constitutes and reconstitutes the nature of a body." Furthermore, distinctions are sometimes drawn between *emotion as a sociological expression of feeling* and *affect as a biological response* (Gorton, 2007). However, regardless of one's perspective, affect is always entangled with discourse, power, and the production of emotive states. In this vein, Gorton (2007, 334) notes that "feeling is negotiated in the public sphere and experienced through the body." Similarly, Pedwell and Whitehead (2012, 116) argue that "power circulates through feeling" and that "politically salient ways of being and knowing are produced through affective relations and discourses."

The present study employs Sara Ahmed's theorization of the relationships between discourse, affect, and orientation. According to Ahmed (2014), affects are not merely expressions of subjective experience; they emerge from and reproduce power structures. Consequently, affects are deeply intertwined with discourse and materialize as emotional states, both physically and existentially. Ahmed further observes that "[e]motions[…]involve bodily processes of affecting and being affected" (Ahmed, 2014, 208), indicating that affect circulates between the subject and discourse.

Ahmed (2004a) also posits that affects are productive in the sense that they orient different (types of) bodies toward or away from specific places and spaces. In *Orientations: Toward a Queer Phenomenology*, Ahmed (2006) raises the question: *How do we find ourselves in the places we inhabit?* She argues that the answer to this question depends on the type of body one has, how that body is culturally understood, and the directions in which one is able or permitted to move within a given cultural context. Furthermore, Ahmed maintains that objects, feelings, and opportunities are perceived as closer or more distant depending on one's physical and discursive starting point. According to Ahmed, *orientation* can occur through various means—some gentle, others harsh—one of which may be the fear or threat of appearing culturally incomprehensible.

This study develops Ahmed's *queer phenomenology* into *crip phenomenology* (cf. Hall, 2021; Lajoie, 2022) by incorporating dimensions of ableism and disability. Following Reynolds, Hall (2021) describes crip phenomenology as an investigation of disability as lived experience, "not in the form of abstract thought experiments but concretely in a world deeply structured by ableism" (2021, 13). In this article, crip phenomenology offers tools that to examine the becoming of disabled bodies and subjects through the welfare state's distribution of resources and possibilities. In line with Lajoie (2022), this analysis centers on "the intersection of bodies, worlds, and the everyday practices and norms that determine the intersubjective shape of belonging" (2022, 319).

Applying Ahmed's understanding, the welfare state can be viewed as *a system of orientation*. By means of its stratification mechanisms, the welfare state redistributes risk from the individual to the collective (Esping-Andersen, 1996; Norberg, 2019; Bylund, 2022). Through bureaucratic tools, economic resources are transformed into services and support, thereby orienting individuals toward specific subject positions. For instance, the Swedish legal reforms governing parental leave enable both women and men to combine parenthood and work life, while support that the LSS Act legislates facilitates disabled citizens' inclusion in society with self-determination in their daily lives. This orientation is inherently discursive and practical since the welfare state measures and enables individuals to imagine and act on particular possibilities. At the same time, the welfare state has existential dimensions since it shapes who individuals can become. Consequently, the welfare state profoundly influences everyday life's practical and existential dimensions, from mundane activities like personal hygiene and mobility to access to the labor market and social participation. This includes the embodied and emotional experiences of daily life (cf. Bylund, 2022; Norberg, 2019).

2.3 Fear, violence, and combat breathing

In her work on affect, Ahmed defines *fear* as an emotion tied to expectation—we fear that something specific will happen to us. From her perspective, fear is linked to an object, body, or event that approaches us (Ahmed, 2014). Fear is thus culturally constructed and shaped by discourse. In the present analysis, fear emerges from the relationships between the interviewees' abilities, their dependency on welfare state services, ableist discourse, and austerity measures.

Barbalet (2001) provides a sociological perspective on fear by relating it to a subject's power in various situations. Drawing on Kemper (1991), Barbalet (2001, 153) argues that fear arises from structural conditions of possessing insufficient power oneself or from the overwhelming power of others. While Barbalet examines fear as a motivator for action in those with power, the present study focuses on his notion of *fear as a response to powerlessness*. Barbalet (2001, 155) also suggests that fear does not always involve a specific threatening agent but can stem from the expectation of adverse outcomes. Similar to the experiences of the Swedish disabled people presented in Norberg (2021), the material analyzed for this study reveals that fear of adverse outcomes—such as a re-assessment of one's eligibility to receive state support or changes in the state's welfare eligibility criteria—is central to the precarity experienced by disabled citizens in times of Swedish austerity.

For Norberg, the concept of 'bureaucratic violence' is key to understanding how discourse forms systems of biopolitical power through bureaucratic processes in contemporary Swedish austerity measures. In agreement with Nixon (2013, 2), Norberg (2021) argues that "[…]we need to engage a different kind of violence, a violence that is neither spectacular nor instantaneous, but rather incremental and accretive." Norberg further states (2021, 657) that a distinguishing feature of bureaucratic violence is its "seemingly non-violent nature." Although the redistribution of resources through the welfare state bureaucracy might appear rational and devoid of emotion, Norberg (2019), Goodley et al. (2018), and McRuer (2018) all show that the impact of austerity measures on disabled people's lives stems from and produces emotions and affects when enacted. In this article, I employ Ahmed's concept of 'affect' as a productive force to examine the experience of bureaucratic violence in the interviewees' accounts.

The analysis of the impact of bureaucratic violence on the becoming of a subject is informed by Fanon's (1970) concept of 'combat breathing'. Fanon was concerned with state violence in the context of colonialism and argued that ongoing colonial violence reduces the subject to a position where merely staying alive and breathing becomes a struggle (Fanon, 1970, 70). Expanding on his work, Perera and Pugliese (2011, 1) propose that combat breathing is an effect of biopower in various settings where individuals face state violence. This study proposes that austerity constitutes state violence, supported by Perera and Pugliese (2011, 1), who state that there is a "strange intimacy" in violence carried out by the state "at the same time as it is located externally, it shapes the somatic being of the target, amplifying its wounding effects across the body." The imagery put forward by Perera and Pugliese aptly fits the experiences of disabled people who depend on welfare state support in their everyday lives. As mentioned earlier, for disabled citizens in need of support, changes in the welfare state bureaucracy not only alter the possibilities available for everyday life but also its very experience. Norberg (2021, 667) notes that the stories from disabled people affected by austerity, in her study, are shared by those "that are still alive" opening for the possibility to make a chilling connection between the austerity of the Swedish welfare state and the breathlessness described in Fanon's concept of 'combat breathing' by highlighting the ultimate consequence of austerity politics for disabled people, namely their death. The very act of breathing has also come under scrutiny in the context of Swedish austerity measures targeting services and support for disabled people. A judicial decision once deemed that the assistance provided by managing and monitoring medical breathing devices did not constitute assistance for a "basic need" [as defined in the LSS Act] and, therefore, did not qualify a person eligible for personal assistance. Although this decision was overruled in court in

2019, such (attempted) changes in eligibility bring the issue of breathing to the forefront—not only as a symbol of livability during austerity but also as a stark example of the profound impact that changes to eligibility criteria for welfare state support have on disabled citizens lives (cf. Norberg, 2021, 659).

Bureaucratic changes to the provision of services and support for disabled citizens under austerity measures result in a form of violence that risks being overlooked. The state violence perpetrated through austerity is not, at first glance, as overtly brutal as the state-sanctioned murders that took place in colonial settings that Fanon discussed (1970). However, austerity is predicated on positioning some bodies [i.e., groups of individuals] as subjugated and disposable through specific discourses and economic policies (cf. Ryan, 2019; McRuer, 2018). Perera and Pugliese (2011, 2) draw a connection between Fanon's concept of 'combat breathing' and other types of state violence, arguing that "[o]ne of the key objectives and lived effects of state violence is precisely to reduce the target body to an expendable body who's right to be is fundamentally questioned…" Thus, the question of expendability lies at the core of austerity measures that target disabled citizens. Austerity measures aimed at reducing or even eliminating services and support for disabled citizens constitute a discursive attack on the personhood of disabled citizens since such measures position them as burdens, parasites, and 'counterfeit citizens' (cf. Goodley et al., 2018; Hughes, 2015; Ryan, 2019; McRuer, 2018). Rose et al. (2018) maintain that combat breathing is intimately connected to physiological reactions. They argue that "[c]onsidered as a contested, disfigured daily pulsation, 'combat breathing' might be recast as a form of chronic stress," further citing Herman (2013), who argues that "whereby protracted exposure to 'a real or perceived threat to homeostasis or well-being[…]can cause pronounced changes in psychology and behavior that have long-term deleterious implications for survival and well-being." My use of the term *combat breathing* in this study refers to the heightened state of vigilance produced by state violence as manifested in affect. I also consider how this impacts the interviewees, revealing the intimate relationship between austerity as state violence and the becoming of a subjugated subject.

3 Method and material

The interview material examined in this study is part of a more extensive set of materials gathered during in-depth qualitative interviews with disabled citizens who required services and support from the Swedish welfare state (see also Bylund, 2022). The interviews were conducted as part of my doctoral research in 2017. Following the interview period, I maintained contact with the participants and made myself available should their living conditions change or should they wish to share additional insights. As a result, the empirical material spans the period from 2017 to 2019. The interview method was grounded in ethnographic and ethnological research paradigms, prioritizing a nuanced, qualitative exploration of individual experiences rather than relying on statistically quantifiable data. The semi-structured interviews, based on open questions, allowed the interviewees to choose what experiences they felt were the most important to share and discuss freely.

The doctoral research project focused on the relationship between welfare state support and the possibilities for disabled citizens in Sweden to engage in romantic relationships, partnerships, and form families. Consequently, a large part of the interview material revolved around changes in the Swedish welfare state, previous experiences, and the interviewees' hopes and dreams for the future. Fear was a central topic in the interviewees' accounts of (i) their relationship to the Swedish welfare state, (ii) the process of obtaining state support, and (iii) contemporary austerity politics. For the present study, I have selected the parts of the interview material that focused on accounts of fear caused by austerity.

The interview material was collected under the principle of 'cross-disability', which proposes a perspective on disability as a socio-political issue and a heterogenous identity that leads to stigma and marginalization in an ableist society (cf. Bylund, 2022). This principle entailed that the criteria for participation in the interviews were not limited to an individual's specific medical diagnosis or impairment. By following this principle, I sought to collect a set of a heterogenous materials regarding the interviewees' disability, gender, age, and class, which made it possible to study the differences and similarities in the interviewees' experiences based on disability as well as other factors such as gender, socio-economic class and ethnicity. A call for participants was distributed through social media, disability rights organizations, and networks of people involved in disability activism and disability research in Sweden.

A noteworthy aspect of gathering the interview material was my repeated engagement with potential interviewees who expressed ambivalence about participating in the study. They described their relationship with the welfare state bureaucracy as emotionally challenging, and, due to fear that their participation could re-actualize previous traumatic experiences when they claimed state welfare support, they ultimately refrained from participating.

In total, thirteen interviewees participated in the study: four men and nine women. Some were physically disabled, some cognitively disabled or neurodivergent, and some were both physically and cognitively disabled. At the time of the interviews, the interviewees were between 20 and 73 years of age, but most were between 35 and 50 years of age. Many of the interviewees had experience working with Swedish disability rights organizations or were politically active. In this sense, the interview material was relatively homogenous in terms of the interviewees' prior experience of engaging in matters related to disability rights and applying for services and support from the Swedish welfare state. These shared experiences also influenced their responses and motivation for participating in the study since many of them possessed in-depth knowledge regarding the changes that had taken place in state welfare support for disabled citizens. Their knowledge was based on their work in the disability rights movement, political party involvement, and personal experience.

Most of the interviewees had accessed or continued to access services and support under the LSS Act, including personal assistance, guidance services, accommodation in group homes, or housing with special services. Several interviewees also accessed support provided by the Social Services Act (SoL), such as home help or guidance services. However, many of the interviewees had been impacted by austerity measures from 2009 and onwards and had suffered substantial cuts to their services and support, either at the time of the interview or prior to their interview. Furthermore, some of the interviewees lived entirely without the services and support they needed, having been denied the services they had applied for.

The impact of austerity politics on the practical aspects of disabled citizen's lives also influenced the choice of research methodology, in response to the inaccessibility and lack of services and support from the welfare state. Following Kerschbaum and Price's (2016) crip methodology, the interview method focused on providing accessibility for both the researcher and the interviewees. Each interviewee's ability to perform personal hygiene and everyday tasks such as getting dressed, leaving their home, or traveling determined how the individual interviews were conducted. Most of the interviews were conducted by phone or video calls because many of the interviewees could not travel. In such cases, the interviewees' needs and their degree of access to state welfare support intersected with my own needs as a researcher. The interview method was thus not only a methodological choice based on accessibility as a principle but also constituted a necessity in times of austerity. As such, this method responded to the doctoral study's overarching research purpose, i.e., to examine how changes in state support informed the possibilities available to disabled citizens in their everyday lives. The interviewees who received adequate support were often more likely to meet with me in a physical meeting or a video call since their control over their personal hygiene and self-presentation allowed for this. Note that these factors are fundamental to a disabled person's sense of equality in social interaction. These circumstances also entailed that even if I could meet the potential interviewee in person, the lack of agency in their everyday lives may have led them to refuse participation in an interview. If the possibility of being interviewed by telephone, video call, or chat had not existed, the collected interview material would only have contained stories from individuals who enjoyed enough support and services to meet in person.

The interviews were audio recorded and transcribed. For the sake of their anonymity, the interviewees were given pseudonyms, and the exact details of where they lived were described in general terms, such as "a small town in the south of Sweden" or "in the capital region." The contents of the transcriptions were initially categorized thematically. These themes were then further analyzed as discourses following a Foucauldian definition of discourse (cf. Foucault, 2010). In the analysis, I classified the interviewees' accounts as narratives. From an ethnographic point of view, narratives are structured accounts of events and experiences that are shared to convey meaning in specific social, cultural, and political contexts (Langellier and Peterson, 2004). Narratives serve to tell stories and function as a medium through which identities, values, and ideologies are communicated and shaped. From a Foucauldian perspective, narratives are part of discursive formations. They are not just stories but are embedded within power relations and help to reproduce or resist dominant discourses (Foucault and Senellart, 2010; Langellier and Peterson, 2004). Narratives act as tools for organizing meaning while simultaneously shaping how individuals and groups understand their social realities. Based on this theoretical framework, I also paid attention to the 'silences' present in the material, made manifest by what the interviewees refrained from talking about and by any contradictions that arose in the interviewees' different accounts.

3.1 Finding fear in the material

Descriptions of fear and anxiety most often emerged in the interviews after I asked the interviewees questions about how they envisioned the future. The interviewees more frequently described various scenarios they were fearful of rather than detailing how they experienced the fear as emotion. Even when they described how past or present fears had affected them physically and emotionally, their responses were often controlled and measured. The interviewees' seemingly 'calm' way in which they described and recounted their experience of strong emotions can be understood through the lens 'bureaucratic violence' described above. In systems of welfare state bureaucracy, the 'non-violent nature' of bureaucratic violence leads us to communicate calmly about matters vital to our lives (cf. Norberg, 2021). Even interviewees who were in difficult life situations at the time of the interview describe these conditions—and their fear that these conditions will persist or worsen—in relatively calm terms. It was apparent that the interviewees were accustomed to describing their living conditions in contexts where the expression of emotions is not attributed much value, for example, in bureaucratic and legal processes. Furthermore, they had discussed their living conditions on multiple occasions and in various settings before the interview. The interviewees felt and continue to feel fear, but how they described their fear was neither new nor raw. Social anthropologist Tamas (2008), argues that academic work that seeks to bring forth voices about difficult experiences, carries an inherent paradox with respect to depicting trauma and fear:

> *We are talking about being broken and undone. But our voices as we speak do not sound broken. [O]ur narrative voice seems to have it all worked out. We know what happened, and we can talk about it in complete sentences that make sense. We can tell others, even strangers, the truth about our experiences. That's how we turn trauma into knowledge.*

Although Tamas highlights this paradox as a limitation in research into traumatic experiences, I argue that the manner in which the interviewees presented their accounts about austerity politics and bureaucratic violence can be traced back to their experiences with said bureaucracy. For the sake of transparency, I have identified specific elements in their responses that I interpret as expressions of fear when relevant. I highlight these elements in bold typeface and explain how the interviewees framed their experiences.

4 Results

4.1 The circulation of fear

When they were asked about their thoughts and feelings regarding the future, many of the interviewees referred to the negative experiences of other disabled citizens as examples of what caused them to feel afraid. Several interviewees referred to media segments on the radio or TV which reported on austerity measures that were directed toward people with similar disabilities and living conditions, describing these reports as triggers for their fear.

For example, Ellen, a woman in her late twenties who has cerebral palsy, relied on home-help services from her municipality for tasks such as getting dressed, preparing meals, and household cleaning. Ellen considered that the number of hours of home-help services her municipality had granted her was insufficient for her support needs. However, Ellen was hesitant to apply for more support. When asked about her future, she stated she was worried about keeping the level of support she had at the moment. Regarding this, she referred to what she had heard from others:

> *If I had lived with my former partner, now that there is to be a re-assessment, it would probably be much more difficult for me to get support. Then there would have been problems /…/ I am not sure, but I can imagine it. I would probably have received less help. I am not very well-read [on the assessment criteria], but I have heard this from others. Now, it does not affect me very much because I do not have a partner at the moment, but I think it will.* (Ellen)

In Ellen's account, her understanding of the future was shaped by stories she had come across through her acquaintances in the Swedish disability rights community and in the media. Although examples of strengthening and uplifting narratives exist in the interview material, Ellen predominantly referenced narratives in which disabled citizens had lost their access to services and support from the welfare state. These reports form narratives (cf. Langellier and Peterson, 2004) of potential outcomes for disabled citizens under austerity and function as a form of external monitoring that compels Ellen to reassess her chances of receiving due recognition from the welfare state bureaucracy.

Using these narratives, Ellen creates a scenario that encourages her to orient herself away from specific choices and living conditions that she thinks would jeopardize her eligibility for the services and support she needs. For Ellen, her fear centers around forming a romantic relationship and sharing her home with a partner, something she actively refrains from doing.

The interviewees often spoke of narratives that originated from other places than their own lived experience, such as media coverage of political debates, government propositions, and parliamentary investigations. For instance, between 2016 and 2018, a parliamentary investigation into the existing LSS legislation took place. Initially, the terms of reference for the investigation were informed by an aim that aligned with contemporary austerity politics, i.e., to explicitly reduce costs for personal assistance offered by the Social Insurance Agency and the municipal authorities (Swedish Goverment, 2016). Charlotte, a woman in her seventies at the time of the interview, was one of several interviewees who spoke about the investigation as something that made her quite fearful. Charlotte contracted polio as a child in the 1950's, forcing her to move to an institution to access education; a life trajectory she shared with many other children affected by polio or other illnesses and impairments at the time. Charlotte was institutionalized in her childhood and young adulthood from the 1950s to the 1970s. After moving out of the institution as a young adult, she lived with home-help services and in residential care until she became eligible for personal assistance under the LSS Act in 1994. When asked what she thought of her future, she responded:

> *You never know what will happen with the investigation. They might say that if you are over 65, you will not get any [personal] assistance. We have been there before, and there are many indications that they would present [such a suggestion]. You are never safe when you depend on these services that can change with political decisions.* (Charlotte)

Charlotte's emphasis regarding how one is never safe when one depends on services and support from the state for one's everyday life lies at the center of her fear. She reported that she did not feel physically threatened at the moment but remained in a state of heightened vigilance (cf. Perera and Pugliese, 2011). The temporal nature of affect is apparent in Ellen's and Charlotte's accounts. When they think of their future, they project a future shaped by austerity measures that negatively affect their everyday lives.

As mentioned, many interviewees had experience working for Swedish disability rights organizations. A personal or professional awareness of current political and bureaucratic processes also seemed to play a part in the feelings that austerity politics evoked. While Ellen described herself as "not being well-read," Charlotte, who had worked within the field of disability rights for most of her adult life leading up to her retirement, could draw a connection between specific government initiatives (such as the investigation into existing LSS legislation) and a fearful future scenario. The more knowledgable the interviewees were in issues pertaining to disability rights, the stronger their feelings of fear. Like the other interviewees who were in their mid-forties and older, Charlotte had previously lived under conditions radically different from those she lived under at the time of the interview. When she spoke about what she was fearful of (at the time of the interview), she referred to previous experiences. I suggest that fear emerges in a pendulum between temporalities, oscillating between past experiences, contemporary media coverage, political debates, and future scenarios (see Knight and Stewart, 2016). Charlotte's previous experiences and the detail in which she can imagine her drastically altered living conditions inform the emotional intensity of the negative future she envisions. The affect generated in the present draws on and resonates with past experiences, thereby amplifying her fear.

Several other interviewees share Charlotte's feeling of "never being safe" since they, too, depend on state support in their everyday lives. Thus, they live in a constant state of *precarity* that previous research has described as a consequence of neoliberal austerity (McRuer, 2018; Saffer et al., 2018). The circulation of affect through the external monitoring of media coverage and personal experiences produces a state of combat breathing through a sense of being encompassed by an ongoing threat where negative consequences that may impact everyday living conditions are a permanent possibility. Under such circumstances, fear is a collective emotion shared by the interviewees; an emotion that does not require physical proximity to a threat (cf. von Scheve and Ismer, 2013). Instead, their positions as 'disabled citizens' in contemporary Sweden and their identification with others whom they perceive as their peers enhance their sense of fear. This identification is not primarily based on medical diagnosis or ability, however. In contrast, it is based on the notion of being part of a collective that needs services and support from the welfare state in their everyday life.

When interviewing Jonna, a woman in her mid-forties who lives with progressive muscular atrophy and receives personal assistance from the Social Insurance Agency, this collective identity was brought to the fore. Jonna strongly expressed being affected by and restrained by feelings of fear in her everyday life. However, in contrast with most of the other interviewees, Jonna was content with the number of hours of personal assistance that had been granted to her. Furthermore, she had not experienced any changes in this arrangement for several years. Nevertheless, she still felt that the media coverage of austerity measures and political debates that positioned disabled citizens as an economic burden (cf. Ryan, 2019; Hughes, 2015) impacted her negatively. She reported:

> *There is a big difference from, let us say, ten years ago. Then, [personal] assistance was not discussed as it is now. You walk around with a fear of losing what you have. Back then, I thought having a family or living in a relationship was reasonable. Now, it is the case that if I were to move in with a partner, it would lead to me receiving fewer assistance hours and somehow becoming dependent on another person, and I do not want that.* (Jonna)

According to Jonna's account, her fear revolves around two themes. As in Ellen and Charlotte's case, she fears losing her state support or having it reduced. Secondly, as a result of that initial fear, she also fears becoming dependent on a person with whom she might enter a romantic relationship. Jonna's fear of either of these scenarios being realized has led her to live alone, even though she previously wanted a romantic relationship and even start a family. In her life situation, the political and bureaucratic sphere conditions Jonna's emotional and social orientation.

Like Ellen, fear causes Jonna to orient away from something she previously not only desired but also considered plausible. Following Barbalet (2001), I argue that even though Jonna can be understood as being restrained by her fear, she remains an actor in her life and expresses agency by *not* orienting herself towards the living conditions she desires since she actively avoids seeking out romantic relationships. Narratives from the media and the disability community alike narrow her horizon of possibility. As with positive orientations offered by the welfare state, such as access to personal assistance, the possibility of experiencing more limited living conditions as a result of austerity restricts what she can do in her life and who she can become.

Jonna also indicated how the media image of disabled citizens who need services and support from the welfare state has changed in times of austerity. Under austerity, disabled citizens are viewed as objects of other people's care rather than citizens entitled to equal living conditions:

> *It is more in the general debate now that you are seen as an object that receives care and not an equal person. There has been a shift in values. There have been some strange discussions with my family, too. Like with my sister; I have been worried about how things will turn out, and she has sometimes said: 'Yes, but if that happens [that you no longer receive personal assistance], then you could move in with me.' And I think, What are you saying (raising the tone of her vioice)? She wants to tell me that I am not alone; that they are there and will care for me. But I feel even more frightened by that. What if it turns out that way in the end?* (Jonna)

Jonna's account aligns with previous research on how austerity politics reproduces a discourse in which disabled citizens are understood as 'undesirable' in comparison to the neoliberal ideal of a free and productive citizen (McRuer, 2018; Hughes, 2015). When she expresses her fear of how a change in her circumstance could affect her everyday life to her sister, her sister's response does not alleviate her concerns. Instead, Joanna expresses dismay that her sister has offered to accommodate her in her family home. In Jonna's example, fear is not only related to proximity but also to probability. Her sister's kind offer brings the imagined negative scenario even closer to Jonna by confirming that she is not alone in thinking of such a negative scenario. Losing her personal assistance is no longer a secret catastrophic thought that Jonna keeps to herself but is something that others close to her have also contemplated.

Jonna's account of her conversation with her sister highlights their different ontological, discursive, and epistemological positions. Although Jonna and her sister share a close relationship, their lives are dramatically divergent in a society shaped by ableism. This divergence is due to differences in their abilities, bodies, and need for support and services in their everyday lives. The impact of austerity politics that Jonna experiences is not experienced by her sister, even though her sister empathizes with the obstacles that austerity policies create in Jonna's life. For Jonna, her fear of potential negative consequences and their outcomes induces a sense of disorientation. As Lajoie (2022) has shown, disorientation occurs when "habits, gestures, or patterns of thought are called into question" (2022, 331). While such experiences may happen to everyone during the course of their life, Lajoie (2022) argues that for most, such experiences do not undermine their fundamental sense of belonging in the world. However, for disabled subjects, disorientation is often more profound, long-lasting, and structurally imposed, frequently involving physical, cognitive, or bureaucratic barriers. According to Lajoie (2022), this means that the disorientation experienced by disabled people compromises their sense of belonging in the world. In the case of Jonna and her sister, their respective subject positions not only create different living conditions but also shape their perceptions of what is 'dangerous' or 'safe'. For Jonna, being cared for by her sister does not foster a sense of safety but, instead, evokes a feeling of dread.

Jonna's, Ellen's, and Charlotte's accounts of what they fear reveal what they perceive as the most significant threat of austerity politics: living with a lack of self-determination and being dependent on others. Butler (2009) discusses how specific lives, bodies, and subjects are constructed as 'grievable' depending on how they relate to the hegemonic discourse in the surrounding culture. Butler (2009) argues that grievable lives are recognizable to the majority of people and are understood as 'worthy of protection'. McRuer (2018) has further developed the concept of 'grieveability' in neoliberal austerity policies so as to include lives or subjects who are understood as productive or profitable, which is in line with the thesis of ableism. In discussing what they fear, the interviewees relate to notions of 'liveability' rather than 'grieveability'. The traded narratives underscore the circulation of affect and the idea that collective emotions, which are rooted in a sense of belonging to a specific social group, do not necessarily require physical proximity to a threat. The sense of sameness, with regard to their life circumstances, that enables the interviewees to relate to the narratives of others is informed by a combination of personal experiences, physical or cognitive abilities, and a shared need for services and support from the welfare state. This sameness of experience, in turn, creates a socio-political position that emerges when changes are made to the bureaucratic governance and distribution of welfare state services. Narratives of adverse experiences of others, such as those reported in the media, heighten the interviewees' awareness of these issues, making them fearful of facing similar negative consequences in their own lives.

4.2 Letters, phone calls, and e-mails: objects of fear

Many of the interviewees described how their fear was directly linked to previous experiences of their welfare state support being (re) assessed. Ellen stated that:

> *Applying for support is always tricky because you are constantly questioned. Every time there is a re-assessment, you are terrified that the support you have will be withdrawn /…/ because they have their rules: 'We can grant you this, but we cannot grant you that.'* (Ellen)

In Ellen's account, her fear appears as a structural condition of insufficient power, as noted by Kemper [in Barbalet (2001)]. When the interviewees apply for services and support during a time of austerity, they enter into an asymmetric power dynamic. Norberg (2021) has contextualized this dynamic as 'bureaucratic violence' that is made manifest physically in meetings between the person applying for support and a Social Insurance Agency or municipal case worker. Norberg argues that "(re)assessments are also contexts where disabled people have little power if they feel that the assessment is inappropriate" (2021, 662). In the interviews recorded for this study, expressions of being "made to," "forced," or "not having a choice" are prominent in the interviewees' accounts of the assessment and re-assessment procedures they have been subject to.

For instance, Marcus, a forty-year-old man with cerebral palsy, who lived with his wife and two daughters at the time of the interview, described how he felt increasingly worried the nearer he was to a re-assessment session regarding his personal assistance at his municipality. Since he had lost his right to personal assistance from the Social Insurance Agency in 2013, the municipal re-assessments had become increasingly frequent. Sometimes, they were only 6 months apart. He provided the following account:

> *I was very anxious that an envelope with a review decision would arrive in my mailbox. I waited every day for it between 2012 and 2013. Your pulse rises when you see a letter with the Social Insurance Agency's or the municipality's logo. It is a real threat, an external threat, to your whole life.* (Marcus)

The physical symptoms of fear presented by Marcus were shared among the other interviewees. Marcus, Charlotte, Eva, Agnes, and Ida described how a general fear of austerity measures gradually transformed into physical reactions and avoidant patterns in their everyday lives. In each of their accounts, they provide several examples of feeling terrified if a municipal case worker calls them on the telephone or if they receive an e-mail from the Social Insurance Agency. Jonna mentioned that, at times, she actively avoids collecting her mail because she is too afraid of seeing a letter from the Social Insurance Agency. Such a letter would cause her anxiety levels to 'skyrocket', she added.

In these accounts affect is simultaneously located both inside and outside the body. Letters and phone calls become imbued with what Butler calls "accumulated violence" (Butler, 1997, 52), which reactivates previous experiences of bureaucratic violence associated with assessments or re-assessments. Such experiences evoke a lack of control over the future and a morbid anticipation of its potential adverse outcomes. When charged with accumulated violence, these objects transform the interviewees' bodily experience and induce a state of combat breathing and a heightened vigilance that is accompanied by headaches, anxiety, and heart palpitations. For individuals who do not rely on services and support from the welfare state but have a disability, a call from the municipality or a letter from the Social Insurance Agency may signal that these authorities are ready to provide assistance or help. However, in the case of the interviewees included in this study, the austerity measures that were in place at the time of the interview had shifted their relationship with these forms of communication from a sense of security to one of dread and perceived threat.

In Marcus' case, for example, any contact with the Social Insurance Agency or the municipality actualized his past experience in performing an ADL (Activities in Daily Life) assessment to confirm his support needs. During said assessment, a vocational therapist was asked to observe Marcus in real-time while he was being assisted in taking a shower. "I had to," Marcus stated during his interview. "I could not risk, for the sake of my children, not being given any support." In Marcus' case, bureaucratic violence (Norberg, 2021) not only breached the verbal boundaries of personal integrity, but even physical and practical acts that targeted the most private parts of everyday life. For Marcus, the fear he experienced, and his physical reaction are not abstract and merely driven by media narratives of a perspective in a political debate. Marcus' combat breathing sprang forth from the very real and physical experience of having to submit to a violation of his personal integrity. In this instance, the use of Fanon's concept of 'combat breathing' highlights the close relationship between restrictive eligibility criteria for services and support during austerity, increased control over the recipient of said services and support through bureaucratic tools, and genuine physical and mental harm.

4.3 Wounding affects: consequences for one's mental and physical health

Some of the interviewees spoke about profound physical reactions or long-term impacts of living with the consequences of austerity politics. Mia, a blind woman in her mid-forties, had had drastic changes made to her services and support conditions. At the time of the interview, she had a home-help permit from her municipality to help her with cleaning around the house and shopping. However, she lacked guidance services that would enable her to participate in social events, leisure activities, and physical exercise. Mia described the physical effects of the lack of support in the following:

> *I became depressed and gained a lot of weight because I was only at home and comforting myself with food. /…/ I felt like my whole life was a bureaucratic obstacle. I had to start taking antidepressants to cope. It is a constant stress when you do not know how life will turn out or what the next assessment will bring. It is not possible to plan your life. I will always have a visual impairment, but I hope that I will not always have my depression.*

Mia described how the lack of support and services causes her to worry about her future and has an impact on her self-image, thus her depression. A lack of physical activity in her everyday life combined with depression prompts her to turn to food for comfort, further impacting her health and sense of self negatively.

Ida, a woman in her forties with cerebral palsy, was also the recipient of home-help services from her municipality. She and her husband, who also had a physical disability, had been through numerous assessment and appeal processes so as to get enough support to take care of their child. She reported how these processes affected her husband's mental health:

> *My husband could not take the pressure in the end, and then it was as if they woke up at the municipality. So, you could say that for us, it took a trip to the psychiatry ward for them to realize what was at stake.* (Ida)

Ida described how the existential threat, to their family life, and the stress of the bureaucratic process resulted in specific psychological consequences for her husband. This, in turn, apparently prompted the municipality case workers to "wake up." For Ida, it was only when the stress took on measurable consequences in a medical sense, with a diagnosis, that the case workers seemed to consider the importance of the support and services that she and her husband needed. Ida's experience aligns with observations made in previous research on how a medical discourse becomes increasingly hegemonic in defining the specific needs or living conditions that render a disabled person eligible for services and support from the welfare state. Previous research has demonstrated that a discursive and legal shift has changed the aims of the support that is provided. The aims have changed from support being a tool for social inclusion and satisfaction of civil rights to a medicalized approach to providing support where only needs considered *integritetsnära* ('pertaining to one's personal integrity') render one eligible for support. Following this, a fragmented approach to assessing the needs of the disabled individual, where, for example, needing help with getting dressed in a coat and shoes, does not count as 'support with getting dressed' (cf. Berggren et al., 2021; Lewin, 2021). In this context, the fact that Ida's husband was visibly affected by the process that he had to follow so as to obtain services and support plays a crucial part in Idas's understanding of what it actually was that made them eligible for the support they needed, i.e., a measurable condition in a medical discourse.

Agnes described a similar situation. She was one of the youngest interviewees, a woman in her twenties living with multiple physical disabilities. At the time of the interview in 2017, Agnes had been involved in an appeal process for the right to personal assistance from her municipality for several years and continued to be so during the following years. In 2019, she sent me a message saying she had been hospitalized for several weeks due to problems with her breathing and blood pressure. It was ultimately concluded that she had developed a chronic illness affecting her lungs and that she would need daily medication and breathing aids. When Agnes's doctor learned that she had been under immense emotional pressure throughout her appeal processes and that a lack of services and support had prevented her from taking proactive action regarding her deteriorating health, he attributed her newly diagnosed medical condition as being caused by a lack of services and support. As in Ida's case, Agnes also hoped these measurable and documented physical consequences of lack of adequate support and services would lead to positive change in her everyday life. "Maybe someone can understand the seriousness of the situation now," she remarked.

Ida's and Agnes' accounts reveal the double-edged sword of medical bureaucratization with regard to disabled citizens' bodies, lives, and possibilities. This issue is further discussed by Lajoie (2022) in the case of accessibility. In Ida's and Agnes' cases, the negative consequences of bureaucratic violence and a lack of support may increase their eligibility for state support since medically measurable negative consequences underpin their needs.

Another interviewee, Leon, a trans man in his late thirties, described how the process of applying for support and making his needs and illness comprehensible to a bureaucratic system also had an impact on his well-being. At the time of the interview, Leon underwent a set of medical investigations that ultimately diagnosed him with Myalgic encephalomyelitis (ME), a chronic illness. One of the symptoms of ME is Post Exertional Malaise (PEM), which may cause a permanent deterioration in the patient's physical health. PEM can be triggered by everyday tasks such as showering, cooking, or taking a walk. However, emotions such as fear, stress, or anticipation of a negative event can also trigger PEM for those most severely affected by the illness [National Institute for Health and Care Excellence (NICE), 2021]. Leon reported how his fear of the consequences of austerity politics, combined with inadequate services and support, caused his symptoms to worsen:

> *I get sick from all the doctor's visits and the workload that bureaucracy entails. If I could get away from that and not be questioned and scrutinized all the time, I would feel better.* (Leon)

In this section, I have presented the interviewees report on how prolonged stress and an emotional state of fear and anxiety, in conjunction with the practical obstacles caused by austerity, have mental and physical consequences. I interpret their accounts as examples of being in a state of combat breathing and its mental and physical effects. Since the 1990s, medical studies have documented that the strain of discrimination leads to poor mental and physical health (Guidi et al., 2014). For example, physical illness due to material and social marginalization is described as an *allostatic load* (ibid.). This term describes the mental and physical strain that an individual experiences if their body's stress reactions are frequently activated or activated for a prolonged period. If the perceived threat that produces a stress reaction is not averted or mitigated, the body is put under constant mental and physical tension that leads to a (measurable) physical illness. Hence, Frantz Fanon's 'combat breathing' concept is an apt metaphor for the consequences of enduring state violence. Paired with the findings of medical research it can be said to describe an actual physiological process that is associated with measurable, physical and psychological consequences.

4.4 "It cannot happen here": disorienting affects

Marcus disclosed that the precarious situation he faced—marked by inadequate and short permits for services and support often re-assed every six or twelve months—had, at times, caused his anxiety levels to rise so high that he had been unable to function in his daily life. However, when he sought help from a psychologist to manage his anxiety, the psychologist found it challenging to make sense of his situation. Marcus considered why this was the case:

> *In Sweden, we do not believe that the state can treat a citizen like this, that it just keeps on happening. There is no language to explain*

> *what is happening. /…/ If this had been a relationship, I would have ended it, but how can you leave your municipality?* (Marcus)

Marcus' poignant account describes how being the subject of constant re-assessment left him feeling being stuck in a destructive or dysfunctional relationship where traumatic events are repeated. As a disabled person in need of services and support in his everyday life, he foresees that he will always be in some form of relationship with a municipality or the Social Insurance Agency. In Marcus' analogy about being trapped in a destructive relationship, a discursive silence emerges around experiences of the Swedish welfare state as 'violent' (cf. Norberg, 2021). Foucault (2010) emphasizes that discourse not only constitutes knowledge but also regulates what *can* be known or said within a particular cultural or historical moment. In Marcus' case, the hegemonic discourse of a 'just and fair' Swedish welfare state is challenged. Marcus felt that his position was as difficult to articulate as the trauma that had initially caused him to be in that position in the first place. The hegemonic discourse of the Swedish welfare state as 'fair and just' offers no language to describe the violence it perpetrates. Accounts of struggling to make sense of their situation when they meet with abled-bodied friends, family members, professionals, or colleagues were reported by several other interviewees. They declared that they could not align themselves with the hegemonic discourse of citizenship and the ideal of a 'just and fair' Swedish welfare state. Instead, this lack of alignment causes them to experience a sense of disorientation. Lajoie (2022) has explored how ableist lifeworlds disorient disabled people and "seriously impede the experience of belonging" (332). When the disabled citizens in this study attempt to articulate their physical and emotional experiences of bureaucratic violence to others, they find that the hegemonic narratives surrounding citizenship clash starkly with the actual conditions of their lives.

Previous research on emotions and citizenship has shown that citizenship, aside from being a legal definition of a person's status in a nation, is constructed by and produces emotions centered around the concept of 'belonging' (Ho, 2009; Fortier, 2016). In line with previous research on 'affective citizenship' (Fortier, 2016), I argue that the effects of austerity politics radically alter the experience of citizenship and the feeling of belonging. If citizenship is a question of belonging, ableist austerity centers around separating out individuals who are categorized as 'not contributing enough to belong', i.e., their right to belong is somehow annulled by their perceived inability to contribute to society. Furthermore, the hegemonic discourse of the well-functioning Swedish welfare state is also based on the notion of a citizen being protected and supported. The interviewees' experiences have tarnished this hegemonic concept of Swedish citizenship, leaving them feeling violated, coerced, and fearful, further impeding their sense of belonging. The emotions generated by these experiences erode their trust in the state's ability to safeguard their rights and provide adequate services and support services. Consequently, their sense of disorientation extends beyond personal aspirations and desires, revealing how citizenship and rights in the welfare state are, in fact, unevenly distributed on account of a person's disability. The disorientation produced by bureaucratic violence exposes an ableist hierarchy that is embedded in austerity measures and is thus also latent in the welfare state's redistribution of resources, where certain citizens are deemed worthy of being safe while others are not (cf. McRuer, 2018; Ryan, 2019).

5 Conclusion

In the accounts analyzed in this study, fear emerges as a distinct part of a collective emotional landscape of Swedish austerity politics aimed at reducing the services and support for disabled citizens between 2009 and 2019. Fear circulates in the form of narratives traded between disabled citizens and in the form of personal experience, media coverage, and political debate. Fear alters the meaning of everyday actions and objects, for example, answering the phone or collecting the mail. Fear also constitutes a wounded body, inflicting harm both physically and mentally as it produces heightened levels of stress and anxiety. Fear has disoriented the interviewees away from their everyday dreams and desires. Bureaucratic violence governed by austerity is the basis of the production and circulation of fear. As such, fear should be viewed as a symptom of disabled citizens' marginalization under conditions of neo-liberal austerity (Ryan, 2019; McRuer, 2018).

Seen through the lens of Fanon's concept of 'combat breathing', the findings of this study add to previous research that has argued that disabled citizens exist in a heightened state of emotional vigilance in times of austerity (Hughes, 2015; Norberg, 2021). The concept of 'combat breathing' does not necessarily signify that one is prepared or able to fight back. Instead, *combat breathing* can refer to a heightened state of vigilance as a consequence of an external threat (Perera and Pugliese, 2011). The effects of fear constitute a driving force in this mechanism of heightened vigilance. This study's findings also reveal how affects are made manifest in the body in a manner that strongly suggests that *bureaucratic violence has consequences equivalent to direct, physical violence.*

In response to Goodley et al.'s (2018) call for the use of affect theory in disability studies as a tool to further investigate the consequences of ableism, the findings of this study reveal an intricate relationship between welfare state governance and the emotional lives of disabled citizens. Consequently, examining how emotion and affect are circulated between political governance, societal discourse, and individuals can provide valuable insight into the importance of emotion in the production of disabled citizens' sense of self and sense of safety.

Fear as a characteristic affect for disabled citizens in times of austerity stems from, (re)produces, and impacts how the interviewees experience physical and mental states. Furthermore, fear determines their orientation toward and away from various actions. As such, fear as affect "define[s] and ceaselessly constitute[s] and reconstitute[s] the nature of a body" (Seyfert, 2012, 37). However, since the production of fear can be traced to specific political, legal, and bureaucratic changes in the welfare state's provision of services and support, it prompts us to ask the question: Would a different discourse and governance create a different affective landscape? As previously mentioned, the interviewees described different scenarios that they are fearful of more often than they described how the fear felt. This way of presenting their feelings, in terms of possible scenarios or previous experiences, reveals the profound connection between the interviewees' dependence on welfare state support and the production of affects. When asked to describe their feelings, the interviewees could not detach their feelings from the bureaucratic and political landscape that formed their everyday life.

The fear that is produced by austerity measures limited the interviewees' ability to imagine and act towards securing a prosperous future, even if they were not physically or practically limited in doing so at the time of their interview. This observation aligns with Saffer et al.'s (2018) argument that fear produces a 'limited subject' who self-restricts out of fear of further restrictions. In this regard, fear as an affect is a symptom of previously experienced trauma and is a traumatic infliction on its own. When one is in a state of fear caused by austerity politics, mundane tasks such as collecting the mail, reading a news report, or engaging in a conversation with friends and family can result in a state of combat breathing. This study's findings also support what Watermeyer and Swartz (2016) has described as 'a battle on two fronts'. Disabled citizen's not only experience material and economic marginalization and a lack of services and support, they also face emotional and existential violence caused by the fear of political, legal, or bureaucratic measures that will enhance this marginalization. Under such circumstances, fear is inherently disorienting because it prevented the interviewees from engaging in things they want or desire for fear of suffering adverse consequences if they did so. The path before them may be open, but they dare not travel along it. However, following Barbalet (2001), I categorize 'choosing not to act on wants and desires' as a deliberate action, not merely a state of inaction or paralysis.

Disorientation (as discussed above) is also related to the notion of 'Swedish exceptionalism', where the welfare state is presented as an inherently just system of stratification that keeps citizens safe (Norberg, 2019). If the welfare state produces adverse affects such as fear, these affects not only cause physical and emotional harm; they also disorient the subject from family members, healthcare professionals, and other citizens. This study thus also contributes to the field of affective citizenship by revealing how the experience of citizenship is not only a question of nationality and belonging but also a question of dis/ability and the biopolitics of the welfare state.

In conclusion, analyzing the feelings of disabled citizens provides valuable insight into the existential and physical experiences of ableism while also revealing the discursive landscape and governance of the surrounding society—an area that warrants further research.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by Swedish Ethical Review Authority. The studies were conducted in accordance with the local legislation and institutional requirements. Written informed consent was obtained from the individual(s) for participation in this study and the publication of any potentially identifiable images or data included in this article.

Author contributions

CB: Conceptualization, Data curation, Formal analysis, Methodology, Writing – original draft, Writing – review & editing.

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Conflict of interest

The author declares that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Walking on eggshells: disabled people's management of emotions during everyday encounters in accessible parking spaces

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This paper explores how disabled people manage their own and other's emotions during encounters with strangers in accessible parking spaces in a UK context. Due to their mundanity, the affective impact of encounters is frequently not considered in the move towards removing barriers to public space for disabled people. Understanding the energy and emotion work that goes into managing these affects therefore offers a crucial new perspective on how we understand what "accessibility" means. Situating my analysis at the intersection between the sociology of emotions and critical disability studies, I present data from 20 disabled interview participants in England on their experiences of accessible parking encounters. This includes a discussion of the impression management and emotion work required to navigate encounters in parking spaces, and the exclusionary impact these encounters can have over time. In the findings I highlight how considering relational and psycho-emotional aspects of disablism are crucial when understanding everyday oppression and offer a way to rethink the negative emotions arising from encounters as a collective rather than an individual experience.

KEYWORDS

disability, accessibility, affect, emotions, encounters, critical disability studies, parking

1 Introduction

This paper explores the extent to which disabled people are managing their own and others' emotions when trying to navigate encounters with strangers while using accessible parking spaces in a UK context. These encounters can have a significant effect on disabled people's emotional experiences of being in public: "Trying to understand the complicated feelings which arise out of our everyday encounters with the world is central to the lives of all disabled people" (Keith, 1996, p. 70). Building on findings from 20 interviews I conducted with disabled adults on their encounters with strangers in accessible parking spaces (also known as "Blue Badge" bays), I consider how public encounters do not just result from difference but can make (a) difference (Wilson, 2017) through replicating and reinforcing power inequalities between non-disabled and disabled people.

Employing an interdisciplinary approach, I weave together theories from the sociology of emotions with critical disability studies to demonstrate how thinking about affect may help us understand experiences of disability in a contemporary UK context. My approach is informed by an explicitly feminist and queer methodology which highlights how emotions play a crucial role in how people rationalise and make decisions when confronted with difficult situations (Ahmed, 2014; Hochschild, 2020). By conceiving of these emotions as a relational rather than a personal phenomenon, a focus on affect thus "offers a way of thinking about subjectivity that is not tied solely to the psyche" (Gorton, 2007, p. 345). In particular, my research is underpinned by the social-relational model of disability. This model draws explicit attention to interpersonal barriers by defining disability as

> "a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional wellbeing" (Thomas, 1999, p. 60).

A key feature of disabled people's exclusion in the social-relational model is psycho-emotional disablism, which restricts what disabled people can be as well what they can do (Reeve, 2004, 2008, 2015). Negative attitudes from others can therefore be just as effective in excluding people as physical barriers, particularly because of "the 'existential insecurity' associated with the uncertainty of not knowing how the next stranger will react" (Reeve, 2008, p. 40). Disabled people who have experienced psycho-emotional disablism during encounters can thus be left permanently ill at ease in public spaces.

My exploration of encounters is thus situated within a broader focus on disability as a relational phenomenon, reflecting how public encounters with strangers tend to reflect power imbalances in society (Valentine, 2008). Simultaneously, this paper contributes to the sociology of emotions by drawing attention to how disability can be created through the strong emotions that can arise during and from interpersonal encounters. Specifically, I explore the relationship between affect and action, with disabled people feeling the need to act on the anxiety, uncertainty, and anger present in accessible parking spaces by managing themselves and others. Disabled people are thus always proverbially "walking on eggshells" in having to assess the risk of the current situation. I build on feminist affect theory which has highlighted both the productiveness of emotions and their power to not just replicate but heighten the "othering" of marginalised groups (Åhäll, 2018; Ahmed, 2014; Gorton, 2007). I link these theories to cultural theories of emotions in order to highlight how "culture conditions our emotional experiences and expression" (Bericat, 2015: 499) while at the same time replicating and reinforcing a culture in which disabled people are always regarded with suspicion. This includes drawing attention to the considerable amount of time and energy that goes into navigating the constant "anticipation of risk" (Burch, 2021, p. 151).

In this introductory section, I explore how Goffman's (1986) concept of stigma has been transferred into a twenty-first century context to explain how stigma is employed at an institutional level to replicate hierarchies of impairment. I then explore how both Goffman's impression management (Goffman, 1972, 1990) and Hochschild's (1979) and Hochschild (2020) concepts of emotion work and "feeling rules" can apply to how disabled people manage the emerging power balances in interactions with strangers. Finally, I also draw on Ahmed's (2014) conceptualisation of "sticky" affects to explore the intersections of emotions, encounters, and public space for disabled people. In the methods section, I give a brief overview of my use of critical disability studies and queer "scavenger" (Halberstam, 2011) methodologies, as well as my approach to data collection and analysis. My findings are structured into three sections, exploring the experience of being under constant surveillance by oneself and others; the need to expend emotional energy to manage potential or actual encounters; and the cumulative impact of relentless abjection and uncertainty. I then offer a discussion of how these findings can help us understand the psycho-emotional impacts of ableism as an integral and shared experience that is central to the disability experience in contexts of austerity and abjection, as found in the UK. I conclude with a challenge to how "accessibility" is conceptualised, as there can be no truly equal access if disabled people continue to face considerable "hassle" (Timm, 2002) and hostility in public spaces.

1.1 Stigma and hierarchies of impairment

Stigma is a key concept in understanding the continual marginalisation of disabled people in contemporary society. Stigma draws attention to the relationality of power, relying on both "the normal [sic!] and the stigmatised" to play their part in rendering the stigmatised person as inferior (Goffman, 1986, p. 33). According to Goffman's seminal work on stigma, this results in encounters being often awkward and uncertain, as the stigmatised can never know "how normals [sic!] will identify him [sic!] and receive him [sic!]" (Goffman, 1986, p. 18). Emotions are thus integral to the stigma process (Brown, 2013). While Goffman's work provides a useful starting point in thinking about how power relations play out in encounters and what may be the resulting affects, his work has been frequently criticised within disability studies as lacking criticality and naturalising rather than challenging stigma relations (Abrams, 2014; Coleman-Fountain and McLaughlin, 2013; Oliver, 1996).

Tyler's (2020) reconceptualisation of stigma offers a useful revitalisation in order to address how stigma operates simultaneously at personal and political levels in the context of twenty-first century Britain. Tyler's stigma recognises how stigma is always intricately connected to broader issues of social and economic power and hierarchies:

> "while experienced intimately through stigmatising looks, comments, slights, remarks made in face-to-face or digitally mediated encounters, [stigma] is always enmeshed with wider capitalist structures of expropriation, domination, discipline and social control" (Tyler, 2020, p. 17).

In particular, stigma in this context is inextricably linked to government and media discourses to justify welfare reform, which have positioned the majority of disabled people as "fakers" and "scroungers", pitted against a small minority of "legitimate" disabled people who are deserving of support (Briant et al., 2013; Garthwaite, 2011; Hughes, 2015; McEnhill and Byrne, 2014). The division of disabled people into "deserving" and "undeserving" is underpinned by disability hierarchies, which suggest that some impairments are more likely to be perceived as legitimate than others. In Deal's (2003) research on hierarchies held by non-disabled people, wheelchair use was seen as the most recognisable and acceptable way to be disabled. Similarly, Briant et al. (2013) found that people with physical impairment and/or sensory impairments were far more likely to be perceived as legitimate by both the media and the public. In contrast, people with impairments including mental health conditions, chronic pain, obesity, or substance dependence were seen as particularly likely to be "cheating the system". Using a "divide and conquer" approach, stigma against those perceived as not deserving enough results in abjection of disabled people "as a mechanism of governance through aversion" (Tyler, 2013, p. 37) and has enabled successive governments to move ahead with cutting disability benefits with minimal public resistance. Understanding stigma as a deliberately created means of controlling populations through negative emotions is thus key to understanding the broader affective environment around disability in contemporary Britain.

1.2 Impression management and emotion work

Interactions with strangers often require significant work and active management in terms of how one is perceived and relates to the other person. The idea impression management is another important aspect of interpersonal encounters in public spaces first emerging from Goffman (1990). While everyone manages their self-representation when interacting with others, the power relations underlying encounters between disabled and non-disabled people mean that this impression management can be particularly fraught and burdensome for disabled people. Managing others' impressions often involves a performance of an "idealized" version of what the other person expects to see (Goffman, 1990). Recent work applying Goffman's work to disability has highlighted that disabled people may employ these management techniques strategically to negotiate difficult interactions (Scully, 2010; Wechuli, 2024). In the case of an encounter where the "legitimacy" of someone's impairment is being questioned by the other person, this can involve performing a "stereotypical" presentation of disability to make it more easily recognisable. What Siebers (2008) terms "masquerade", i.e. exaggerating a limp or using a mobility aid more than strictly required, can be one way to manage the requirement to "look disabled" in order to be deserving in accessible parking spaces, particularly given the considerable suspicion around "fakers" prevalent in British society. The performance of disability is thus a survival mechanism (Scully, 2010; Wechuli, 2024). However, appearing to "look disabled" alone is often not enough to satisfy suspicions, as disability stereotypes also prescribe how a disabled person should act. Incompetence and inferiority are thus integral aspects of the disabled role:

> "the cripple [sic!] must be careful not to act differently from what people expect him to do. Above all they expect the cripple to be crippled; to be disabled and helpless: to be inferior to themselves, and they will become suspicious and insecure if the cripple falls short of these expectations. It is rather strange, but the cripple has to play the part of the cripple." (Goffman, 1986, p. 88)

The reproduction of power imbalances is thus crucial to encounters. Building on Goffman's work, Hochschild's concept of "feeling rules" describes how interactions with others are guided by "what is emotionally due another person" (Hochschild, 2020, p. 19). Feeling rules are infused with unequal power relations. While Hochschild's original work focuses primarily on gendered power dynamics in an employment context, it has since been adapted to explore how disabled people are often expected to take responsibility for how we make others feel (French, 1994; Garland-Thomson, 2006; Keller and Galgay, 2010; Pritchard, 2021; Scully, 2010). This often means performing significant emotion work (Hochschild, 2020), modifying one's own feelings and behaviour to remain polite and deferential even when the other person is not, for example not getting angry when being stared at, patronised, or asked intrusive or personal questions. Key to being disabled in public is not just having an easily recognisable impairment, but to put in the emotion work needed to perform the role of the "good" disabled person who is always grateful, good-humoured, and compliant (Cahill and Eggleston, 1994; Keith, 1996; Reeve, 2006, 2008; Wilkin, 2020).

While the performance of emotion work can be extremely draining, refusing to abide by the established "feeling rules" by resisting stereotypical expectations can be equally fraught. Challenging others on their harmful assumptions can potentially result in extreme reactions from the other person, including outright hostility and aggression from the stranger (Burch, 2021; Morris, 1991; Siebers, 2008). Disabled people who do challenge others may feel guilty about provoking them into anger, or worry that this challenge may have negative consequences for other disabled people in future encounters (Cahill and Eggleston, 1994; Morris, 1991; Tregaskis, 2003). The emotions arising from encounters thus have the power to influence how disabled people navigate public space.

1.3 Affect, encounters, and space

The affects resulting from impression management and emotion work in interpersonal encounters are not just the final outcome of an unpleasant interaction, but are productive, shaping the encounter as it unfolds. The idea of emotions as affective practises that are "always 'turned on' and 'simmering', moving along" (Wetherell, 2012, p. 12) is key to understanding how encounters cannot just produce negative emotions such as anxiety, but also spur disabled people on into taking action. Thinking about emotions not as individually held feelings, but as affects which "stick" to both individuals and spaces (Ahmed, 2001), can help illuminate why accessible parking spaces are particular hotspots for intense emotional encounters. As one of the few spaces where disability is expected in public life, they draw attention to disability and thus serve as a location where societal prejudices of disabled people as either helpless, "vulnerable" recipients of charity, or as feckless scroungers, are concentrated. While accessible parking has been exempted from public sector cuts, the emotions of resentment and envy associated with government "scrounger" rhetoric (Hughes, 2015) nevertheless stick to disabled bodies. Conversely, emotions felt by disabled people such as anxiety and fear can become "sticky", particularly in spaces where hate was previously experienced, creating a negative "affective atmosphere" (Burch, 2021, p. 65) which means they can never be at ease in these spaces.

Spatiality is thus crucial in exploring encounters, with emotions, space, and the people within it mutually constituting. Conversely, encounters play a key role in shaping disabled people's experience of space (Cahill and Eggleston, 1995; Morris, 1991). A defining feature of encounters is that they are naturally uncertain and ambiguous (Wilson, 2017), with the possibility of escalation at any point. It is precisely because encounters are common and everyday occurrences that they are impactful. Hate and abjection of disabled people in public space is not extreme or exceptional, but a commonplace phenomenon in disabled people's everyday lives (Burch, 2021; Hall, 2019; Hall and Bates, 2019; Piggott, 2011; Wilkin, 2020; Hollomotz, 2013). Recent research on disability hate crime highlights the importance of space to acts of harassment and violence, with public transport and accessible parking bays emerging as particular hotspots (Hall, 2019, 2024). Occupying public space is thus not a neutral act, but rather, spaces are fundamentally social, both shaping and being shaped by the people within them (Lefebvre, 1991). It thus requires a great deal of care and attention to navigate certain spaces.

Another way in which space and affects are mutually affecting is through the emotional impacts of systematic exclusion. Encounters are effective in stirring up negative emotions about disability precisely because disabled bodies are still often absent from public spaces. Perpetual inaccessibility in the public built environment continues to exclude disabled people on a physical level (Hall and Bates, 2019; Hall and Wilton, 2017; Imrie, 2001). Disabled people thus become Ahmed (2000, p. 56) "stranger", a body that is recognised as out of place and fundamentally other to themselves. While accessible spaces such as parking spaces are seemingly a solution to the issue of structural inaccessibility, it has been argued that segregating accessibility into dedicated spaces in fact perpetuates "othering" by normalising inaccessibility elsewhere (Reeve, 2014, 2008; Slater and Jones, 2021; Titchkosky, 2011). The presence of signage such as the International Symbol of Access (better known as the wheelchair symbol), which marks accessible spaces, further shapes the encounters and affects present, but marking out which bodies are and are not welcome in this space (Slater and Jones, 2021). In a context where disabled people are under constant suspicion of "faking", this signage can therefore leave disabled people who are not visible as wheelchair users anxious about potential challenge from others. Accessibility is thus not a fixed state but shaped in large part by the interactions with others and their associated affects.

2 Methodology and theoretical approach

2.1 Framework

Employing a critical disability studies (CDS) lens, my research takes an "eclectic approach" (Meekosha and Shuttleworth, 2009) to interdisciplinarity, bringing together the sociology of emotions, psychology, human geography, and cultural studies to understand encounters. CDS thus opens up the possibility for multiple epistemological approaches and understandings of disability to co-exist and sometimes even merge (Meekosha and Shuttleworth, 2009; Flynn, 2017; Egner, 2017). My framework for this research is informed particularly by feminist and queer emancipatory methodologies.[1] My interest in the impact of public encounters, especially in accessible parking spaces, stemmed from my own experience of using these spaces as a disabled person. I experienced these spaces as anything but "accessible", and rather as places where I felt I needed to modify my own behaviour in order to manage or avoid actual or potential encounters. Using the feminist lens of the personal as political (Morris, 1992) I sought to make sense of my own emotions through research. My research is thus deeply indebted to the feminist disabled theorists who pioneered writing about psycho-emotional disablism and the impact of interpersonal encounters (Keith, 1996; Morris, 1991; Reeve, 2008; Thomas, 1999).

In order to explore encounters in all their complexity, I employ a mixed-method approach which for the answering of multidimensional research questions (Collins, 2015). Mixed methods approaches are also frequently employed in feminist and intersectional research approaches, allowing room for contradictions and multiple ways of knowing (Cram and Mertens, 2015; Hesse-Biber and Griffin, 2015; Hankivsky and Grace, 2015). Likewise, critical and transformative designs often include a mixed method approach that aims to centre marginalised voices (Creswell and Plano Clark, 2018; Cram and Mertens, 2015; Plano Clark and Ivankova, 2016).This can include the use of quantitative methods, which can be compatible with empowering approaches (Cornelius and Harrington, 2014) and have been employed effectively in feminist research to "dismantle the master's house" (Hesse-Biber and Griffin, 2015, p. 76). Transformative mixed methods research thus tend to have a "de-disciplining" effect (Hesse-Biber, 2015, p. xxxiv), with a tendency to focus on transformative concerns over epistemological or disciplinary conventions. In this way, my approach can be likened to a queer "scavenger" methodology, which puts the centring of marginalised voices above epistemological congruity:

> "uses different methods to collect and produce information on subjects who have been deliberately or accidentally excluded from traditional studies of human behavior. The queer methodology attempts to combine methods that are often cast as being at odds with each other, and it refuses the academic compulsion toward disciplinary coherence." (Halberstam, 2018, p. 13)

Intersectionality is a central focus for me within in this research, in line with concerns within critical disability studies to understand how disablism intermeshes with other forms of prejudice including racism, sexism, and homo-/transphobia (Schalk and Kim, 2020; Siebers, 2008). This has informed my sampling strategy in aiming to recruit participants with diverse experiences and identities. I have also sought to centre during my analysis how participants reflect on the impact of their intersecting identities. Another

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[1] In solidarity with other queer disability scholars, I have made an explicit choice not to cite work published in the *Disability and Society* journal after 2018, given its executive editor's anti-trans stance (Slater and Liddiard, 2018).

feature of my approach which is immersed in both queer and postmodern approaches which is my desire to resist and where possible, actively deconstruct, binaries (Egner, 2017; Halberstam, 2011) and to disrupt the status quo by going against conventions (Kafer, 2013; Slater, 2013). Some binaries challenged in this paper include the ideas of accessible/inaccessible, deserving/undeserving, and "looking"/"not looking" disabled. Challenging these binaries is central to highlighting the murkiness, ambiguity, and uncertainty disabled people often feel when they do not fit into these neat categories.

2.2 Data collection and analysis

The findings presented in this paper come from data collected in 20 semi-structured interviews, which formed the second phase of the mixed-method project. Mixed-methods approaches are common in feminist designs (Creswell and Plano Clark, 2018; Hesse-Biber and Griffin, 2015), and I employed this approach based on my commitment to capturing the nuances and complexities of encounters. Throughout the research process, I worked with an advisory group of 7 Blue Badge holders, to ensure that the research reflected the experiences and concerns of other disabled people as well as myself. The advisory group members were consulted before the launch of each data collection phase as well as afterwards to sense-cheque the results. They were compensated for their time and expertise with an honorarium. Ethics approval for each phase was gained from the relevant institutional review board. Given my own experience with such encounters, I was particularly aware that they may be distressing, so participants were provided with a list of resources for practical and pastoral support during each stage.

The 20 interviewees were recruited from a pool of over 300 disabled people who had previously completed a survey on Blue Badge encounters during the first phase of the research. This survey was shared through social media (Twitter, LinkedIn) and sent to 178 Disabled People's Organisations in England. It was open to disabled people aged 18+ resident in England who currently or in the past held a Blue Badge for themselves. Participants for the follow-up interviews were selected from those who had indicated their interest in this during the survey. Invitees were chosen using a purposive, heterogenous sampling approach (Aidley and Fearon, 2021) to ensure I collected as many diverse experiences as possible. Interviewees were invited in stages to cover a variety of impairments, ages, genders, ethnicities, sexual orientations, and types of encounters experienced. In total, I interviewed 10 men, 9 women, and 1 non-binary person. 16 participants were white, 1 was Asian, 1 had a mixed ethnic background, and 2 did not give their ethnic background. Interviews took place online via videocall, by telephone, or by email, depending on each participant's preference. Participants were also asked to self-define whether their impairment was visible. Most participants had an always visible impairment (11 out of 20), 6 had a sometimes visible impairment, and 3 had a never visible impairment. Interviewees were invited to review the transcripts after the interview and to choose their own pseudonyms. Table 1 provides a full summary of the interview participants' characteristics.

The approved transcripts were analysed using Braun and Clarke's (2022) approach to reflexive thematic analysis. This widely used analytical approach is about critical and questioning engagement with qualitative data, seeking to capture "nuance, complexity and even contradiction" (Braun and Clarke, 2022, p. 7). Further, its centring of reflexivity in the analysis is embedded within feminist research approaches which value the subjective experience and skills of the researcher (Braun and Clarke, 2021). This allowed me to bring in my own experiences of accessible parking encounters, and reflect on how they shaped my own analytical choices and interests (Braun and Clarke, 2022; Trainor and Bundon, 2021). In particularly, I realised that I was particularly interested in interrogating the spoken and unspoken contradictions within my participants' account. My analysis process for the reflexive TA closely followed Braun and Clarke's (2022, 2006) six-step process of (1) Dataset familiarisation, (2) Data coding, (3) Initial theme generation, (4) Theme development and review, (5) Theme, refining, defining, and naming, and (6) Writing up. Through this process, I generated four themes with a total of ten subthemes. The findings discussed in this paper come from four subthemes relevant to the field of emotions and impression management, titled "Hierarchies and legitimacy", "Walking on eggshells", "Abjection and hate", and "Slow death and exhaustion".

3 Findings

3.1 (Self-)Surveillance and impression management: "that balance is always there"

The first way in which disabled people manage emotions in accessible parking spaces relates to the way in which we manage our own behaviours and appearances to defuse or avoid encounters. This is often shaped by what Manji (2017) terms "sousveillance", a bottom-up approach to surveillance that encourages communities to police each other through acts of vigilante enforcement. Media reporting on taxpayer's money being squandered by benefits scroungers and cheats creates a sense of entitlement amongst the non-disabled public to cheque whether disabled people are really "legitimate" and deserving, as illustrated by Amir's experience:

> I usually sit in a seat in the car. And my wheelchair gets folded up in the boot. I don't sit in the wheelchair in the car. So, if you walk past the car window what you see is a, quote, "normal looking person". And people will.... will say things to me or my parents. Along the lines of "Why are you parked here?" And if... it might be a bit less polite. The things they usually say are, "Why the fuck are you parked here?" That's the kind of things people will usually say. "You don't need that space." "It's for real disabled people". "You don't look disabled." Because while I'm sitting in a car seat... I mean, I look... "ordinary". I hate this term, but it's kind of, a good description, I think. (Amir, Asian man with always visible impairment, age group 18-29).

A particularly frequent question my participants received from strangers is "What's wrong with you?" The question is "othering" through reinforcing the medical model assumption that disability

TABLE 1 Overview of interview participants.

Participant pseudonym	Gender	English region	Age range	Ethnic background	Sexual orientation	Impairment type(s)	Impairment visibility
Amir	Male	Midlands	18–29	Asian	Bisexual	Mobility, mental health	Sometimes
Anna	Female	South	40–49	White	Straight	Chronic illness, mental health, mobility	Sometimes
Charlie	Non-binary	South	30–39	White	Lesbian	Chronic illness, mobility	Sometimes
Chris	Male	Midlands	60–69	White	Straight	Blind, chronic illness, deaf, mobility	Always
Elizabeth	Female	South	70+	White	Straight	Mobility	Always
Emma	Female	Midlands	50–59	White	Bisexual	Chronic illness, mobility	Sometimes
Frank	Male	Midlands	70+	White	Straight	Deaf, mobility	Always
Frederick	Male	South	70+	White	Straight	Chronic illness, deaf, mental health, other	Always
George	Male	Midlands	50–59	White	Straight	Chronic illness	Always
Henry	Male	London	40–49	White	Gay	Chronic illness, mobility	Never
Isabella	Female	London	30–39	White	Bisexual	Chronic illness, mental health, mobility	Always
Ivy	Female	North	18–29	White	Bisexual	Chronic illness, mental health, neurodivergence	Sometimes
John	Male	Midlands	60–69	White	Straight	Mobility	Always
James	Male	London	50–59	White	Gay	Chronic illness, mobility	Always
Julie	Female	North	50–59	White	Straight	Chronic illness, mobility	Always
Katie	Female	South	18–29	White	Straight	Chronic illness, mobility	Sometimes
Louise	Female	South	50–59	Unknown	Straight	Chronic illness	Never
Lydia	Female	North	40–49	Mixed background	Straight	Chronic illness, mental health, neurodivergence	Never
Richard	Male	North	70+	Unknown	Straight	Chronic illness, mobility	Always
Will	Male	London	30–39	White	Straight	Mobility	Always

as a defect or a "problem" that makes someone different from a "healthy", "normal" person. It is also bound up in power relations. The surveillance of disabled bodies becomes a form of disciplinary power (Foucault, 1991), enacted by governments and replicated by the public upon disabled people to ensure only the "right" kind of disabled person is able to access certain accommodations, welfare payments, or accessible parking. Disabled people are thus under pressure to ensure they are always perceived as "legitimate" by strangers in order to access spaces.

Being perceived as "not looking disabled" can be a considerable source of anxiety. In an environment of suspicion and distrust of disabled people, those who feel they do not fit the expected image can feel constantly on edge about a potential confrontation. Hierarchies of disability lead to a narrow view of how disability should present, and rejection of anyone who does not adhere to this stereotypical image. The stereotype of a typical disabled person has previously been conceptualised as either a "young, male, white wheelchair user" (Shakespeare, 1996, p. 195) or an older wheelchair user (Reeve, 2008). My participants were acutely aware of this stereotype and the potential consequences of not "looking disabled". Younger disabled people particularly felt they were frequently targeted because of their age, and several female participants spoke about never travelling alone due to feeling unsafe. Even several of my wheelchair-using participants, such as

Amir, were subject to intrusive questions or looks, usually before they had got their wheelchair out of the car. All disabled people are thus potentially at risk of being questioned in accessible parking spaces, and were often acutely aware the different ways in which they were potentially inconsistent with a stereotype, as shown in Emma's interview:

> I think they seem to think that Blue Badge holders are wheelchair users, which is not the case, and I don't know… if I get targeted because I'm a Goth. You know, I dress like a Goth. I am a Goth, and have red and black hair, and I don't know if… because I look quite different that I'm targeted and… I don't know, from talking to all Blue Badge users, we're all targeted. We're all told, "I don't think you should be in that space", when it's got nothing to do with them. You know I do feel there's a real policing by the public of the Blue Badge spaces, Blue Badge holders. Um…yeah. But I just think, I just think you can't look like that. You can't look like me, you know, from a subculture. You can't be young. You can't not be in- not use a wheelchair. You can't not have a visible disability. (Emma, white woman with sometimes visible impairment, age group 50-59).

Emma's storey illustrates the many different ways in which she understands herself as not matching what a stereotypical disabled person should look and behave like. Incongruence is policed heavily precisely because of its potential to destabilise the disabled/non-disabled binary which underpins ableism (McRuer, 2002). Disability is required to be "fixed, permanent, internally homogenous and, moreover, oppositional" to the non-disabled body (Shildrick and Price, 1996, p. 95). Experiencing these confrontations in addition to the inescapability of "deservingness" discourse in wider society alongside means that we may internalise these discourses. Some of my participants who were closer to the top of the legitimacy hierarchy (e.g., older white men with physical impairments) spoke about sometimes doubting whether others were legitimate. Charlie on the other hand, had only recently transitioned to using a wheelchair and used accessible parking primarily for the extra width. They felt that their use of accessible parking bays was not just shaped by encounters with others, but also by self-doubt about whether they were "deserving" enough to use the bays:

> So you go into a spiral […] with some of that kind of challenge over looking young. And relatively healthy until they saw something. Or… you got the glares, you got the… the "Shouldn't you leave that bay? Shouldn't you leave that parking for somebody who needs it?" with the, you know, the implication being that you don't need it. And it's still some of that fuel of my knowing I don't need to be so close to the storefront, I can feel quite self-conscious about using blue badge parking. Especially when it's very clearly blue badge parking that's mostly full because what if somebody who does need to be near the store needs it? But that isn't a confrontation I'm having. That's still that relic of the "Perhaps you're not disabled enough…" voice in the back of your head. (Charlie, white non-binary person with sometimes visible impairment, age group 30-39).

The anxiety and doubt experienced by disabled people when worrying about being confronted meant that many of them took action in order to reduce the risk of confrontation. Like Foucault's panopticon, those under constant surveillance internalised this practise and managed their own behaviour to adapt to the required standard (Burr, 2015; Foucault, 1991). This included the employment of impression management skills to try to convey recognisable "disability" to others. Two of my participants, who were both young women under 30, spoke about using masquerade to do this:

> But there's definitely things I do to protect myself like I said, I use my walking stick when I'm on my own to get from the front of the car to the back, which I wouldn't do when someone's with me. And… I think… [pauses] sometimes my limp is probably a bit more pronounced when I am on my own as well than when I'm with somebody. And I think it's things like that, that it's just… trying to stop other people from kind of… judging me. And yeah. (Katie, white woman with sometimes visible impairment, age group 18-29).

For both Katie and the other participant, masquerade was a tool to reduce the potential risk of an encounter and helped to manage the anxiety they felt as a result. However, not all self-management necessarily involved the performance of an "idealized" version of disability. A few of my other participants felt that being *too* visible as a disabled person produced a different kind of risk, that of being targeted for disability. Julie (a white woman with always visible impairment, age group 50–59), who had experienced a hate crime perpetrated by teenagers who assaulted her while in an accessible parking space, felt that the wheelchair stickers on her car where part of the reason why she had been targeted. Similarly, Emma felt hesitant about using her walking aid in public because it would mark her out "as vulnerable" and potentially an easy target for harassment:

> But I've noticed that having that walking stick changes you from an invisible disability to a visible disability. But the other thing that concerns me about this is, it also makes me look a bit more vulnerable. So I'm always a little bit wary. But now I use my stick whenever I go out, because one of my knees gives way. So I'm trying to attend upon the deck again. And I just kind of… I'm just really careful about getting that balance between… I need to look like I've got a disability, because, you know what, I might need to sit there, or I might need to park there or do whatever. But also I don't want to feel quite so vulnerable. And yeah, that always… that balance is always there. (Emma, white woman with sometimes visible impairment, 50-59).

These storeys highlight how managing visibility of one's impairment is an ongoing and complex process for many disabled people. It requires much more nuance than captured in Goffman's type of impression management performed by us all, with careful judgement and constant re-evaluation of the situation in order to gauge the "risk" of a confrontation. This leads to parking spaces being associated with being spaces of anxiety for many disabled people, as well as taking considerable energy due to the high demand of continually reflecting and assessing on one's own and other behaviours. However, the emotional and physical costs of self-surveillance are just one part of the storey and are added to the need to manage interactions with others, which will be explored further in the next section.

3.2 Emotion work and feeling rules: "you've got to be the bigger person"

As well as managing oneself during an encounter, my participants also performed emotion work to manage the interaction with the other person involved. Overall, many of my participants were strongly guided by a sense of needing to remain polite and non-confrontational in Blue Badge bays. This was the case even where the disabled person initiated an encounter; for instance, when challenging someone who was using a parking bay without a permit. Elizabeth, who out of principle challenged people who abused accessible parking bays without a Blue Badge, discussed how she used politeness as a tool to manage the risk of an encounter escalating:

> I will put notes on people's car and just say "Whoops, you've forgotten your Blue Badge." Or I say to people, you know, if the person's there, I'll say "Ooh. Have you forgotten your Blue Badge?" I will try that angle. Because yes, people do get very, very stroppy and very aggressive. And I don't want to sort of rile them up. So I think if you sort of approach it from that angle, you're giving them an opt out. Or you're maybe embarrassing them. <Interviewer: Do you find that most successful than direct confrontation?> Elizabeth: Um… I don't find that either works, to be honest. I've tried both. And yeah, people, if people are gonna abuse a Blue Badge bay, they will. (Elizabeth, white woman with always visible impairment, 70+).

Storeys such as Elizabeth's highlight the extent to which emotion work is bound up with power relations (Hochschild, 1979). My participants were acutely aware of the expectations of disabled people to be polite and well-behaved in public and suppress the urge to show one's frustration or anger. As my participant Anna (a white woman aged 40-49 with sometimes visible impairment) put it: "You do feel like being rude back sometimes. You've got to be the bigger person really, you know, not let them get to you."

The affective atmosphere of anxiety permeating accessible parking spaces was a key factor in shaping this very careful approach of "walking on eggshells", with my participants perceiving this as a particularly perilous and uncertain space where a confrontation could escalate at any moment. While the term "vulnerable" has rightly been criticised for being assigned to disabled people as a way of reinforcing medical model stereotypes of disability (Finkelstein, 1998; Garland-Thomson, 1997; Hughes, 2007; Ralph et al., 2016), some of my participants used this term to describe how they felt in this situation and why they chose to avoid confrontation rather than challenge the other person about their poor behaviour:

> I just tend not to look at people if I think that somebody's… you know. And I do see sometimes that there are a couple of people arguing and I think, well, I don't really want to get involved because I feel vulnerable. And being in a wheelchair, if somebody tipped me out of my wheelchair and took my wheelchair away, I wouldn't be able to move. You know, because I can't physically stand and I can't crawl or move like that… So I tend to avoid stuff because I'm inwardly nervous. I'm quite a strong character, but then I don't like getting into confrontation with people because I don't want to deal with the aftermath, if that makes sense. So I try and avoid it as much as I can. (Chris, white man with always visible impairment, age group 60-69).

The effort that goes into managing encounters, then, is not just the emotion work of suppressing one's true feelings, e.g., of annoyance or anger at the person misusing the parking space, and reflecting the expected emotions prescribed by feeling rules. In addition, considerable work goes into "reading" the situation and the other person to weigh up what is the best strategy for handling a particular encounter. This complex process involves a split-second assessment of the situation, including determining one's own energy levels, gauging how the other person may react (e.g., will they be receptive or potentially aggressive), and then choosing how to manage the encounter. Charlie, who was naturally assertive, described the assessments they make before choosing whether to challenge someone about their attitudes:

> I am a little confrontational… There are people who I will avoid. Getting into that one with…. It tends to be about the body language. It's not specifically about gender, race, or sex. It's "How much of a fight are they looking for?" If they're being snide but it's snide in the "I'd like to get into an argument with you to prove a point or something", that one I will just try and ignore it. Um… If the person having a go at somebody else in the blue badge is going to be aggressive, it will be a case of me looking for like, is the shop security or something nearby? Um… rather than necessarily getting into it myself. But I think I am probably a little bit more arsey [sic!] than some people would because of the how and the why of - like previous experiences and stuff. (Charlie, white non-binary person with sometimes visible impairment, age group 30-39).

Charlie's approach to weighing up the risk of confronting another person lays bare that choosing how to react in an encounter is often based purely on instinct. As Scully (2010) asserts then, there is no right or wrong way to handle an encounter, as disabled people do not have a genuinely free choice in how to react. While disabled people can choose "emotional deviation" (Bericat, 2015, p. 499) to break "feeling rules", asserting oneself comes at potential risk of one's own safety and disabled people who do challenge may feel also guilty about provoking anger in others, or worry about their behaviour having negative consequences for other disabled people in the future (Cahill and Eggleston, 1994; Morris, 1991; Tregaskis, 2003). The power asymmetry that underpins "feeling rules" means that disabled people cannot win, even when the other party does not adhere to the same feeling rules, for example through making patronising comments, invading the disabled person's personal space, or asking intrusive or personal questions. For example, when Ivy lost her temper with a woman who questioned the legitimacy of her Blue Badge, the confronter became offended and defensive, rather than reflecting on the inappropriateness of her own behaviour:

> And I said, you know, like "It's none of your business." I swore a bit. I was like, "Leave me alone. This is nothing to do with you." And then she reacted really badly, like "Ohhh… well, I have to check!" No, you don't have to check! [laughs] Like, you're not a warden of the car park! It's not your… And I said something where I was like "Well, who are the fuck are you, the Blue Badge police?" And she got really offended. And I was like, "Look, I'm going to be angry because you just literally confronted me when I'm just trying to get to my appointment." Sorry, am I allowed to swear, is that okay? (Ivy, white woman with sometimes visible impairment, aged 18-29).

During the interview with Ivy, she clearly felt very guilty about the incident, telling me she regretted her reaction and wish she had handled it differently: "I do regret shouting at that woman and swearing because that was rude. My mum raised me better, you know." When I asked Ivy if she thought the woman would have listened to her if she had explained herself more calmly, Ivy conceded the conversation would have probably played out in much the same way. This highlights how breaking "feeling rules" can be difficult in its own right, with going against the norms of politeness and public order (Goffman, 1972), and in Ivy's case, against what our parents have taught us, resulting in feelings of guilt.

Ivy was not the only participant who struggled to control her reaction to someone else's inappropriate behaviour. The abjection disabled people experience in accessible parking spaces can feel intensely personal. As a result, several of my participant found it difficult to manage the anger they felt and not lose their temper. Anger is one of the emotions antithetical to disabled people's expected presentation as always cheerful and grateful: "We are certainly not supposed to get angry" (Keith, 1996, p. 81). Managing anger, then, was a central aspect of the emotion work that takes place in parking spaces to many of my participants. For example, Will discussed how he was happy with his "performance" of containing his anger during an encounter that had the potential to turn into a violent situation:

> Yeah, particularly that one with the guy who nearly got into a fight, which I thought was a bit odd. Uh… I was quite actually pleased with that one that I reacted how I did cause I… I didn't react. Sometimes I can react a bit agg- a bit angrily to people, but that one I managed to stay really calm because he got very, very angry and was literally coming up right in our face and saying "Do you want to fight about it?" And we were like - I was like, "Well, I don't wanna fight about a car parking space." And yeah, I was quite happy with my response to that one. Sometimes, yeah, if I argue, it can just stay on my mind and kind of run over and over, and what might have happened, kind of thing? (Will, white male with always visible impairment, age group 50-59).

The requirement to manage both one's own emotion and those of others mean disabled people need to perform considerable work to be able to exist in public spaces (Burch, 2021; Scully, 2010; Thomas and Sakellariou, 2018; Watermeyer and Swartz, 2008), in addition to and going far beyond the kind of impression management performed by all of us on a daily basis. This is not only physically and emotionally exhausting but comes associated with the constant worry of making a wrong decision which could lead to an escalation of the situation. The resulting existential insecurity (Reeve, 2008) is reinforced through the cumulative impact of encounters over time, and this will be explored in the final section of this analysis.

3.3 Microaggressions and slow death: "it's often not worth the hassle"

Negative encounters with strangers can encompass a wide variety of interactions. Recent research on disability hate has shifted to focusing on the full spectrum of these experiences, recognising that most incidents are not extreme acts of hate, but that low-level discrimination and abjection are pervasive everyday experiences for many disabled people (Burch, 2021; Hall, 2019; Hall and Bates, 2019; Piggott, 2011; Wilkin, 2020). Collectively, my participants had experienced the full range of the "continuum of hate" (Hollomotz, 2013), ranging from hate crime and physical violence to threats, verbal abuse, and to more subtle, passive-aggressive provocations, such as tutting and almost invisible stares.

While at least two of my participants recounted clear hate crime incidents in which the police had been involved, many others had experiences that in themselves could have seemed innocuous, but for the participants were deeply upsetting. Everyday encounters often took the form of microaggressions, low-level and subtle behaviours which intentionally or unintentionally "communicate hostile, derogatory, or negative […] slights and insults to the target person or group" (Sue, 2010, p. 5). Anna described how being stared at while getting out of the car in a Blue Badge bay was an encounter that stayed with her, precisely because of the "respectability" of the man doing the staring, and her own perception of herself as visibly and therefore "legitimately" disabled due to her use of mobility aids:

> Yeah, I still think about the person that stared at me the most. And I felt it especially as it was in quite an affluent area of our city. And I thought… I kind of presumed, and this is me showing presumption, he looked well-dressed, he looked respectful. And he just stood there and stared at me completely Ignorantly, almost as if… and you could see I was on crutches. Even when the car pulled in, the crutches were in the front seat with me. So, because I need to get out quite quickly, we couldn't wait to get them from the back of the car. You could actually see above the door line that I was holding the crutches up, off my knees. (Anna, white woman aged 40-49 with sometimes visible impairment).

Anna's storey highlights how the feeling of anxiety stemmed not just from being stared at, but also from the dissonance between Anna's perception of the visibility of her disability, and the challenge she nevertheless experienced. It is precisely the subtlety of microaggressions such as staring that contribute to disabled people experience of them as psycho-emotional disablism. Due to their uncertainty and ambiguity the disabled person may be second-guessing their own perception of the event, wondering if it really happened, or if they are overreacting. The insidious nature of microaggressions also makes it difficult for others to understand their true impact. James spoke about how his non-disabled friends and family did not fully appreciate the gravity of encounters and how much they affected him:

> It's like everybody tunes out to it. "Oh, it's just - it's happened again." Well, life's… and the actual kind of feelings that it can… trigger off. People don't want to hear about, you know, all that side of things. And I don't think they… I don't know that they get that. "Oh, it's just a parking space, Jim, and don't get so obsessed by it" or that kind of… and you think it's - but that's the thing, it's not just a parking space. It's whether or not I can do what you've just taken for granted. (James, white man with always visible impairment, age group 50-59).

Another key feature of microaggressions is their effect over time, leading to "death by a thousand paper cuts" (Nittle, 2019, p. 9). Many of my participants, including Anna and James, still vividly remembered and replayed particularly impactful encounters in their heads. Louise spoke about how she felt that an encounter that tainted a rare day out with her extended family had affected her in such a profound way that it intermeshed with her existing PTSD:

> And, you know, it definitely put a dampener on the day and I kind of feel like if I could have erased that day, not had it, and, you know, done what we all do another time without that encounter, then that's great. You know. And… I mean… you know… I had a lot of things to you know, memories, and I try to not focus on these things, so I don't want that to be a lasting memory of the day, but it hasn't gone out from my mind and I think it's because.... it's actually created trauma. It was traumatic. And… so it's unfortunately stuck in my mind because you know, because he intimidated me, he was aggressive and so… so yeah, it's still here because one of my diagnoses is PTSD, so you know, it if a man… or someone is confrontational and aggressive and I feel the need to protect myself and… it creates a PTSD sort of cycle. (Louise, white woman with never visible impairment, 50-59).

While not all encounters are necessarily traumatic, Morrigan's (2017) conceptualisation of living with trauma as being like time travel is useful to understand the multiple temporalities involved in repeated encounters, as the trauma of past experiences shapes the possibilities for action in the present and the future. The lingering negative emotions associated from past encounters thus may contribute to the expectation of having further encounters (Mclaughlin and Coleman-Fountain, 2018).

The anxiety underpinning the need for impression management and self-surveillance discussed in the first findings section is always present in accessible parking bays, regardless or not whether an actual encounter takes place. Even when no encounter occurs, the possibility of one is always looming. Memories of encounters are thus a constant "absent presence" (Burch, 2021, p. 165), which disabled people have to actively address. Indeed, one of my participants had never experienced an overtly negative encounter, but nevertheless felt worried based both on her experience of negative encounters in other public spaces and from hearing about negative parking incidents from other disabled people:

> Interviewer: You said you've mostly had positive interactions [...] in what situation would you want to avoid an interaction? Is it just that you don't feel like talking to people or just..? Isabella: I suppose because it *could* be a negative interaction. And I, sort of still feel.… Um… from some people you know that in society, there is hostility and discrimination. And I suppose… um… perhaps I'm worried that something might happen, even though nothing has happened to me. I know that people can have some worrying and distressing interactions. And I wouldn't want to put myself in that position. (Isabella, white woman with always visible impairment, age group 30-39).

Isabella's cautious approach informed by her anxiety over a potential encounter at any moment illustrates how disabled people live "in a constant state of "questioning"" (Sue, 2010, p. 73), with accessible parking spaces just one of many locations where we can never feel fully secure. It also highlights how the anxiety and uncertainty associated with experiencing psycho-emotional disablism is not just an individual experience but takes on a communal nature with parking spaces acquiring notoriety among the disabled community as a space where we are particularly at risk. This highlights how encounters are not necessarily an individual, private event, but the affects resulting from microaggressions can be transferred between disabled people to create an atmosphere of fear and anxiety, always "linked to a wider sociopolitical context of oppression and injustice" (Sue, 2010, p. 96). Several of my participants shared storeys about encounters with other disabled people, either in person or through online forums and social media networks. This sharing of experiences was a crucial support mechanism to reduce the isolation and self-doubt inherent in psycho-emotional disablism for these participants, providing confirmation that it was not just all in their heads. However, as Isabella's comments shows, it could also result in "second-hand" anxiety from other's encounters. Encounters thus became a communally shared experience among disabled people, influenced by the knowledge that these kinds of events are commonplace in accessible parking spaces, and highlighting another way in which affects are constituted relationally between people and spaces (Ahmed, 2014; Lipman, 2006; Wetherell, 2012, 2015).

The knowledge that sooner or later an encounter is inevitable sentences disabled people to a form of slow death (Berlant, 2011) through ordinary and taken-for-granted everyday moments contributing to their wearing down as a group. Along with repeated encounters comes the realisation that our existence in public spaces is always at best conditionally tolerated and at worst there is a constant risk to our safety. The contingent acceptance of our presence by others in public can be just as effective as excluding disabled people from public spaces as physical barriers (Reeve, 2008). Many of my participants spoke about no longer going out due to past negative encounters, either temporarily after an encounter had occurred, although some limited themselves to essential journeys more permanently:

> So I think this is part of the fact that sometimes it's easier not to go out than it is to go out. It's often not worth the hassle. I'd love to go to town and buy a hat for example. I want to buy it. I lost my hat, so I want to replace it. But It's so much trouble trying to get to the… to park outside the shop that… what is it, since October last year I've been planning to go but I won't go because it's too much hassle. So, yeah, I would say it's more of a "I avoid getting into that" situation. (George, white male with always visible impairment, 50-59).

While negative attitudes towards disability persist and their affects permeate public spaces, no space can be truly "accessible". Rather, it puts disabled people in a no-win situation where we either limit our own access to public space, or need to perform significant management and emotion work to negotiate public spaces as a trade-off for the participation in public life that others take for granted.

4 Discussion

The experiences of my participants in navigating the affective landscape of accessible parking spaces highlights the difficulties of access to public spaces for disabled people, who are at best tolerated but can never be truly at ease as the potential for an encounter always looms. In considering how relational encounters and their associated emotions shape experiences of supposedly "accessible" spaces we need to rethink what we mean by access. As Titchkosky (2011) reminds us, getting people in is only half the issue. The affective impact of encounters means that even if they are no physical barriers, due to the impact of psycho-emotional barriers disabled people still cannot gain access to public spaces on the same terms as others. Rather, there is a significant cost of emotion work and energy needed to simply exist in public. It is no surprise then, that "going out in public so often takes courage. How many of us find that we can't dredge up the strength to do it day after day, week after week, year after year, a lifetime of rejections and revulsion?" (Morris, 1991, p. 25).

My participants' experiences also highlight the importance of considering the wider cultural and political context in which encounters take place. Many of my participants' encounters were explicitly shaped by the specific British context of over a decade of austerity politics, which at the time of writing is set to continue with further plans for disability welfare reform by the new Labour government (Helm, 2024). This results in prejudice and resentment against disabled people based on the false and harmful binary of the many "fakers" or "scroungers" vs. the few "deserving" ones (Briant et al., 2013). The resulting negative affects towards disability stick to disabled people, becoming stronger over time (Ahmed, 2001). While the Blue Badge accessible parking scheme is not directly linked to the welfare system and has been largely exempted from cuts and associated negative media coverage in the UK, this "stickiness" means my participants nevertheless experienced these negative attitudes in parking spaces. While "scrounger" rhetoric persists in politics and media and encourages the public to police disabled people's behaviour in parking spaces, most disabled people risk facing hostility when in public space.

As well as sticking to disabled bodies and spaces, the negative affects associated with accessible parking encounters can also shift between people, as highlighted by my participant who felt anxiety based on storeys she had heard from other people. While Reeve (2008) posits that psycho-emotional disablism occurs primarily in the private sphere whereas structural disablism happens in the public sphere, I argue that the pervasive "stickiness" of affects blurs the boundaries between the public and private. The wider abjection of disabled people in public discourse is replicated in encounters, meaning they are never just individual experiences, but rather reminders of the wider hostility and abjection in society. Anxiety about potential confrontation is a daily reality for many disabled people and these negative affects circulate in public spaces (Burch, 2021), meaning that the psycho-emotional disablism does not happen purely on an individual or personal level. Rather, the sharing of these experiences with others is, for better or worse, an integral aspect of encounters. While storeys from others can contribute to anxieties, sharing our everyday experiences with other disabled people can also be liberating and an expression of solidarity. As Keith (1996) highlights, swapping storeys about encounters is often the first thing disabled people do when we meet. Several of my interview participants also described being able to speak about their experiences (both during the interviews themselves and more generally with others in the disability community) as cathartic. Many were also connected with other disabled people through social media or through Disabled People's Organisations. As Summers-Effler (2002) argues, solidarity with others can be crucial in forming a collective and political identity as a disabled person, confirming to the disabled person that their experiences and the resulting emotions are reasonable, and understanding them as injustices done to them. For many of my participants, this solidarity was an essential survival mechanism for how they managed encounters and resisted the negativity found in accessible parking spaces.

The societal and communal affects attached to accessible parking encounters, then, frame the difficult and highly emotional decisions disabled people must make to navigate everyday public life. While my initial aim was to explore in detail the management strategies disabled people employed, it quickly became clear during the interviews that the difficult emotions my participants felt, as well as the work they put in to navigate them, were very similar despite the different strategies employed. While some participants were highly conflict-avoidant, others tended to be more assertive and even "belligerent" (a term my participant Frank used to describe himself). It thus becomes clear that there are no right or wrong ways to navigate encounter. Rather, in line with the social-relational model of disability (Thomas, 1999), disabled people in public are being "disabled" by other people's attitudes and assumptions. The social-relational model of disability's focus on the role of interpersonal interactions therefore facilitates a radical approach to disability by exposing how disability is not just about impersonal and static barriers such as steps. Rather, it is also something that is actively done *to* us by other people, in the same way as other marginalised groups experience prejudice and oppression. Indeed, for many of my participants with multiple marginalised identities, these experiences intersected with other forms of discrimination they experienced; for example, Amir highlighted how he could never be sure that his encounters were not also racially motivated. While marginalised groups often face being accused of overreacting and even being pathologized as paranoid when expressing their fear of discrimination and oppression (Schalk, 2018), exploring the context of encounters highlights that the anxiety and anger felt by my participants in these spaces are not unreasonable at all. Rather, these emotions are a perfectly logical reaction to the hostility and discrimination faced by disabled people on a daily basis (Morris, 1991; Reeve, 2006).

In conclusion, this paper has made a contribution to the sociology of emotions by uncovering "the affective structures and the emotional dynamics of social reality" (Bericat, 2015, p. 499) in the context of disabled people's experiences of everyday psycho-emotional disablism arising from encounters with strangers. This leads to a more nuanced understanding of the role of affect in contributing to experiences of exclusion and oppression for marginalised groups. I have laid bare the daily work that goes into navigating public space and the emotional energy that is required by disabled people to make difficult decisions and navigate precarious interactions in order to access the same spaces that others take for granted. I have explored the affects of public encounters through the lenses of impression management, emotion work, and microaggressions, highlighting how disabled people are required to manage both themselves and others and put considerable work into assessing the situation to ascertain the risk of an escalation. The title of this paper, "walking on eggshells" helps to visualise the careful balance disabled people have to strike between appeasing others and standing up for themselves. I have also examined how negative discourses around disability and welfare fraud lead to suspicion of disabled people in public, particularly for those who are incongruous with a stereotype of disability, and explored some of the intersectional concerns in these stereotypes. The resulting (self-)surveillance means disabled people can never be unwatched in public, and by having to perform both impression management and emotion work, disabled people need to spend considerable emotional energy to survive in public. While everyday encounters are often low-level incidents rather than outright hate crimes (Burch, 2021; Hall, 2019), they nevertheless have a cumulative emotional impact on the disabled person, reflecting the abjection and prejudice that persists against disabled people at a societal level. By drawing attention to encounters as a substantial barrier to disabled people's participation in public life, this paper has highlighted how disability is "constituted by and between people" (Titchkosky, 2005, p. 220). Through focusing on this impact and examining the psycho-emotional disablism (Reeve, 2008) that occurs as a result of encounters with strangers, we can thus better understand realities of everyday oppression faced by disabled people. While negative attitudes and emotions towards disability persist and stick to disabled bodies, there can be no truly equal access even in supposedly accessible spaces.

Data availability statement

The datasets for this article are not publicly available due to concerns regarding participant/patient anonymity. Requests to access the datasets should be directed to the corresponding author.

Ethics statement

The studies involving humans were approved by Humanities and Social Sciences Ethics Committee, University of Birmingham. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

VK: Writing – original draft, Writing – review & editing, Conceptualisation, Formal analysis, Investigation, Methodology.

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Conflict of interest

The author declares that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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"I am used to being extremely patient because I'm forced to be": the affective politics of accommodation for disabled archivists

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Archives—repositories that store, organize, and give access to historical materials—produce a constellation of affects for both the people who use them and work within them. This article, drawing on data collected through semi-structured interviews with 12 disabled archivists in Canada and the United States, focuses on how disabled archival workers experience, manage, and perform emotions while navigating work-related access and accommodation in archival institutions. The ineffectiveness of traditional systems of individual accommodation—which sometimes forced them to disclose their access needs or, alternatively, feel pressured into denying their own needs—produced complex emotional responses among participants. Many spoke about the emotional toll of requesting accommodations, while others described their exhaustion and refusal to engage with such processes. Yet, participants highlighted how collective (rather than individual) approaches to access transformed the affective experience of access towards ease and empowerment. Centering this affective reality for many disabled archivists, this research echoes the growing body of research and theory around access labor, while also adding focus on *the affective debt of archival access* that occurs through accommodations processes—both an internal indebtedness, where one "borrows against" their patience and energy to survive, and an external indebtedness, where one is required to "pay" in gratitude, vulnerability, and being nice in order to be deserving of accommodation. We draw attention to how the very people who facilitate access to historical documents are also navigating their own access—performing additional forms of labor to manage inaccessible, precarious, or hostile work while also imagining access otherwise.

KEYWORDS

disability, archival studies, critical access studies, emotional labor, archival access, workplace accommodation, disability accommodation

1 Introduction

In her book *Crip Spacetime*, Margaret Price describes how "emotionally devastating" it is for disabled employees in higher education to experience "the nearly constant dissonance of being assured that accommodation is a straightforward, legally protected process while also navigating the endless obstacles and sometimes open cruelty encountered along the way" (p. 120). Accommodations can be a wide range of formal modifications that are made to remove barriers and facilitate access for community members with a variety of disability experiences, including physical, mental, and developmental disabilities. In the United States and Canada, national and local legislation can require that places open to the general public, such as schools, hospitals, businesses, and workplaces, have a process for accommodating people with disabilities.[1] Though meant to facilitate full and equal participation, accommodation processes—whether for work, education, or daily life—are often complicated, bureaucratic, difficult, and insufficient (Titchkosky, 2011). For example, in Price's study, disabled academics highlighted a wide range of economic and noneconomic costs and harms they incurred while seeking accommodations at work. Primary among these were emotional costs. As Price explains, the "emotional costs for disabled employees are high in part because they must work so hard, and often in very personal and emotionally charged ways, to negotiate access" (p. 123). Echoing and building on this work, we focus on the emotional and/or affective, impacts of navigating access within archives—repositories that store, organize, and give access to historical materials. Archives produce a constellation of affects: from the ways marginalized communities feel erased through the ways they are underrepresented or misrepresented in archival materials (e.g., Caswell et al., 2016), to the ways disabled archival users feel the violences of the past—histories of institutionalization, medicalization, and spectacularization—as embodied through records (Brilmyer, 2021; Rinn, 2018), archives shape users' sense of themselves, others, and history. Archival spaces, through their partial or complete inaccessibility, can produce feelings of alienation for disabled archival users (Brilmyer, 2022). Disabled archival workers, in particular, have long been integral to understanding disability in archival material, preserving disability histories, and building and facilitating accessibility in reading rooms.

This article focuses on archival workers: drawing on interview data as well as archival and disability studies scholarship to highlight how disabled archival workers experience accommodation processes and their affective responses to this landscape across different archival institutions. We first explore relevant ways of understanding labor, drawing from works in archival studies that illustrate the many affects of archives and the ways archival labor is understood in addition to works in disability studies' that explore access labor, as in "the work and effort that goes into making things accessible" (Fink, 2020). After detailing the methods for this research—semi-structured interviews with disabled archival workers at a range of archival institutions in Canada and the United States—we then outline two main clusters of findings. First, we highlight the many ways that interviewees spoke about seeking accommodations, sometimes being forced to disclose their access needs or, alternatively, feeling pressured into concealing them and denying their own needs. Second, we illustrate archivists' responses to their experiences with accommodations: the emotional toll, their refusal to and exhaustion with such processes, and the collective nature of access that is possible. Together, this research echoes much existing work on access labor, while also adding focus on *the affective debt of archival access* that occurs through accommodations processes—both an internal indebtedness, where one "borrows against" their patience and energy to survive, and an external indebtedness, where one is required to "pay" in gratitude, vulnerability, and being nice in order to be deserving of accommodation.

2 Literature and theoretical background

2.1 Archives, affect, labor

Archivists shape and are shaped by their work. While there is a growing body of literature that emphasizes the ways that archival users are impacted by archives, archivists have also drawn attention to the ways that archival work is multifaceted and involves many types of labor. In general, archivists perform a variety of tasks—from appraising, describing, processing, outreach, and helping users and giving access to materials, to name a few; archival labor takes many forms. In addition, recent scholarship has begun to address the affective—the internal, visceral, and/or emotional aspects that shape someone's experience of the world, themselves, and relations to power (Pedwell and Seigworth, 2023) —impacts of archives. Marika Cifor, for one, implores the archival field to center affect:

> "In order to be accountable to the individuals and communities that are affected, and to live up to the obligations of facilitating larger societal reckoning processes, the archival field needs to expand its ethical orientation to address considerations of emotional justice (Cifor, 2016, p. 9)."

While many have drawn attention to the affective impacts of archival users (e.g., Brilmyer, 2022; Gilliland, 2014; Guerrero, 2022; Caswell et al., 2016; Caswell et al., 2017; Cifor and Gilliland, 2016), we focus here on the affective dimensions of archival workers. We think about affect and emotion as referencing similar phenomena: internal experiences of emotion, intentional performance of emotions, how emotional experiences are shaped by power and through ableism, and how the emotions surrounding accommodation processes within archival institutions converge in a pattern. This understanding reflects an understanding of affect "as part of what emotions do" (Schmitz and Ahmed, 2014, p. 97), in the sense that the emotions that arise in response to another "do not respond the way they do because of the inherent characteristics of others: we do not respond with love or hate because others are loveable or hateful. It is through affective encounters that objects and others are perceived as having attributes, which 'gives' the subject an identity that is apart from others" (Ahmed, 2014, pp. 52–53).

The emotional landscape around workplace accommodation reflects a broader history of affective encounters around disability and access. For example, when employers treat access as charity and burden, this way of orienting is historically rooted and results in the negotiation of several emotions tied to charitable giving: feeling generous, feeling thankful, feeling patient, feeling humility. Within archival institutions, these histories of encounter are particularly salient because archival workers negotiate them through real-time emotional encounters while also encountering them through

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[1] For example, nationally, the Accessible Canada Act, although not universally applied across Canada, aims to create barrier free access to the public or the public sector, and the Americans with Disabilities Act requires that public spaces have "a path of travel — safe harbor" to public spaces including government buildings, educational settings, and public transportation.

historical records about disability and disabled people (Brilmyer, 2021). We refer to this complex landscape as the affective politics of accommodation.

This study contributes to a growing body of scholarship and conversations around the underrecognized forms of labor that archivists regularly perform, such as navigating the emotional and traumatic elements of archival work (i.e., Arroyo-Ramírez et al., 2021; Caswell and Cifor, 2016; Guerrero, 2022). Trauma has come to the fore in the archival landscape to draw attention to the felt realities of archivists. For those processing violent histories, traumatic collections can cause distress (Regehr et al., 2023; Nathan et al., 2015). In their report on the international landscape of trauma and archives, Nicola Laurent and Kirsten Wright highlight how most archivists they surveyed have experienced "distressing content, distressing situations (for example, a distressing interaction with an archives user) and experiences of vicarious trauma" (Laurent and Wright, 2023). Others have highlighted how archivists experience secondary trauma both by processing traumatic materials as well as supporting or interacting with users, donors, or creators (Lassere and Whyte, 2021; Laurent and Hart, 2020; McCracken and Hogan, 2021). They state how participants reported feeling like they should "tough it out" or questioned whether some of their upsetting experiences "qualified as traumatic" (Sloan et al., 2019, p. 13). Importantly, archival workers in many of these studies have reported not being taught about trauma in their archival education[2] or professional development, not receiving support at their organizations around traumatic materials and their emotional well-being, or even being "discouraged [from] talking about emotional matters on work hours." (Sloan et al., 2019, p. 14).

In addition to exploring the emotional impact of navigating traumatic content within archives, scholars have also highlighted other forms of emotional labor that constitute a significant part of archivists' roles (e.g., Douglas et al., 2019; Lowry, 2019). For example, the practices of empathy that archivists engage in as they form and navigate relationships with creators, donors, users, and communities have become an important area of focus within critical archival studies. In 2016, Michelle Caswell and Marika Cifor proposed "radical empathy" as a core tenet to archival work within "a web of affective responsibilities" for archivists. Their introduction of a feminist ethics of care has been widely taken up and was revisited in a 2021 issue of the *Journal of Critical Library and Information Studies*, where contributors illustrated, shifted, and expanded how this framework could be applied and envisioned. In the issue, contributors mark the many people, affects, and politics that archival work involves and the responsibilities that archivists have in stewarding materials for various communities (Arroyo-Ramírez et al., 2021).

Although this growing body of scholarship recognizes the complexity of archival labor, archival work has historically been undervalued and often invisibilized. Michelle Caswell, critiquing the ways that scholars in the humanities have routinely erased the labor of the archivists who support their research, highlights how, "almost none of the humanistic inquiry at 'the archival turn' (even that which addresses 'actually existing archives') has acknowledged the intellectual contribution of archival studies as a field of theory and praxis in its own right, nor is this humanities scholarship in conversation with ideas, debates, and lineages in archival studies." (para 4). Tracing the lineage of how archivists have historically been deemed "handmaidens of history"—expected to "be an invisible caretaker, a docile handmaiden," (Cooke et al., 2021, p. 507)—Lapp (2019) shows the ways in which nineteenth-century characterizations of archival neutrality invisibilized the work of archivists in support of the masculinized work of historians. She articulates how this is not a phenomenon of the past, that:

> In the field of library and information studies, a rhetoric of cultural caretaking as the purview of white, educated, middle-class women continued well into the twentieth century constructing and perpetuating the "ideal archival worker" through reified categories of race, gender, sexuality, class, and ability.

Thus, many scholars and practitioners have been critical of the guise of neutrality behind archival work—that also makes possible the invisibilization of labor[3]—and have highlighted the ways archival norms exclude many ways of knowing, working, and being. In other words, as Elvia Arroyo-Ramírez, Jasmine Jones, Shannon O'Neill, and Holly Smith point out, "As practitioners in this field, we have inherited a professional and institutional culture of toxic ambition," one that exploits, underpays, or expects free labor from students and early professionals, over-relies on contract work and low wages, and prioritizes "hyper-productive approaches over slow and deliberate work," amongst many other things (Arroyo-Ramírez et al., 2021, p. 2–3). S. Williams pinpoints the slow ways in which such norms might change:

> Perhaps we are so terrible at advocating for the importance of what we do because to be good at that advocacy means acknowledging that the manner in which we conduct this labor is often times unequal, rooted historically in sexism, racism, ableism, and classism, and that will always present a challenge to the access we hope to provide.

Yet, many are pushing back. Arroyo-Ramírez et al. powerfully note, "As an archival professional, you are meant to keep a straight face, a stiff upper lip, to toe the line. We reject this." Instead of complying with and maintaining professional norms that undergird harmful practices and the status quo of the profession, archival scholars and practitioners are identifying the many harmful aspects of the archival profession, the impacts on archival workers in addition to users, and the ways that practice and the profession needs to change today and into the future.

2.2 Access labor and the actualities of accommodation

Just as archival scholars and practitioners are challenging constructions of archival work as neutral and objective, so too are

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[2] Many archival workers complete advanced degrees, frequently in library sciences or history, prior to entering professional archivist roles.

[3] Sloan et al. (2019) note "the extent to which archivists are expected to remain neutral and objective, and to maintain a certain distance between themselves and the records with which they work" (p. 15).

critical disability studies and critical access studies scholars expanding beyond the construction of access as a neutral object, “a substance to be measured for its presence or absence, as exemplified by the ‘yes/no’ check box found on university website descriptions of classrooms” (Titchkosky, 2011, p. 41). While early scholarship and activism around access focused on advocacy and “making the case” for physical accessibility standards and universal design approaches (Hamraie, 2017), in recent years, scholars and activists have increasingly documented and theorized access as a process (e.g., Acton et al., 2021; Fink et al., 2020; Schalk, 2017). In this theorizing, the process of access is as much about practices and tools that create access as it is about the “politics of knowing” that shapes how access is understood, recognized, and facilitated within society (Hamraie, 2017, p. 14).

As part of this shift, scholars have explored the political and relational nature of access work, for example, documenting how accessibility guidelines and standards were originally developed to accommodate and facilitate the participation of white disabled veterans in public institutions (Williams, 2016); how traditional approaches to accommodation require an inordinate amount of administrative labor and are designed to be intentionally cumbersome, complex, and costly (Emens, 2021; Price, 2021; Titchkosky, 2011); how power dynamics with supervisors and the precarity of employment status shape decisions around disability disclosure (Damiani and Harbour, 2015); and how rights-based, individualized approaches to accommodation have reduced understandings of access to a set of procedural and logistical considerations (Mingus, 2012; Valentine, 2020). Through this research, scholars have developed several concepts to help describe access as a relational and political phenomenon. For example, Emens (2021) conceptualizes the labor involved in maintaining disability benefits as a specific category of what they call “life admin,” as in “all the office-type work that it takes to run a life…like scheduling and ordering and answering calls and filling out forms [as well as] long-range planning and financial decision-making” (p. 2335). Emens (2021) highlights “disability admin” as distinct because of the amount of labor that is demanded to not only manage access to formal services and accommodations but also, more broadly, to negotiate access in day-to-day life.

Importantly, as scholars document the experiences of disabled people with navigating access and accommodation, they have challenged the way disability legislation in the United States has framed accommodation as inherently benefitting disabled individuals, without considering the ways formal accommodations can be logistically, financially, and emotionally burdensome for individuals (Emens, 2021). For example, Price’s (2024) recent study about the experiences of disabled faculty with accommodation vividly captures how university accommodation processes are designed to be delayed, restrictive, and complex, despite being framed as linear and straightforward. Price (2024) explains how, because of this design, disabled faculty are forced to incur several types of costs, including additional administrative labor such as coordinating appointments to get documentation, financial costs related to self-accommodation, the relational injury of insulting and demeaning interactions with colleagues and administrators, as well as the stress and frustration of living through these processes. As Price (2021) explains, these harms put disabled faculty out of time with the normative timelines of the university, creating an experience of professional life that is “extraordinarily hard to understand from a nondisabled point of view” (p. 263). For several faculty members in Price’s study, the misalignment between processes of accommodations and the expectations of university culture forced disabled faculty out of the academy altogether.

2.2.1 Access labor as emotional labor

In documenting the actualities of requesting accommodation, disability studies has pushed towards a more robust conceptualization of *access labor*, which Fink (2020) defines as “the work and effort that goes into making things accessible.” Significantly, scholars and activists have documented the political, emotional, and relational components of access labor that are enmeshed in what has traditionally been understood as a purely logistical and administrative process (Emens, 2021). This paper expands upon literature highlighting the emotional labor implicated in negotiating access. In doing so, we weave the study of access labor into broader ethnographic and qualitative research about workers’ experiences of emotional labor.

Wharton (2009) describes the sociology of emotional labor as fundamentally concerned with “understanding how emotions are regulated by culture and social structure and how emotional regulation affects individuals, groups, and organizations” (p. 148). Building on the foundational work of Hochschild (1983), research on emotional labor at work has historically focused on how workers in service industries are expected to manage their feelings as part of interacting with the public (Wharton, 2009). This literature offers several concepts that are relevant to the study of emotional labor within accommodation processes, most notably *surface acting*, wherein workers project an emotion different from what they feel to manage others’ feelings (Hochschild, 1983).

Several studies have sought to measure the “affective requirements of jobs… the degree to which workers’ perceive their jobs as requiring them to display certain emotions or be sensitive to the emotions of others” (Wharton, 2009, p. 158). This scholarship has mainly focused on emotional labor as it is performed in relationship to clients or customers—in roles such as service work (Leidner, 1999), care giving (Sass, 2000), and customer service (Totterdell and Holman, 2003). Scholars have detailed how these service-oriented industries have implicit and, sometimes, explicit expectations that workers will manage their own emotions, perform emotions that they may not feel, and manage or elicit customer or client emotions (Hochschild, 1983; Sass, 2000). Managing the emotions of others serves the interest of service-oriented workplaces by facilitating the compliance, comfort, dignity, and satisfaction of customers and clients (Leidner, 1999; Sass, 2000). Scholars have documented that when this type of emotional management masks conflicting internal feelings, meaning workers are required to perform emotions they do not feel, it often leads to burnout (e.g., Glomb and Tews, 2004; Ozcelik, 2013).

Yet, there has been limited research on how workplace structures require workers to engage in emotional labor with colleagues, rather than clients, and how this labor affects workers (Gabriel et al., 2020; Ozcelik, 2013). This study contributes to this emergent sub-area by considering how disabled workers engage in emotional labor to facilitate access to work itself. Put another way, the emotional labor that this study explores is distinct because (1) disabled archivists are engaging in emotional labor to remove barriers to doing their job, and (2) this labor is not a standard, work-related responsibility for all archivists. Thus, this study offers insight into how ableist norms create disparate experiences of emotional labor at work.

In addition to building with research on emotional labor in the workplace, this study extends emerging scholarship within disability studies on the emotional costs of accommodation for people with disabilities. Konrad (2021) documents "how a lack of familiarity with disability and practices of accessibility places pressure on disabled people to teach others how to participate in access" (p. 183). They note that "the specific labor of involving others in accessibility" requires four rhetorical techniques—a performance of self, confronting audience reactions, a value exchange, and rhetorical pedagogy—that all hinge on the moment-to-moment capacity of disabled folks to deflect and manage the harmful affective politics of dis/ableism (p. 183). For example, this labor might involve mitigating the anger and paternalism that arises in response to naming access barriers by performing a polite, calm, and knowledgeable disabled self (Konrad, 2021). In highlighting the fatigue that accumulates through this labor, Konrad (2021) makes the point that energy and emotional labor required to navigate social spaces often reflects the contours of power and oppression within those spaces.

By studying the energy and emotional labor that is demanded in traditional processes of accommodation—in addition to the emotional labor that archivists may perform as part of their work— we can trace and better understand how power and (in)equity function within organizations. By focusing on access labor within archival institutions, this study dialogues with existing research on accommodation processes for public benefits (Emens, 2021) and within university spaces (e.g., Titchkosky, 2011; Dolmage, 2017) by documenting how emotional management functions as part of the labor of access for disabled archival workers.

3 Materials and methods

Engaging and building on the aforementioned literature on affect, archives, labor, and accommodations, this article draws on data collected through semi-structured interviews with 12 disabled archival workers. Participants were recruited through archives-related listservs and social media. To qualify, participants had to be located in the US and Canada, and needed to (a) self-identify as disabled, (b) have worked as an archivist or an archivist-related job within an archive, special collection, or museum or completed an archives-related degree (such as a Masters of Archival Studies or a Masters of Library and Information Science) in the past 15 years in the US and/or Canada, and (c) be at least 21 years of age at the time of recruitment. Interviewees were paid $50 CAD for their time, could also specify access needs and if they wanted to be interviewed by either or both PIs and a student research assistant, and were given the interview questions in advance. Each interview was conducted using video conferencing software, lasted 60–90 min, and was recorded with the consent of each participant. The recordings were transcribed, and the transcripts were collaboratively coded by the research team using coded methods based in grounded theory such as open coding, axial coding, and focused coding (Saldana, 2015; Charmaz, 1994; Glaser and Strauss, 2009; Thornberg and Charmaz, 2013). Through our collaborative and iterative coding process, we located clusters of codes and discussed their definitions, differences, and relationships, as we made sense of the data; these major themes shaped this article and others (Brilmyer et al., 2024; Denison et al., 2024).

As we iteratively coded the transcripts we also reflected on our own experiences as disabled people researching disability. We recognize how our own positionalities inform how we interpret these conversations, that some of the situations we report on are also personal or familiar to some of us, yet, we also recognize how we are each coming with our own differing experiences, intersecting identities, and politics around how we understand disability, archives, and labor. Julia is a mixed-race, Black, disabled, and cisgender woman with a professional background in postsecondary disability services. Her scholarship uses qualitative methods to explore access labor within U.S. higher education institutions. Tara identifies as a disabled, neurodiverse, brown, and Canadian woman. Gracen is a white, non-binary, disabled, chronically ill, and neurodivergent person currently working in academia and from a middle-class background. They write from their position of organizing, researching, and building community in both archival and disability spaces. Veronica identifies as a white, disabled, cisgender woman who was a first-generation college student and works as an archivist in academia. Her research centers around access and use in the archives, as well as trauma-informed archival practices. Tara identifies as a disabled, neurodiverse, brown, and Canadian woman. As a team of disabled researchers with a wide range of experiences and intersecting identities, we are both insiders and outsiders to this research—we recognize how we share some experiences of access and accommodations with our participants, but also try to honor the differences that each of our experiences brings.

Importantly, as we navigate our interpretations of the interviewees' words, we center a process of ongoing consent, where each participant has multiple opportunities to approve and edit their words and our analysis of them. Each interviewee read and signed a consent form before the interview, which we also went over together at the beginning of each conversation to answer questions or provide clarification. For each manuscript we write using their words, we first send them a copy of all the quotes we plan to use and then a copy of the full manuscript. During each, they can change how they want to be cited (by name, an alias, or anonymously), edit or remove any of their quotes, and suggest changes to the ways we interpret their words or each manuscript overall. Participant edits are prioritized in this piece as they clarified their ideas and further reflected on their experiences, and we take their feedback seriously. Our hope is that with multiple rounds of review, that the interviewees see their words reflected in ways that feel true to them as well as feel the collaborative nature of this research as it could not be done without their powerful reflections on their lived experiences.

4 Results

What lays a foundation for the findings that follow is how, in many of the interviews, archivists described their places of employment as professional environments built around a culture of compulsory abledness (McRuer, 2018). This is not to say that some workplaces were not accommodating or openly hostile, or that accommodations were necessarily unavailable, but that the general ethos assessed from the interviews emphasizes the common experience of inaccessible workplaces, laborious accommodations processes, and other ableist norms that participants experienced. While this culture was reflected in a variety of organizational and interpersonal norms, a defining aspect of this culture was the frequent lack of effective accommodation processes across departments. For example, several participants described it as common practice for archival institutions to assume that job applicants would not require accommodation. For one, Michelle Ganz, a mixed race (Indian and Polish) disabled woman who is severely deaf and very nearsighted and wears assistive devices, a hearing aid and glasses to interact with the world, explained how, out of hundreds of interviews, there was only one institution "where someone actually asked me if I'm [needing] any sort of accommodation. Everybody else just assumed I would tell them if I needed so, or figure it out as I went along" (Denison et al., 2024, p. 299). Another interviewee, Joy Rowe —a cisgender queer woman in Canada with hearing aids, described herself as a white settler who is unprecariously housed and employed, with all material and social needs met— similarly described how at the archives in which she worked: "There's no formal process at all, but you really just need to ask for what you need. And there's not a lot of–I mean, you cannot really ask directly, but eventually you'll–some needs are met." Once disabled archivists were hired, this ableist professional culture often extended into the workplace. Interviewees frequently recalled how their attempts to address access barriers and engage in an accommodation process resulted in a lengthy and onerous struggle in which their access needs often remained unmet. Participant 2, who has multiple invisible disabilities (psychiatric, neurodevelopmental, and musculoskeletal), an archivist with "an amalgamation of physical and mental disabilities" explained how even "just the simplest facilities fix was unbelievably time-consuming and lengthy and bureaucratic."

With this background, the following two clusters of findings center the narratives of disabled archivists as they conveyed how resistant archival institutions were to facilitate access as well as the layers of access labor that were regularly exacted from disabled workers. The first finding highlights the lived experiences of disabled people navigating the accommodations process. Specifically, interviewees described being forced to disclose their access needs repeatedly and publicly and compelled to conceal their access needs or "power through" work without accommodation. The second finding illustrates archivists' responses to their experiences with accommodations: the emotional toll, their refusal and exhaustion with such processes, and the collective nature of access that can be possible. Interviewees also conveyed how emotional labor was entangled in negotiating access at work, including processing internal feelings of hurt, anger, and stress and managing the emotions of others through patience and gratitude. While individual accommodation processes were a source of frustration and difficulty for all interviewees, several found a sense of purpose and confidence in shifting their efforts towards developing a culture of access at work and improving access for future disabled colleagues.

4.1 Navigating the accommodation process

4.1.1 Forced to (repeatedly) disclose

Many formal accommodations processes involve a component of disclosure, the naming of an access need and justification of that need through personal narrative and frequently biomedical documentation. However, interviewees experiences of disclosure extended far beyond a confidential process with human resources; several described being forced to discuss their disability and access needs day-to-day at work as part of an ongoing process of negotiating access in their workplace. This repeated disclosure was often compelled because the department's day-to-day work took for granted a certain set of abilities, e.g., the ability to process information verbally or to use steps to access different floors within the archives. As a result, although accommodation processes in the workplace are intended to be confidential, several participants described how often they were either forced to disclosure or had their disability information disclosed by others in front of coworkers.

These forced disclosures included, for one, supervisors and colleagues publicly asking questions about participants' access needs. For example, Participant 3, a white woman, from a middle class background, who has an invisible disability (dyslexia), recalled a supervisor discussing their accommodations in front of another colleague without her consent:

> Having someone that you disclosed to be like, 'Oh, do you still want that [accommodation]?' And I was like, 'Oh, well, yes,' but like, maybe this wasn't the moment to talk about it? Maybe you should have asked me if I had talked to the other person before you brought it up in this scenario? That's where I have a little bit more of a—that wasn't very professional and that wasn't the nicest move, you know?

Workplace accommodations are confidential processes, which means that only individuals involved in the administration of an accommodation, such as Participant 3's supervisor, would be provided with information about an employee's access needs. As such, discussing access needs in front of other colleagues is a nonconsensual sharing of personal information. Several interviewees also described being forced to disclose access needs to explain to coworkers why work wasn't being done in the expected way. For example, Raegan Swanson, a second-generational white settler with an invisible physical disability and learning disability, recalled asking for help and being questioned by her coworkers about why she needed help with a task she had previously done:

> They had seen me move boxes previously and they are like, well, why aren't you helping today? And it's like, well, today, today I cannot move. Like, I'm in an extreme amount of pain and having to go through it all with them and like the personal details of how pain works to try to justify my request to them.

Participant 2 similarly described multiple experiences at work where, "I'm literally in a position where I'm forced to disclose, or there's going to be a question of why I'm not doing that aspect of my job." Many interviewees expressed frustration, feeling like they needed to disclose personal medical information to colleagues in order to get their access needs met at work. For example, Joy was required by her employer's human rights office, who managed accommodations, to repeatedly submit medical documentation to support her accommodation request. As she explained, "They made me submit so many documents. Just every time it was like and more documents. They're like, *oh no, it's so easy, just this document from your doctor.* So, I submitted that. And then it was another… that just went on so long, honestly months." Eventually, Joy had to involve her union representative to get approved for an accommodation she described as "not even hard" to administer. Similarly, Participant 4, a white, cisgender woman who has non-epileptic seizures, described having to get detailed, third party documentation to validate what she felt was an observable disability experience. As she reflected: "This is just not great, right? I have to rely on my relationship with my boss, who, you know, can see that I am in a lot of pain essentially, trying to go through this process. The fact that I have to open up my whole medical history to people [HR staff] who are, like, essentially insurance brokers." For these professionals, the need to disclose was compelled by organizational cultures where ability was presumed to be static or where colleagues were, in some cases, empowered to manage, question, and even push back on requests for access.

Even in situations where their requested accommodations were approved, some participants described having to repeatedly advocate for their implementation. For example, Participant 2 continuously struggled with coworkers in the company's technology department over access to real-time captioning in virtual meetings: "I've said that, like, you know, I cannot caption myself. I'm hard of hearing. I do not know what more I can say." Participant 2 shared how even after frequently raising their access needs with colleagues, "there's still no move to accommodate it. There's no move to add closed captions to our webinars or Zoom meetings or anything like that. There is no advocacy on behalf of my supervisors. Like, nothing changes." Another participant, Participant 4, relied on an elevator to move around the building and retrieve items from the archive where they worked. They described how the elevator was often not fully functional (and never fully repaired), which meant they regularly needed assistance to operate it. As they explained: "most days I have to call somebody while I'm in the elevator to go up and down," which meant that over the course of the 4 years they had been working in that archive, "everybody's watched me struggle to do this stupid thing," which required them to repeatedly ask for assistance from their colleagues. This experience of being forced to struggle with an inaccessible environment was also shared by Zachary, an Autistic, white, cis, heteroflexible man, who described how, even after clearly and carefully articulating his access needs during an interview process, accommodations were not provided: "There was a point in the interview where I'm just like, 'I know that I'm not doing well, but I asked to know who I would be meeting with. I asked to know what the questions would be. I did not get those things. And so I am struggling.'" For Participant 4 and Zachary, the resistant culture around accommodations meant not only having to repeatedly disclose, but also having access needs repeatedly put on display in front of colleagues because their accommodations were not provided.

This first finding illustrates the multitude of ways that the people who we spoke to experienced forms of forced, repeated disclosure. Some described the invasive process of having co-workers share details without consent, while others spoke about having to continually ask for the accommodations they need and nonetheless have them denied or ignored. These experiences highlight ways that ableism is embedded in some professional workplaces through the lack of accommodations, the denial, neglecting, or "forgetting" of accessibility measures, as well as the interpersonal ways that these are enacted.

4.1.2 Forced to conceal and "power through"

In a context where accommodations were challenging to secure and inconsistently implemented, several disabled archivists described feeling forced to conceal their access needs and "power through" by finding ways to complete their work without accommodation. These decisions were often motivated by the recognition that access was a scarce resource that needed to be strategically rationed and politically managed through relationships with colleagues. For example, Zakiya Collier, a Black, queer, chronically ill, and disabled cisgender woman living with systemic lupus erythematosus (SLE) and other autoimmune and long-term conditions, recalled weighing the limited sick days they had available when considering whether to go into work when their chronic pain was higher (Brilmyer et al., 2024, p. 123):

> I tried to sometimes power through and like save my sick days. Cause I do not know if there's like a extended sick period coming up. And so it's like, it just feels very like I'm rationing my like… kind of doing a scale like they do at the doctor's office for myself. Like, is it [my pain] a seven? Okay. You know, like if it's seven and above, you should take sick time. If not, power through and just like be in pain to, to like avoid the stress of like figuring out what would happen next.

Another resource that interviewees perceived as scarce was their colleagues' understanding and support around access. In particular, some interviewees expressed concerns about how their supervisor would respond to accommodation requests. For example, Chris Tanguay, a queer, white, gender-ambivalent woman with reoccurring depression, generalized anxiety disorder, and thoracic outlet syndrome, felt like they could *not* refuse to do tasks that caused them pain because of the anticipated response from their former supervisor. They told us, "I do not think it was necessarily the disability, but at the same time, I feel like if I said I cannot do that, she would've just responded, 'I have no sympathy for that. You know, this is what you were hired to do.'" Jade Finlinson, a white paraplegic with spinal cord injury who uses a wheelchair for mobility, similarly worried that repeated requests around access might lead their supervisor to perceive them as "not having the skills to do it [their job]." (Brilmyer et al., 2024 p.130).

Interviewees' deliberations over whether to try and "push through" without accommodations spotlight the power dynamics that emerge as supervisors can function as gatekeepers around access at work. Several participants considered how (in)secure they felt in their current position when making decisions about how to navigate access barriers in the workplace and whether to advocate for accommodation. For example, one archivist, Chris, described feeling like they could not say no to tasks that left them in pain for days afterwards because they were hoping to be promoted. As they elaborated: "I felt like I had been given my current position as a favor. … I did not feel like my boss liked me. … So I would kill myself trying to get [the top review] and, you know, trying to be the good worker and not make waves." Chris had been able to secure an informal accommodation from their new boss that allowed them time off for therapy appointments. They had previously been unsuccessful in getting a formal accommodation approved through human resources "because the HR representative did not want to fill out the paperwork for it." Although their boss approved their informal request to flex time, "I also worry like, well, this is not written on paper anywhere, so this could come back to bite me, especially since I've been active in unionization." This concern that access arrangements at work were conditional on the goodwill of their supervisor was similarly echoed by Participant 2, whose sense of job precarity factored into their unwillingness to "fight" for their accommodations: "I'm not willing to completely fight for it until I'm in a really stable position where I know that that's not gonna cause me to like, not have a contract renewed or like not get tenure or something." They told us about how they had waited to disclose and advocate for accommodations until felt their job was secure: "I'd also passed probation at that point. So, I knew like it would be difficult to fire me if they wanted to for that."

In summary, within some hostile and/or ableist workplaces or workplace cultures—where some participants described having to continually disclose their disabilities in order to get accommodations or where accommodations were routinely ignored or denied—some participants also described choosing to "power through" or deny their own needs. This response was described by some as rationing time off, choosing not to repeatedly ask for accommodations, or not feeling as if they could say no to tasks in order to keep one's job in a precarious landscape.

4.1.3 Forced to manage the emotions of others

Adjacent to the theme of relational power dynamics shaping how disabled archivists advocated for access was how interviewees described needing to manage the emotions of others while negotiating access. Interviewees identified worry as the primary managing emotion that emerged as they advocated for access at work. Several worried that colleagues would perceive their need for access as 'too much.' For example, when discussing how it felt to advocate for herself, Michelle stated:

> My thing is, I'm always worried that I'm overstepping the bounds of the kindness that they are giving me. Which is an incorrect way to feel because the things I am asking for are not so unique or costly or difficult or time consuming, that I should feel like it's a burden. But it still feels that way until I get the reaction from the person I'm asking.

Even Joy, who served as a director, had not brought up her access needs even when her employer was "asking us for input" because "I'm just worried about it." This worry was common for participants and had several dimensions to it, which included concern around drawing negative attention and being perceived in a negative light. For example, Participant 5, a disabled, gay Black man with chronic back pain who often depends on muscle relaxers to perform daily tasks, recalled hesitating to use seating accommodations at an archival conference, explaining: "I do not think people would see me as somebody who needs to be sitting in the accessible seating area, you know? … Maybe I 'should not be so caught up in their perceptions,' but I think certainly at [a professional conference], when you go there, it's paid for by your employer, you, you have to certainly be a certain way, right?" Chris similarly reflected on the physical lifting that was included in their job description and how they did not want to "draw attention to the fact that I struggle with that sometimes."

Another dimension of interviewees' worry was that they had low expectations about colleagues' capacity to understand and accept access needs, particularly ongoing and changing needs. For example, Zakiya worried about their colleagues' capacity to understand the episodic nature of their disability, and felt burdened by the pressure to predict their access needs accurately: "having to always think about like, 'Am I going to have to explain this to somebody? And will it make sense?' Because it does not make sense to me all the time." Similarly, Participant 4 spoke about how the experience of "asking people again and again and again and again" about access was emotionally stressful and meant "I am used to being extremely patient because I'm forced to be all the time." Over time, they described how the experience of predicting and catering to colleagues' anticipated responses "feels like I'm doing this like kind of like mothering, or emotional labor where I'm constantly questioning what does this person respond to? What approach should I take?" Finally, Raegan, who has invisible learning and physical disabilities, spoke about having to get used to colleagues' negative attitudes towards her access needs, "dealing with people being extremely rude or doubting like what I have to say," and figuring out "how to not take that too personally while like I'm trying to either do my work or, you know, just live my life" (Brilmyer et al., 2024, p. 124).

On the rare occasion when interviewees received support from colleagues, it was notable that they framed this access labor, even if it was partial or inadequate, as nice or as acts of kindness. For example, Participant 4 shared how a colleague's unsolicited offer of help surprised them because it meant that person had noticed the episodic challenges associated with her disability. As she reflected: "That's really nice that they actually understand on this level that it's a stress that I am dealing with constantly, which I did not really expect. … It's hard to tell what people think, but it feels like there's a lack of recognition." Still, she elaborated that even this provision of access produced complex and conflicting feelings:

> The genuine gratitude I feel, regardless of whether necessary, is complicated further by THEIR feeling of 'being nice' or the social exchange that is expected out of this. This feels cynical—though is still a reality—on an interpersonal level, but on a social one it can easily put me in a kind of debt—i.e., perception that I cannot be deserving of accommodation or recognition and be anything less than grateful at the same time.

Put another way, she was mindful that her colleague's feeling of 'being kind' posed its own emotional demand that forced certain kinds of responses, such as performing appreciation or gratitude. Across interviews, only one participant, Jade had recalled feeling supported by their supervisors, as they explained: "That made a big difference, just to feel that even if there were going to be problems–and we all acknowledged that there would be problems and that I would need help, and that I would have to ask for help for certain things–and that was okay. And so I felt very supported."

In summary, these words highlight the ways the disabled archival workers that we spoke to experienced and managed emotions as they navigated accommodation processes. Some participants described worrying about if their accommodations requests would be seen as "too much," while others chose not to disclose so that they would not encounter such attitudes, expecting that colleagues would not understand or be accommodating. Finally, interviewees described gratitude as a particularly complex emotion because it was sometimes performed out of obligation or anticipated discrimination but could also be genuinely felt when access and support were provided.

4.2 Affective impacts and responses

4.2.1 Emotional responses: stress, fatigue, and hurt

Archivists described hurt and stress as the primary emotional toll of battling consistently inadequate and complex accommodation processes that slowed or inhibited access in their workplace. Archivists like Raegan spoke about the toll of "navigating the bureaucracy of filling out forms for disability services and stuff like that with the government" and how it factored into her "general exhaustion" when she is at work. Michelle shared how ongoing workplace stressors, including inaccessible spaces but also challenging and discriminatory organizational dynamics, took a physical and emotional toll: "it was super unhealthy. My blood pressure was too high. My stress levels were too high. My weight was too high. Everything was too high." Participant 4, who had experienced a seizure related to stress at the office, described "getting really upset" when her department not only consistently failed to meet her access needs but also, through this, added to her stress. As she explained "I kept being like, 'This thing is not working, this thing is not working' … There should be better ways that we can deal with these conflicts or long-ignored stresses or interpersonal things that kind of led me to this point."

For several archivists, the emotional labor of navigating access in the workplace was holding feelings of being hurt after humiliating interactions with colleagues. For example, Raegan described encountering ableist assumptions from supervisors after requesting extra time to review written work (Brilmyer et al., 2024, p. 117):

> I've had employers … who go, 'Oh, do you even know to like write? Can you write like words?' And I'm like, 'I have a fucking master's degree. I need you to think about what you say before it comes out of your mouth.' … And so that in a professional workplace has been extremely unsettling.

This type of condescending attitude was also part of Michelle's experience at work, who had been chastised after a challenging incident "where there were some chaos going on and I was trying to listen to the phone call while talking to someone–which is not a thing I can do." Their coworker had aggressively intervened and "grabbed the phone out of my hand" and later "informed me that I just need to 'figure out my disability, cause that was unacceptable.'" Michelle recalled feeling really hurt by that interaction: "I went home crying that day and it was not, not cool" (Brilmyer et al., 2024, p. 116).

Interviewees reflected that working in inaccessible spaces and dealing with hostile workplace cultures contributed to their stress. This hostility was also harmful, causing physical and emotional pain that only compounded the existing inaccessibility of the office.

4.2.2 Pushed to the limit: refusal

Several archivists described getting to a place where they decided not to continue engaging in accommodation processes at work and these decisions were largely framed as refusing to continue engaging in the emotional labor produced by an ableist culture. As Participant 4 succinctly expressed while describing their frustration at how a simple access request had morphed into multiple medical appointments just to get supporting documentation: "I was just like, fuck this. I'm not subjecting myself to this bullshit for them to literally give me a key to a door that I can covertly open anyway, but of course there are different types of risks." Participant 2 similarly explained how, "once it passes a certain level or a certain threshold of labor for me, I just give up. Which is not the greatest way to deal with things, but I definitely do it. I just get too stressed out and I just—I do not have the patience or energy to deal with this anymore." These expressions of running out of patience and interest in subjecting themselves to exhausting administrative labor hint at the constrained agency of disabled archival workers in transforming or avoiding the emotional labor of accommodation processes; their agency was their ability to refuse to participate entirely as a strategy for self-preservation.

This strategy of refusal was similarly evident in Michelle's decision to avoid professional spaces where she anticipated her access needs would not be met, as she shared: "there were a couple of events I just would not go to because I'm like, I'm not going to be able to hear anything. All I'm going to do is, you know, feel uncomfortable and be bored." Over time, the cumulative effect of these experiences was that Michelle had considered more broadly leaving archival institutions, "just bailing on the field altogether," in anticipation that the inaccessible culture would not change, even though "so much of who I am is an archivist." Both Michelle and Zakiya shared that they knew of disabled colleagues in archival institutions that had left the field because of a lack of access. Zakiya explained how their colleague's decision to leave after being denied a requested accommodation to attend therapy,

> …told me a lot about, you know, where I was working and like what their values are. And I've been able to like, communicate that to other people, like this is not a completely safe space. It's accessible legally, but culturally not so much. I'm just like, why would you want someone to not be mentally well at work?

Their critique of the organization's values echoed a sentiment that came through across many interviews: that the difficulty accessing accommodations reflected a deep-seated culture of ableism in the workplace that prioritized abstracted ideals of ability over employees' wellness, safety, and basic needs.

In response to the pain, hurt, and exhaustion they experienced through accommodations processes (or lack thereof), several participants chose to stop participating in these processes. These acts of refusal included declining to provide additional medical documentation to support an accommodation request, running out of patience and "giving up" on negotiating accommodations,[4] and leaving a workplace and even the archival field altogether. These refusals functioned as forms of self-preservation in the face of processes that were burdensome, unproductive, and ultimately hostile to disabled workers.

4.2.3 Finding confidence by contributing to a culture of access

The lack of effective accommodation processes at most archival institutions represented in this study meant that disabled archivists regularly felt forced or compelled to repeatedly disclose disability information with colleagues and also to "power through" without accommodation. Archivists described the process of navigating ableism at work as a battle, something they had to fight for with their

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[4] Earlier in the findings, we identified "powering through" as one way that disabled archivists navigated (a lack of) access in their workplace. While the outcomes of "powering through" and "giving up" were similar: disabled archivists found ways to work without formal accommodations. However, participants described the purpose of these practices differently: "powering through" was a strategy for getting work done when access was scarce, "giving up" was a move away from the accommodation process itself. The latter took on a self-protective quality, as in refusing to continue engaging in harmful negotiations and the pressure to produce more and more documentation.

supervisors and colleagues. By contrast, when participants had opportunities to advocate for access to benefit other disabled archivists or to build community with and for other disabled archivists, they described those experiences as creating a sense of ease and satisfaction. For example, Raegan described advocating for an update to her institution's human resources policies to make the processes for requesting accommodations clearer. Initially, "there wasn't anything about accommodations in the HR policy. So like, that was something that I went in and made sure was added so that when folks come in, they know that this is the kind of space where they can talk about it or ask for things." When asked how it felt to update the policy, she said: "it was very satisfying to me to be able to put that in."

Similarly, Joy shared how it felt "easier for me to advocate for others," knowing "I'm not just fighting for myself for this thing I can talk myself out of not really needing, but somebody else might use this physical thing too." She explained that knowing "someday, somebody will benefit from this even if I do not," which made it easier to process the harms and hurt emotions that came up in fighting for access. Joy also described how interacting with other disabled co-workers or students and sharing stories and challenges around accommodations had helped her:

> Students talking about what their experience was really amazing. I was like, 'oh crap, this is not even difficult.' It was so easy to see that like, wait, either there's something wrong with me that I feel that this is very, very reasonable, or there's something wrong with them [the employer].

Although, on an individual level, Joy would often respond to having her access needs dismissed or challenged by minimizing and doubting the importance of those needs, observing others advocating for what she needed empowered them to continue advocating for change at work. This was similar to Chris's experience, where finding community with other disabled people had empowered them to continue pushing for what they needed at work. As they explained, "It's good because I learn more about the things that I can ask for. … Being in a community where people actually actively talk about self-advocacy, I feel like it kind of legitimizes a lot of my thoughts."

This second cluster of findings shows the variety of responses to the accommodations process in archives. Participants described a range of affective responses to accommodations processes: from stress and hurt to fatigue and exhaustion. Being pushed to their limits, participants also described being fed up or refusing to participate in harmful processes. Yet, they also described feeling empowered when contributing to a broader culture of access in their workplace, one where they could depend on others to support their access needs, share access labor by advocating for others, and collaboratively build accessible workplaces.

5 Discussion

This research outlines the complexity of disabled archival workers' lived experiences—the ways they navigate accommodations and the affective impacts of employment, workplace policies, institutional culture, and professional norms. Across conversations, the archivists we spoke to described negotiating ineffective systems for work accommodations and having to weigh complex considerations around how and when to formally request an accommodation or informally raise access needs with colleagues. For participants, negotiating access was highly political: for example, several archivists spoke about waiting to raise access needs until they felt more secure in their position out of fear of retaliation. Even when accommodations were approved, interviewees often had to proactively and continuously advocate for those accommodations to be implemented. Their stories align with previous research documenting the repetitive administrative and relational labor that is required to secure and maintain disability-related accommodations and benefits (Damiani and Harbour, 2015; Konrad, 2021; Price, 2021; Titchkosky, 2011).

5.1 How organizations (En)force emotional labor within accommodation processes

Hochschild (1983) frames emotional labor as how organizations use and demand emotional expression from their workers. Our research considers how organizational accommodation processes and norms around workplace access demanded certain types of emotional expression and management. In doing so, we build on scholars' theorizing and documentation of access labor, what Fink (2020) has defined as "the work and effort that goes into making things accessible." Interviewees referenced several types of access labor that they felt compelled to engage in as they negotiated access at work, such as being forced to repeatedly disclose their disability and access needs, being compelled to conceal access needs and "power through" without accommodation, and being forced to manage the emotions of others.

These experiences of access labor, first, exemplify what Mingus' (2017) has conceptualized as forced intimacy, as in the "common, daily experience of disabled people being expected to share personal parts of ourselves to survive in an ableist world" (para. 1). Forced intimacy emerges out of the relationality of access, and the how access often becomes dependent on the way non-disabled people feel towards the person requesting accommodation (Mingus, 2017). As a result, disabled people are often forced to be vulnerable by exchanging personal information for basic access in formal spaces, like work and school, as well as less formal spaces, like being at the grocery store or on public transit. While Mingus describes the intimacy of access as having the potential to be "magnificent," "powerful," and "transformative" when mutually embraced through a politics of love and solidarity, in the context of an ableist world, this intimacy is often experienced as a loss of consent as well as a source of frustration and harm. In this "caged reality," Mingus (2017) explains how disabled people are expected to manage the emotions of others to survive, for example by being friendly to strangers, responding to harmful actions with patience and forgiveness, or performing gratitude for "whatever crumbs [of access] are thrown our way."

The findings in this study demonstrate how forced intimacy was a normalized experience for archivists with disabilities in professional spaces. Archivists relied not only on administrators and supervisors who were involved in formal accommodation processes but also colleagues who were involved in the day-to-day facilitation of access; for example, turning on captions for Zoom meetings or providing assistance in operating an elevator to navigate through the archives. As a result, several interviewees' were not only compelled to discuss disability information and access needs but also were forced to struggle with access barriers in real-time in front of colleagues and co-workers, as Raegan described, "having to go through it all with them and like the personal details of how pain works to try to justify my request to them." As Mingus (2017) explains, forced intimacy "is a cornerstone of how ableism functions in an abled bodied supremacist world. Disabled people are expected to 'strip down' and 'show all our cards' metaphorically in order to get the basic access we need" (para. 3). Beyond the intimacy inherent within having to disclose personal information to coworkers, interviewees also described worrying about how colleagues and supervisors would react to access requests and needing to negotiate access patiently while expressing gratitude for minimal accommodation.

The second key contribution of this study is around the emotional management and labor that is embedded within formal and informal navigations of access at work. This study not only aligns with Mingus' (2017) depiction of emotional labor as part of forced intimacy but also extends previous research with disabled people that has documented emotional labor as a central dimension of negotiating access and navigating ableism day-to-day (Konrad, 2021; Price, 2021). These scholars highlight how despite access being framed as largely procedural or logistical, it is inevitably dynamic and relational work that takes an emotional toll (Price, 2024; Titchkosky, 2011; Valentine, 2020). For example, in their work with people who are blind and visually impaired, Konrad (2021) highlights how the rhetorical demands of negotiating access–such as teaching others about access, performing a palatable disabled self, and dealing with people's reactions to disability–-produced fatigue. Specifically, they coined the phrase "access fatigue" to name the everyday labor of "constantly needing to help others participate in access" but also the ongoing demand to care for others' emotional experience as part of this helping process. Many of the archivists in this study similarly highlighted how the management of emotions was a central dimension of negotiating access at work. This management included holding and experiencing internal emotional states like stress, hurt, and fatigue but also strategically deploying certain affects, such as gratitude and patience, to manage the emotions of colleagues, as Michelle told us, "I'm always worried that I'm overstepping the bounds of the kindness that they are giving me." This research thus also adds to emotional labor, empathy, and relationality of archival work (e.g., Regehr et al., 2023; Nathan et al., 2015, Laurent and Wright, 2023, Caswell and Cifor, 2021) and the emotional management that is sometimes part of (or expected for) archival work.

5.2 Surface acting, emotional costs, and emotional gifts as central dimensions of access labor

There are several concepts from studies on emotional labor that are useful in theorizing the emotional experiences of disabled archival workers with access and accommodation in the workplace. This section will explore three: surface acting (Hochschild, 1983), emotional gifts (Clark, 2004), and emotional costs (Price, 2024). Participants described engaging in a form of surface acting: the transmutation of negative feelings like frustration into affects like patience and gratitude to manage the emotions of their colleagues. In this way, disabled archivists regulated their affects to ensure the cooperation and compliance of others in workplace accommodations. This emotional management was consistently perceived by disabled archival workers as an implicit, "affective requirement" of negotiating access to work (Wharton, 2009, p. 158). Price (2024) describes this as "impression-management work" and explains how masking inner worry, hurt, and stress with performances of positive or neutral emotions can, itself, exacerbate the emotional pain of negotiating access (p. 117).

This management of internal and external emotional experiences affirms an understanding of emotion as "flow[ing] between and among people" in ways that are "patterned rather than random" and often reflect relative positions of power (Clark, 2004, p. 403). Clark (2004) notes that the logics of "feeling rules" are gendered, and this study demonstrates that emotional experiences are also patterned based on disability status. For the disabled archivists in this study, their emotional labor was directed towards coworkers and supervisors, whose participation was necessary for accommodations to be implemented. This echoes previous research on disabled women leaders in the workplace, which identified surface acting as a relationship management strategy that women with disabilities used with coworkers, regardless of their seniority (Boucher, 2017). Surface acting within the accommodation process reflects the relational and precarious nature of disabled workers, who use affective strategies to prove and perform deservingness within ableist workplace cultures that treat access as a burden and practice of charity (Gerrard, 2019). Interviewees described making decisions around access based on the anticipated reactions of colleagues and supervisors, in particular, interviewees worried about their needs being perceived negatively, as 'too much' or overstepping. Anticipating being perceived negatively, interviewees were compelled to conceal their access needs and "power through" without accommodation to avoid negative emotions, dismissive reactions, and harmful judgments, exemplifying what Ahmed (2012) describes as practices of "institutional passing" or "going along with" (p. 157). Clark (2004) frames positive emotions like gratitude, respect, and deference as gifts, "emotions that one social actor expresses or displays (verbally or nonverbally) to another that have value because they are scarce—that is, they are not giving indiscriminately or limitlessly—and because they create positive emotions in the other" (p. 404). On the surface, this framing is useful in theorizing why disabled archivists might offer patience and gratitude to a coworker or employer to build up "socioemotional credits" that can be effectively traded for cooperation and assistance. However, Clark's use of gift feels inadequate in conveying the weight of feeling forced to exchange of positive emotions for basic material needs, such as safe and equal access to the workplace. For example, Clark describes how "a social actor who fails to receive expected emotional gifts might feel slighted and in turn withhold his or her own emotional gifts," but what is at risk of being withheld in interactions around access is not only reciprocal emotional gifts, but employees' safety, dignity, and ability to work.

Furthermore, the internal emotional experiences of disabled archivists as they navigated access at work came at a significant cost to participants' well-being. Price (2024) borrows from understandings of personal cost and emotional labor in describing emotional costs as the negative emotions, such as sadness and anger, that are experienced in relation to navigating access. These emotional costs were evident in the experiences of disabled archivists in this study as well. Beyond feelings of frustration, hurt, and sadness, participants also described the weight of internalizing the ableist logics through which they were perceived (and devalued) in order to strategically navigate workplaces defined by these logics. These experiences reflect what Titchkosky (2011) identifies in Audre Lorde's writings on anger, how she was "forced to incorporate a response to others' destructive recognition of her into her self-understanding" (p. 146–7). And while participants negotiated around and through ableist logics, several described hitting the limit of their capacity to tolerate the emotional management demanded by accommodation processes—opting out of a formal accommodation process entirely, declining to participate in work-related events, and even considering leaving the field.

Yet, while refusal or opting out of traditional accommodation processes can function as a strategic move for survival and self-preservation for disabled people (Damiani and Harbour, 2015; Emens, 2021; Karpicz, 2020), the emotional labor demanded of the disabled archivists we talked to functioned as what Emens (2021) describes as "a hassle cost," a way of rationing access by making it impractical and challenging to request and secure accommodations (p. 2348). The emotional labor required to survive and secure basic access in archival institutions was demanded in both formal accommodation processes and in day-to-day interactions with colleagues and supervisors, effectively serving as a hassle cost that preserved a status quo that privileged and legitimized the labor of nondisabled professionals. These demands—for patience, vulnerability, worry, and gratitude—formed a unique affective landscape for disabled archival workers that had to be continuously performed and managed as part of negotiating access, affirming the harmful and uneven impacts of surface acting for marginalized workers (e.g., Glomb and Tews, 2004; Ozcelik, 2013).

5.3 Collective approaches to access shift the affects of access labor

It is also significant that the emotions disabled archival workers experienced around collective approaches to access—ease, empowerment, and confidence—differed from those they experienced and navigated under traditional accommodation processes, which were either negative or paternalistic. This contrast reinforces that approaches to access are encoded with possible and permissible emotions. Collective approaches to access, because they are rooted in solidarity and embrace disability culture, produced positive affects that were neither performative nor superficial. Contributing to a culture of access within the workplace affirms access as both a collective responsibility and a shared asset (Hubrig and Osorio, 2020; Long and Stabler, 2022; Fritsch, 2024).

On the contrary, traditional approaches to individual accommodation reinscribe access as charity. This was evident in Participant 4's awareness of how providing access created a feeling of "being nice" that functioned as a demand for gratitude. As she explained, a social and emotional debt was produced when access was provided, namely that "I cannot be deserving of accommodation or recognition and be anything less than grateful at the same time." Thus, the findings of this study contribute to an understanding of how organizational approaches to access structure, as in shape and constrain, affect.

5.4 Theorizing "emotional expense" and indebtedness within archival organizations

Importantly, this paper outlines an *indebtedness* that emerges through accommodations processes because of and in response to inaccessibility at work. Interviewees incurred an external indebtedness—to colleagues, human resources, other people involved in the bureaucracy of access —'paying' with gratitude, giving vulnerability, being patient, and nice, to be deserving of accommodations. This external indebtedness emerged in the ways participants worried about exhausting their colleagues' willingness to negotiate access, reinforcing the idea of access as a form of benevolence that is conditional on not "overstepping the bounds of the kindness that they are giving to me" as Michelle explained. Yet, this also included an internal indebtedness—borrowing against your patience, energy to survive, and work—which was reflected in interviewees narratives about running out of these internal resources. This internal indebtedness expands upon Price's (2024) conceptualization of emotional cost as involving both external or "human-to-human" personal costs as well as internal negative emotions that were not tied to feeling indebted to another person (p. 114). This study expands this concept of emotional cost by demonstrating how indebtedness, not just negative emotions, is experienced internally as part of negotiating access at work. Together, these external and internal emotional debts underscore the frictions produced through inaccessible workplaces and bureaucratic and demanding accommodation processes, as well as the way disabled people incur emotional tolls as they navigate constrained and uneven relationships. To be in such emotional debt shapes an affective landscape, as Participant 4 articulates, navigating the ableist power dynamics around access, "can easily put me in a kind of debt—i.e. perception that I cannot be deserving of accommodation or recognition and be anything less than grateful at the same time."

Building on Brilmyer's (2022) articulation of the "emotional expense" of archival inaccessibility for disabled archival users, we draw attention to *the affective debt of archival access*: the complexity of inaccessibility, where such expenses—because of the requirements to manage internal emotional costs on top of system demands, bureaucratic processes, and interpersonal interactions with colleagues—create many types of indebtedness, many (if not all) of which are required to keep ones job. We outline the debt of such affective demands—emerging across different archives and therefore showing the prevalence in the field—to illustrate how many of the interviewees developed a deep awareness around having to share details about their disabilities in order to gain accommodations, deal with harmful processes and people, and manage the futility and incurring cost of it all. This term aligns and builds with Cuellar et al.'s (2023) conceptualization of "archival debt," which they describe as the "problematic legacy issues" that have accumulated over time as institutions take shortcuts and make compromises in archival practice, such as "harmful or inadequate description, performative or competitive collecting, languishing backlogs, failure to recognize staff potential, shortsighted fund management, neglected constituencies, a lack of documentation, and poor project management" (p. 1). The findings of this study expand on this concept of archival debt by documenting how delays and shortcutting accommodations processes preserves the inaccessibility of archives. For example, delayed and underresourced accommodations shape who can work, who gets promoted, whose contracts do not get renewed, and therefore who are the stewards of archival materials and access to histories. The concept of *affective debts of archival access* also captures how indebtedness preserves the power dynamics that contribute to disparate emotional experiences; disabled workers continue to be put in the position of requesting access at an individual-level and coworkers and supervisors continue to be empowered to invalidate, delay, and/or deny access needs.

The concept of *the affective debt of archival access* affirms how phenomena like forced intimacy (Mingus, 2017), institutional passing (Ahmed, 2012), surface acting (Hochschild, 1983), and emotional hassle costs (Emens, 2021) emerge as disabled archival workers maneuvered accommodation processes and the emotional labor that was exacted through these processes. Participants described feeling forced to experience or unable to avoid this emotional labor, whether it was experiencing the vulnerability of repeatedly disclosing personal information or managing the emotions of colleagues as they provided, contested, and/or denied access. Though the affective demands of accommodation processes felt unavoidable within traditional accommodation processes, disabled archival workers described how collective approaches to access transformed the affective experience of access towards ease and empowerment. Their narratives affirm that different affects are facilitated through workplace structures and cultures. Within archival institutions, the affective demands on disabled archival workers were deeply shaped by structures and cultures that preserved abledness as the norm.

Building on the literature that highlights the affective aspects of archival work (e.g., Arroyo-Ramírez et al., 2021; Caswell and Cifor, 2016; Guerrero, 2022; Laurent and Wright, 2023), we highlight new facets of archival labor related to accommodations and access, how they are often invisibilized (Lapp, 2019), and how this shapes how and if archival work is done. By drawing attention to how the very people who facilitate access to historical documents are also navigating their own access, this research, then, connects the workplace conditions for disabled archival workers with the experiences of users (e.g., Brilmyer, 2021, 2022, Brilmyer et al., 2024; Duff et al., 2019).

6 Conclusion

The findings from this study affirm how, as Ahmed (2006) theorizes, "spaces acquire the 'skin' of the bodies that inhabit them," meaning that organizational norms and cultures are shaped by the people who have historically occupied and preserved their power within and through institutions (p. 132). And though individual accommodations may temporarily modify the 'skin' of an organization, they rarely alter its culture such that disabled people truly feel a sense of welcome and belonging (Piepzna-Samarasinha, 2018). In sharing their experiences with access at work, interviewees documented how archival institutions of all kinds—whether community-based archives, university archives, large or small collections—had embedded organizational norms that presumed and privileged abledness. Within these cultures, archivists experienced a broad range of access barriers: from a lack of information about how to request accommodation as a job candidate to having colleagues repeatedly forget to turn on the captions, an approved accommodation, in virtual team meetings. Abledness was enforced as the norm and made compulsory through this difficulty (McRuer, 2018). Disabled archivists found themselves continuously bumping into entrenched understandings of "that which is expected" of archival workers and archival work, which did not include either the labor of providing or the experience of receiving accommodation (Garland-Thomson, 2011, p. 593). Interviewees largely had low expectations for the quality of access they would receive and navigated with an awareness that every request for access could become a protracted struggle with supervisors, colleagues, and administrators.

The affective debt of archival access draws attention to how these struggles to negotiate basic access at work revealed "sedimented patterns of relating and belonging" within these institutions that forced disabled archivists to regularly disclose personal information and advocate for their access needs to survive in the workplace (Valentine, 2020, p. 77). Negotiating access in this context resulted in a complex affective landscape for disabled archival workers. In particular, this study contributes to understandings around the emotional cost of access by documenting the internal debts that accrue as disabled archival workers navigate access at work. Participants' narratives highlight how these affective politics are normalized for disabled workers in archival spaces, where workers feel obligated to make their hurt and anger small and then transmute it into patience and gratitude in order to get the basic access they rightfully deserve—producing internal and external indebtedness, costs that aaccumulate across the archival profession.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding authors.

Ethics statement

The studies involving humans were approved by the McGill University Research Ethics Board and the Kansas State University Institutional Review Board. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study. Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

Author contributions

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Struggling for epistemic and emotional justice—a collaborative autoethnography of personal assistance

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The present article explores the intersection between disability and the emotions evoked by the experience of living with Personal Assistance (PA) in everyday life. The aim is to explore the emotion work around navigating the emotional and epistemic injustice faced by disabled people and their family members. As family members, mother and daughter, we are bound by our mutual experiences of being recipients of disability support. Research tends to focus on the professional gaze. Hence, the emotion management of disabled people living with disability support and their family members needs to be better understood. Life with PA provides a context that illustrates what epistemic and emotional injustice in various forms feels like. Our narratives may help to increase the understanding of the complex interplay between assistance coordinators, external personal assistants, young adults in need of PA, and family members involved in providing PA in everyday life. Focusing on our experiences of having linked lives underlines the entanglement of having different roles vis-a vis each other. Utilizing a collaborative autoethnographic approach we have identified three themes, *The interconnectedness between emotion invalidation and crip time*, *The expectation of emotion work* and *Managing conflicting needs in the light of emotion work and linked lives*. The findings show a difference concerning the expectation of emotion management, where external PAs perform emotional labor during work hours, while assistance users and family members perform emotion work throughout the day. Professionals often cause epistemic injustice in different situations and increase the need to perform emotion work in implementing PA instead of acknowledging the lived experience of assistance users and family members. When assistance coordinators or external PAs seek to eliminate certain emotions from the experiences of users or their family members, they overlook valuable insights about the situation. Silencing those with lived experiences risks dismissing individuals who possess relevant first-hand knowledge due to their emotional connection to the experienced injustice.

KEYWORDS

epistemic injustice, emotional injustice, personal assistance, collaborative autoethnography, crip time, linked lives, emotion work, emotional labor

1 Introduction

Epistemic injustice (Fricker, 2007) is concerned with forms of unfair treatment that relate to issues of knowledge, understanding, and participation in communicative practices (Kidd and Carel, 2017) in which the voices and experiences of marginalized individuals are not being taken seriously (Cummings et al., 2023). Emotional injustice occurs when the treatment of emotions is unjust, or emotions are used to treat people unjustly (Pismenny et al., 2024). The psycho-emotional aspects (Reeve, 2002; Thomas, 1999), "work" and "performances" of the "disabled" identity are themes explored within disability studies (Goodley, 2010). To some extent, "emotion work" and "emotional labor" have been explored regarding disabled people's experiences (see for example, Liddiard, 2014; Goodley et al., 2018). Emotion management is both an inner process and an outward expression, frequently involved in preserving social bonds and social rules (Williams, 2003). As such, it becomes relevant for disabled people with PA. This article addresses epistemic and emotional injustices experienced by people living in Sweden with PA in everyday life. We want to underline the difference between the expectations of professionals and service users in handling the emotional aspects of PA, since discarding emotions profoundly impacts both emotional and epistemic injustices. In this article, the aim is to explore the emotion work around the navigation of emotional and epistemic injustice faced by disabled people and their family members, evoked by our experiences of living with PA as a mother and daughter. The former being a parent and the latter a young disabled female PA user.

The first part of the article is mainly theoretical, and the second part is empirical, based on autoethnographic narratives related to lived experiences with PA in our everyday life. We draw on notions of epistemic injustice (Fricker, 2007), emotional injustice (Pismenny et al., 2024), emotion management (Hochschild, 2012) and crip time (Kafer, 2013) to make sense of our autobiographical experiences of living with PA in Sweden, where our experiences of emotion management underline the complex interplay between emotional and epistemic injustice.

PA is a consumer-directed support where disabled people are in control of recruiting, training, and managing the people who support them (Porter et al., 2020). PA differs from other forms of care because the assistance user controls how, when, and by whom they are supported. The relationship between personal assistants and assistance users is fundamental to ensure self-determination in everyday life (Giertz, 2012). However, a well-functioning relationship between the assistance user and the PA is required. Assistants take on different roles for assistance users (Guldvik et al., 2014). Due to the interpersonal dynamics of PA, which can be characterized as a "hybrid form of work and care" (Ungerson, 1999, p. 538), some assistants consider the relational aspects as the most challenging parts of their work (Egard, 2011). PA involves inherent tensions and ambiguities: part personal, part professional; instrumental, yet at the same time emotional (Porter et al., 2020). Power is relational in the relationship between the assistant and the assistant user. Previous studies have recognized tensions about different roles and expectations, whether it be "paid friends" or "professional friendship" (Larsson, 2004; Christensen, 2012; Hultman et al., 2017, 2023).

1.1 Negotiating PA in the backdrop of austerity measures in Sweden

Traditionally, Sweden has had a high standard of social welfare to support people against social risk. Austerity measures in social welfare are changing the direction of social policy (Järkestig Berggren et al., 2021), for instance, when cutbacks are justified by the framing of PA as a "cost problem" (Altermark, 2017). Since 2014, policy decisions have dealt with how the costs of PA can be reduced. In the 2016 regulation letter to the Swedish Social Insurance Agency (SSIA) (Ministry of Social Affairs, 2015), the SSIA was instructed to slow down the cost development for the provision of PA.

Consequently, these austerity measures have created a debate regarding society's support for disabled people, whereby rights are being renegotiated or eroded (Ehliasson and Markström, 2020). The National Board of Health Welfare (2024) has established that several aspects indicate a worrying development that harms the quality of life and health of disabled people and their families.

Encounters between people seeking disability support and professionals are infused with routinized, invisible epistemic injustices, such as privileging professional expertise over experience-based knowledge of people with their own experiences (Carel and Kidd, 2017). Instead of focusing on its core mission, establishing a relation to the applicant, to enable a fair social needs assessment that focuses on the applicants identified needs and wishes, employees and managers in public welfare organizations often spend a considerable part of their working time on different forms of administration. Detailed control and formalism sometimes make cooperation difficult, contributing to service users with complex needs not always getting the help they need (Bringselius, 2017).

In Sweden, support and service for disabled people are provided under the Act concerning Support and Service for Persons with Certain Functional Impairments, known as the LSS Act (SFS, 1993). In LSS, it is central that disabled people are recognized as citizens and are assured equal rights as other people in society have (e.g., Grunewald, 2008). To apply for PA, the applicant must make an oral or written application and provide a detailed description of support needs in terms of the type of support needs, frequency, and duration. Needs are divided into "basic needs" and other needs, which are defined as needs connected to integrity-sensitive needs, which entail support in relation to meals, personal hygiene, dressing, undressing, and communication. Since the LSS Act came into force, additional basic needs have been added (Ministry of Social Affairs, 2022). When the granted assistance hours exceed 20 h per week, the assistance user is more likely to receive enough support to engage in leisure activities. However, if <20 h of assistance per week are granted, those hours might not cover more than assistance to fulfill basic needs.

Over the years, government reports have repeatedly drawn attention to SSIA's difficulties in operationalizing the LSS Act. Research implies a shift from the idea of PA as a social right for citizens toward a medical model (Brennan et al., 2016) where PA resembles medical care rather than activities fulfilling policy goals such as equality and full participation in society (von Granitz, 2022). Due to the ongoing medicalization of PA, some assistance companies downplay the difference between demand-driven and supply-driven services, which implies the abolishment of user control (Ratzka, 2017).

2 Theoretical frameworks

2.1 Emotion management, emotion work, and feeling rules

Emotions are not simply an expression of individual experience. They also express collective and institutional experience (Morrison, 2007) since they are deeply embedded in and influenced by the broader social context and changes in the welfare state (Turtiainen et al., 2022).

Collins (2004) indicates how power and status affect people's ability to express emotions. Power positions and interaction create complex emotions where the actors share emotions but from very different positions. Even when the professional (the person in a superior position) understands and feels the fear of the assistance user (the person in a subordinate position), it is not the same fear that the subordinate person experiences.

Emotion management and feeling rules are focal conceptual lenses for exploring the intra- and intersubjective dynamics of people living with and being dependent upon access to PA, and people who are either making decisions about access to PA or providing PA. Instead of viewing emotions as irrational, Hochschild (2012) argues that they are subject to rules and norms, much in the same way as other behavior, which "govern both the display and the experience of emotion. Feeling rules tell us not only what emotions we should feel but also how long and how intensely we should feel them" (Lively, 2006, p. 570). The self-regulatory process of emotion management is guided by formal and informal internalized feeling rules to achieve desired emotional responses. Both emotional labor (formally internalized feeling rules) and emotion work (informal feeling rules) require a person to manage a wide range of feelings and become aware of which situations call for specific emotional responses. Those situations demand that people actively manage emotions by ensuring that their response is appropriate to the situation at hand (Lively, 2006). The emotion management perspective fosters attention to how people try to feel, not how people try to appear to feel or unconsciously feel. Emotion management is described as a behavior where "the interactive account of emotion points to alternate theoretical junctures-between consciousness of feeling and consciousness of feeling rules, between feeling rules and emotion work, between feeling rules and social structure" (Hochschild, 1979, p. 560). Influenced by Goffman (1956) Hochschild (1979) distinguishes between surface and deep acting. In surface acting, the facial expression or the body's posture feels "put on"; it is not "part of me" in contrast to deep acting, where thoughts and memories are manipulated to make feelings correspond to social norms (Lively, 2006).

2.2 Emotional injustice

Emotional injustice occurs due to social norms that impact the treatment of emotions (Jaggar, 1989; Ahmed, 2004; Cherry, 2019). Within Western culture, people have often been encouraged to control or suppress their emotions (Jaggar, 1989), since the inability to manage emotions has often been associated with members of subordinate groups, such as women (Cherry, 2019). For Ahmed (2004), emotions are "intentional in the sense that they are 'about' something; they involve a direction or orientation toward an object." Emotions always imply an act of interpretation: The "aboutness" of emotions involves a way of apprehending the world. Accordingly, when people express certain emotions, they will be perceived as having no rational (or moral) ground to have them.

In our paper, we draw upon the definition of emotional injustice coined by Pismenny et al. (2024), whereby emotional injustice is understood as an arbitrarily imposed disadvantage, i.e., features of a person or situation that are morally irrelevant or fail to justify the disadvantage or mistreatment. Emotional injustice can involve material resources, opportunities, dignity, status, free expression, and decisional capacities. Emotional injustice occurs when people in a privileged position use emotions to treat people unjustly or when the treatment of the emotions is unjust (Pismenny et al., 2024). The concept of emotional injustice has been operationalized as a taxonomy consisting of seven different categories of emotional injustices: misinterpretation, emotion discounting, extraction, emotional policing, exploitation, inequality, and weaponizing. This paper focuses on emotion discounting, an emotional analog of testimonial injustice (Fricker, 2007). One example of emotion discounting is emotion invalidating when one's responses are taken to lack credibility or worth, for example, women's anger is typically dismissed or deemed illegitimate because of the stereotype that women are "emotional" (Cherry, 2019). Another example in this category is emotion defaming, which relates to the concept of dynamic hermeneutical injustice, in which there is an intention to misrepresent (Medina, 2012). As Pismenny et al. (2024) pointed out, both misinterpretation and emotion discounting involve responses to emotions after they occur. Another category that becomes relevant for studying the intersection of disability and emotions is unjust emotional policing that underlines normative assumptions about emotion management. Emotional policing involves determining what emotions people are allowed to express, affecting their shape. One aspect of emotion policing is stereotyping, which informs our beliefs about people and can contribute to emotion misinterpretation. Stereotypes also play a role in governing the emotions of disabled people (see also Eickers, 2023) where the concept of "super crip," contributes to the expectation of emotion work, i.e., suppressing negative emotions so those are aligned with behaviors corresponding the expectation of the "super crip," namely, overcoming adversity and being inspirational.

2.3 Epistemic injustice

The concept of epistemic injustice, theorized by Fricker (2007), refers to a form of direct or indirect discrimination arising from identity prejudice of marginalized groups. When individuals or groups in society are not being listened to, nor asked to present their thoughts and experiences in matters that profoundly impact their everyday lives, they are exposed to testimonial injustice, which is one form of epistemic injustice (Fricker, 2007). Unequal power relations make disabled people vulnerable to the arbitrariness of professionals' judgments and changes in policy and legislation. It undermines the status of individuals or groups as epistemic agents (Fricker, 2007)—their capacity to act and be accepted by others as "knowers." Fricker (2007) identified two forms of interrelated epistemic injustice. The first form, "testimonial injustice," refers to situations in which individuals' knowledge or interpretation of events or experiences is unduly dismissed because their credibility is deflated due to prejudicial beliefs about some aspects of their identity. The second form of epistemic injustice is hermeneutical injustice, in which the actions of prejudice contrive to undermine the ability of a group of people to contribute to the collective "pool of ideas" in a society for making sense of events or an aspect of human experiences (Fricker, 2007). Hermeneutical injustice occurs when specific experiences are difficult to mediate due to a lack of a common language that makes it possible to describe a specific type of social experience that makes those experiences comprehensible to others and oneself. The possibility to describe specific social experiences entails the need for epistemic tools to perceive, describe, account for, and evaluate experience, including "language to formulate propositions, concepts to make sense of experience, procedures to approach the world, and standards to judge particular accounts of experience" (Pohlhaus, 2012, p. 718). Those in power accumulate and perpetuate power and resources for their benefit (Payne, 2002). Because language is not always seen as a means of power, its influence may go undetected by those with less power.

2.4 Normative life course, crip time and linked lives

The need for PA makes it more challenging to follow a normative life course. Crip time highlights the connection between following a normative life course and the ability to live according to a normative perception of time. However, living with PA destabilizes notions of normative time. For assistance users and family members, negotiating needs and wishes becomes difficult, creating linked lives between parents and disabled grown children.

The notion of a normative life course is based on a normative perception of time, chronological sequence, and particular bodies and minds (Wälivaara and Ljuslinder, 2020). In addition, a normative life course implies a linear development from childhood, adolescence, and adulthood that includes specific life events (Kafer, 2013). These life events are also structured in time to occur in a specific normative order, such as getting an education and a job, finding a partner, getting married, and having children. Crip time (Kafer, 2013) is an analytical concept that creates an understanding of time that differs from ableist time, an understanding that make us aware of the entanglement of time and the ability to follow the normative life course. Since time intersects with the life course, it shapes social norms about appropriate transition points, which contributes to creating a vulnerable life situation for disabled people who are unable to live according to normative time.

All lives are not linear yet still living in crip time challenges normative notions of straightforward time. Kafer (2013, p. 34) describes crip time as extra time, and as a departure from straight time, "whether straight time means a firm delineation between past/present/future or an expectation of linear development from dependent childhood to independent reproductive adulthood" Contrary to normative perceptions of time, crip time destabilizes normative notions of time and pace. It includes ways of being in and moving through time which are distinctly crip (Sheppard, 2020). Crip time means having both a flexible standard for punctuality and the extra time to arrive or accomplish something (Kafer, 2013, p. 26) contrary to normative time, which requires to be at the right time and use the right amount of time. Implying being "too slow, too fast, too uncontrolled, too reliant, too different, too much and also not enough" (Sheppard, 2020, p. 39). In the words of Samuels (2017, n.p.) crip time has its inherent logic:

> For crip time is broken time. It requires us to break our bodies and minds to new rhythms, new patterns of thinking, feeling, and moving through the world. It forces us to take breaks even when we do not want to, even when we want to keep moving. It insists that we listen to our bodyminds so closely, so attentively, in a culture that tells us to divide the two and push the body away from us while pushing it beyond its limits. Crip time means listening to the broken languages of our bodies, translating them, honoring their words.

Living with a disability shapes the individual's subsequent life course in terms of choices, opportunities, and pathways that are either followed or expected. It also shapes the trajectories of those closely linked to the disabled person. Being dependent on others makes it more difficult to display negative emotions, such as anger, resentment, or sadness (Hultman et al., 2023).

Erickson and Ritter (2001) suggested that managing anger and frustration is a form of emotion work likely associated with increased feelings of inauthenticity. The linked lives perspective (Elder, 1998) makes ripple effects across the entire family visible. For instance, when one family member experiences stress, other family members are also affected—even if individual family members lead independent lives (Nair et al., 2022). In addition, life course trajectories that deviate from the normative life course can lead to stigmatization or even social inequalities (Ljuslinder et al., 2020).

3 Method

Autoethnography aims to systematically describe, analyze, and connect personal experiences to the broader social context (Ellis et al., 2011), with the researcher occupying the unique dual roles as both the object of, and the subject undertaking the investigation. Like others (e.g., Chang, 2016; Griffin and Griffin, 2019), we have tried to combine elements from different autoethnographic approaches; the "analytic" approach, to ground the findings in context (Anderson, 2006), and the emotive "evocative" approach (Ellis and Bochner, 2000), to facilitate greater understanding and evoke emotions. The continuous struggle in our everyday life, and our previous experience of writing an article about mental health care practices (Hultman and Hultman, 2023), inspired us to conduct a collaborative autoethnography (Anderson and Fourie, 2015) that enabled us to "keep our voices while creating a collective one" which offered a richer account of our experiences' (Lapadat, 2017).

Our personal experiences may differ from the experiences of other assistance users and family members. We treat our subjectivity as an approach to understanding our ways of knowing while exploring what living with PA entails. The fact that one of us holds a faculty position as a disability researcher in the global north has provided us with a "voice." Thus, we have an epistemic privilege compared to other disabled people relying on daily assistance, whose stories remain untold due to a lack of financial and hermeneutical resources such as funding and knowledge of academic language and writing processes. Therefore, utilizing our epistemic privilege is justified because it enables us to provide an inside perspective on issues of epistemic and emotional injustices that need to be addressed.

In this study, we are bound by our mutual experiences of receiving disability support, sharing the role as supervisors for PAs, and negotiating support from professionals in charge of PA schemes. Nevertheless, as mother and daughter, our experiences differ. One of us, the daughter (Maya) is a young disabled woman — a community researcher with own experience of cerebral palsy and living with PA, and the other (Lill) is a single middled-aged woman with two children, without own experience of a mobility impairment, with a background as a social worker and disability researcher.

Critical reflexivity was applied throughout the process and was fundamental to our interpretations, which were conducted in a "back-and-forth movement between experiencing and examining a vulnerable self and observing and revealing the broader context of that experience" (Ellis, 2007, p. 14). We have explored our experiences from our differently situated knowledge (Harding, 1991). It underlines our different perspectives on handling the presence of PAs in our everyday life. Encountering each other's storying has resulted in a gradual restorying and understanding of our experiences. In this text, we utilize our positions (as people with lived experience and knowledge of theoretical concepts) as a vehicle for change by highlighting the social injustice that people needing PA may encounter. To mitigate hermeneutical injustice among ourselves, we utilize the method of talk/writing, i.e., the first author (Lill) writes while the second author (Maya) talks and is not allowed to interrupt or ask clarifying questions until the second author is finished. The initial text was written in Swedish, and we have discussed and agreed upon the theoretical concepts included in the deductive analysis we conducted together.

The analysis began with the second author identifying critical incidents, i.e., Critical Personal Narratives (CPN). For this paper, we have generated six CPNs that highlight our intertwined personal experiences. Based on these CPNs, we discussed our experiences and the relevance of our varying emotional responses to living with and being dependent on PA in everyday life. The first and second CPNs are written from Maya's perspective, and the third and fourth CPNs are written from Lill's perspective. The fifth CPN reflects Maya's perspective, and the sixth reflects Lill's. Combined, all the CPNs reflect our different but interrelated perspectives. The selected situations are used to criticize, analyze, unsettle, and defamiliarize what is often passed off as the ordinary, everyday life routines (Chapman, 2004). The narratives illustrate critical incidents involving PAs and assistance coordinators at the assistance companies involved in providing PA in everyday life. The second step was to create themes based on the chosen CPNs and analyze them deductively by utilizing concepts such as crip time, epistemic injustice, emotional injustice, emotional labor and emotion work.

We did not apply for ethical permission to conduct this study since the data consists of a text-based analysis of our personal narratives. As authors and participants, we both agreed to share our personal reflections and thoughts with each other.

4 Findings

Based on the CPNs, the following themes emerged: *The interconnectedness between emotion invalidation and crip time* (Section 4.1), *The expectation of emotion work* (Section 4.2), and *Managing conflicting needs in the light of emotion work and linked lives* (Section 4.3). The themes illustrate our separate and mutual voices.

4.1 The interconnectedness between emotion invalidation and crip time

> My municipal assistance company coordinator says I must think about not using my PA at night. Because then I will not have enough hours to use the following day. She continues, by saying that: "she knows that I only use PA at night when I have to go to the hospital," and she insinuates that I do that too often. I respond that I only go to the hospital when it is necessary, and add: "according to my neurologist, I have migraines with aura, and it could be dangerous for me to have migraines for too long." She interrupts me and questions why migraine attacks must happen at night. I try to explain that I can't help it. What bothers me the most is that she tries to tell me what to do. She cannot possibly know how my body works. I desperately want to end the conversation, but before she ends the conversation, she says: "It will be a problem if you run out of assistance hours." It almost makes me doubt myself – Am I making the right decision? Do I have the right to make the decision that I'm making? (Maya)

For Maya, the consequences of living with cerebral palsy fluctuate over time and can vary depending on the situation and context. During cold weather and stressful situations, her body responds with high levels of pain. She becomes more tense and sensitive to pressure. Even though she has lived with cerebral palsy all her life, her lived experience is disregarded. Thus, a nondisabled person defines what is considered a legitimate need for her. She doubts that the assistance coordinator understands varied and variable needs and how this affects the everyday lives of disabled people. It makes us think of Alison Kafer, quoted by Samuels (2017), "rather than bend disabled bodies and minds to meet the clock, crip time bends the clock to meet disabled bodies and minds," hence, the jerky experience of living with cerebral palsy implies living in broken time—needing "extra time" for medical appointments. During specific periods, Maya's increased medical needs demand frequent hospital visits. The difference between crip time and normative time makes it difficult for Maya to translate her lived experience of variable needs neatly into a PA scheme. Contrary to a simplistic view that relies upon the proposed binaries of disability and non-disability, disabled people, like her, experience disability as fluid, which implies varied and variable needs.

Since Maya's decision regarding the provision of PA does not allow her to have assistance hours for active and practical support during the night, she risks having a shortage of assistance hours since the provision of assistance hours is based on "ideal situations" (normative time and normative needs). Thus, when there is a deficit in assistance hours, she must use assistance hours allocated for other needs or activities. Maya has to consider the practical consequences of utilizing assistance hours to which she is not entitled. In the short term, this means that she does not receive care, which can have negative health consequences in the long term. If Maya receives care, it means that there is a shortage of allocated time, which contributes to her not being able to participate in social activities. Being aware of negative consequences makes it difficult for Maya to be honest with herself. In addition, it creates a feeling of anxiety because it is impossible to make the "right choice."

Even though the assistance coordinator has no formal power to decide how allocated time is utilized, Maya seeks her approval. To avoid emotion invalidating, it becomes important for Maya to justify her emotions by formulating arguments in a nonaggressive way. Nevertheless, anxiety connected with not being heard, or having one's emotions dismissed due to lack of credibility, makes Maya angry and fearful. At the same time, she knows that she must hide her authentic emotions since showing emotions such as anxiety and anger that are perceived to overrule normative feeling rules, connected to gender roles will only diminish her capacity as "a knower." Emotion invalidation happens when what we do or say is not taken seriously, not taken in context, or not taken for its intended meaning.

To strengthen her epistemic agency, Maya ignores her bodily symptoms and suppresses her emotions, which creates a dissonance that makes it necessary for her to perform emotion work. If she admits her authentic feelings, it increases the amount of internal stress, reinforcing the dissonance between what she experiences and what she perceives that the assistance coordinator wants her to feel, which exemplifies emotional policing. When she adjusts her physical and emotional experiences to fit with normative expectations that are grounded in the idea of the "overcoming adversity" narrative, she learns how to distrust her feelings and ignore her own needs, which makes it easier for others to ignore her feelings (emotional discounting) as well as material needs which reinforce testimonial injustice. This policing of emotional expression can cause serious epistemic harm, both in how it influences what we define as credible testimony and in how confident we can be in the reality of our own lived experiences.

The disqualification of her lived experience and her need for hospital care that demands the presence of personal assistants exemplifies how she is wronged in her capacity as "a knower." Acts of testimonial injustice may be described as involving disrespect and disesteem simultaneously or separately. It starkly contrasts how it feels when 'She is safe'- sharing her experience with people who validate it and express gratitude to access experience-based knowledge grounded in an inside perspective. As a minority group (Botha and Frost, 2020), there is a risk of not valuing one's perspective, which includes downgrading other people with similar experiences, as a kind of internalized ableism (Kumari Campbell, 2008).

Because of the assistance coordinator's disbelief, Maya eventually becomes silent, reluctant to continue sharing her lived experience since it becomes impossible to mediate experiences to someone who does not validate one's emotions or want to understand or consider varied or variable needs which could be understood in terms of people having different energy levels or non-normative perceptions of time. Since Maya's experiences are not considered common knowledge, the lack of legitimate concepts invalidates her narrative regarding testimonial and hermeneutical injustice (cf. Fricker, 2007). In addition, she suppresses feelings of anger and hopelessness. She cannot risk upsetting the assistance coordinator with her, since she depends on the assistance coordinator's goodwill, her being the link between Maya and her PAs. Maya perceives that she is expected to suppress anger, being able to formulate her opinions in a calm voice, without hurting other people's feelings. If she develops a poor relationship with the assistance coordinator, she risks being perceived as "difficult", which could lead to a lack of support from the assistance coordinator. Since the assistance coordinator represents the formal employer (the assistance company) this role requires the ability to balance Maya's interests and the interests of the PAs that work with her.

> My phone is ringing. It is my coordinator at the assistance company. I answer even though I'm too tired to answer. She speaks fast, and I speak slow. She says, "If you are ever mean to your personal assistant again and say you do not want to see her. She can go home, and I will send a substitute." I try to explain that I didn't mean what I said. She briefly replies that she understands that I get upset. I notice she does not seem to understand what it is like to be upset and say something you do not mean. I say: I cannot bear to keep talking to her because she does not seem to understand me. She replies that we must continue this conversation. I listen to her and respond to the best of my ability. I feel like I want to be able to promise that I will never say something that I feel without considering the consequences it may have for others. But the question is, does she understand why I lose my temper sometimes? Because I often feel pressured, I swallow and swallow, and to avoid assistants questioning my decisions, I let them choose when things should be done and sometimes how things should be carried out. I do this because I depend on the assistants all the time. I swallow and swallow, until I can't take it anymore. (Maya)

In the conversation with Maya, the assistant coordinator takes on the dual role of employer and "knower." The coordinator seems to ignore the essential difference between being a PA and someone needing a PA. For the assistants, it is a workplace. When they end their shift, they have their place to go, where they can relax, choose to be alone or socialize with friends, without someone else being present. For Maya, it is her private space and sanctuary. It is where she should be able to be "backstage," not having to perform a role or have the ableist gaze bestowed upon her.

Instead of acknowledging Maya's emotions regarding the difficulty of having a PA present around the clock, the assistance coordinator wants to find a quick solution and possibly a scapegoat. When there is a disagreement between Maya and one of her PAs, Maya often feels that the assistance coordinator sides with the PAs, instead of being neutral and listening to both sides. Maya experience that the assistance coordinator blames her for being "difficult and demanding", that she should be able to do emotion work and obey feeling rules, since displaying strong emotions such as anger is considered an "inappropriate response" contrary to the idea of women being sweet and considerate of other people's feelings. Being dependent on maintaining good relations with PAs makes it difficult for Maya to display authentic feelings. Therefore, she tries to suppress the anger and disappointment felt toward her PAs. By engaging in surface acting, Maya tries to adapt her emotions and behavior to other people's expectations.

4.2 The expectation of emotion work

For Lill, contact with different assistance providers evokes conflicting emotions. On the one hand, it feels like an obligation to secure her daughter's right to obtain high-quality PA and to ensure that the assistance company fulfills its duties. On the other hand, she is tired of being involved in all aspects of her daughter's life. It feels like some professionals think she is unwilling or unable to allow her daughter to become independent since there is a general misconception that parents of disabled children are being overprotective (Holmbeck et al., 2002).

> Sometimes, I am afraid of being perceived as unreasonable or "a know-it-all" and that my involvement might backfire and reduce my daughter's chance of gaining access to PA according to the intention in the LSS legislation. Depending on which professional I meet, I could be cast as the overprotective, heroic, or selfish mother. At the same time, speaking for oneself and utilizing the same language as professionals makes it easier for us to gain access to support. I suspect that if I have a nervous breakdown during an assessment meeting, I'd probably get more sympathy and less power. I often get frustrated that we must fight for our rights. The struggle never ends. It is so exhausting, frightening, and overwhelming that professionals have so much power over our everyday lives. It is so unfair. Over the years, I have become a warrior. I feel that being in touch with my anger has helped me continue fighting for our rights. At the same time, awareness of the discrepancy between policy and practice has created enormous feelings of hopelessness. (Lill)

Being squeezed between different expectations from others and her own needs, working full time, having "me-time" to recuperate, tending to household chores, and being a "good mother" to siblings. Lill often feels that she is expected to do emotion work. Cast in the "good mother" role, she experiences herself being restrained by feeling rules that expect her to provide accurate and nuanced descriptions of her daughter's needs in a neutral manner or possibly display feelings of acceptance or sadness. When she fails to display "the correct emotions," by neither complying with feeling rules nor gender roles, i.e., displaying anger instead of maintaining her composure, she has experienced that some of Maya's assistance coordinators have expressed their disappointment in her. They expected her to do better, i.e., to be "professional" and act as a "role model" for personal assistants. This creates internal stress, as it is difficult for her to perform surface acting which is reinforced by the fact that she is aware that her ability to control her emotions can affect if professionals perceive her as knowledgeable. When she can be both determined and friendly, she stands a better chance of advocating for her support needs.

Contrary to Lill's own beliefs, some health care professionals attribute her stress to Maya's disability, according to narratives framing disability as a personal tragedy. Denied epistemic agency can be understood as a combination of epistemic and emotional injustice exposure. Even when different professionals say that they understand that her anger and frustration are rooted in an overwhelming life situation, it does not change the fact that she feels obliged to act according to gendered feeling rules, such as trusting professional judgement and being greatful for the support received. Since Lill knows that she is feeling something in opposition to what she is "allowed" to feel, she tries to regulate her expression by adapting her presentation of emotionally charged information so that the intended audience, i.e., professionals, will feel more comfortable with what she is saying. She cannot risk jeopardizing access to support and the quality of the support provided. In this situation, Lill perceives that the existence of "socially unacceptable emotions" in her testimony undermines the validity of all components of the testimony, including the reason or fact-based aspects, even when they are entirely relevant and appropriate to the context of the testimony.

Being dependent on others to get to work creates stress. Lill can recall many times when PAs have not arrived on time, and she has been unable to leave home until they arrive. She wishes it were not so obvious how she feels in such situations, as it only makes things worse both in the short term and in the long run. Making the PAs feel uncomfortable can make future interactions difficult, especially when there is no time to talk things over and things are left unsaid.

> When I am stressed out, I cannot display a poker face and express myself in a polite manner. How practical it would be if I could quickly switch to a more neutral state of mind, instead of being upset. The chronic stress of constantly being forced to be in a stand-by mode sometimes makes me react this strongly. It probably seems unreasonable to a person unaware of the "big picture." I do not want to feel like this. I want to relax, feel safe, secure, and content with my life. I wish I did not have to be around unfamiliar people, unknown bodies, and voices. It feels like our house has revolving doors, and sometimes I get the urge to hide in my bedroom, which I sometimes do. However, then I feel like I am being unfair, and ungrateful, because when PA works as it should, it is a relief for all of us. It allows us to live our separate lives according to our own choices – to do all the things most people take for granted; to work, study, be spontaneous, and meet friends. (Lill)

Even though Lill has empathetic colleagues at work, it is difficult to explain that gaining access to PA is not the same as having well-functioning assistance in everyday life. In periods of their life when there has been a high rate of staff turnover, it has had an immediate impact on her involvement in care work, which affected her being on time at her regular job. Hence, the broken time (Samuels, 2017) also becomes her time. Lill fears the consequences of departing from the normative life course, even though she is tired of being worn out and constantly worrying about Maya. Discussions with colleagues sometimes feel superficial. On the one hand, she wants to be authentic and able to talk about her family life, including living in a vulnerable situation. On the other hand, she is tired of focusing on challenges and hardships and explaining her situation to people unfamiliar with her circumstances. These mixed emotions make her feel obligated to obey feeling rules, such as having a positive attitude, being focused on not taking up too much space, and being considerate toward other people's emotions and well-being since she does not want to make anyone else feel uncomfortable or stand the risk of being perceived as an object of pity. Sometimes she becomes envious of colleagues with grown-up children, since this enables them to prioritize their own needs. Some days her major fear is to leave her professional job and identity, becoming isolated at home, or being reduced to being the primary caregiver. It becomes an impossible equation to balance her needs with different family members' needs, and still, that is what many parents with disabled children must cope with.

4.3 Managing our conflicting needs in the light of emotion work and linked lives

For the assistance user and other family members, access to PAs is a prerequisite for living independent lives. The absence of PAs creates a stressful situation for the entire family, and it can contribute to strained relations between different family members. The occurrence of linked lives can create a situation where we experience mutual lock-in effects that create feelings of guilt and frustration. Being forced into the roles of assistant and assistant user makes it difficult to appreciate each other's company. The relationship between PAs and assistance users is asymmetrical. It is a professional relationship where PAs and assistant users must maintain a professional yet friendly relationship. This role expectation can become complicated when the assistant is a close relative since the relationship is more complex, and there can be a higher expectancy of reciprocity.

> Periodically, I have had assistance where I felt like a person of my own age, free and independent. When it does not work, I feel locked in. I become stuck in a way that reduces my identity to being an assistant user. I only get one type of relationship: I become the person who receives support, and the other person gets reduced to someone who provides support. It feels like I've taken up too much space. (Maya)

For Maya, it creates an experience of being off time. Being dependent on support from her mother creates a situation that is more like what she experienced as a child. It becomes emotionally challenging to have those dual roles of being mother/daughter and PA/assistant user, which highlights our conflicting needs. It is accentuated by Lill having to cover up for external assistants when they are absent. It makes it difficult for Maya to plan her time and makes her feel guilty for Lill having to put other tasks aside, even when she does not have the time. It makes both of them miss many parts of what is perceived as ordinary, following a normative life course, such as dating, going to the pub, or haning out with friends.

> Being forced to be with each other around the clock dulls even the fun things. Then it is easy to forget that we enjoy each other's company. Sometimes it feels like the assistance company takes advantage of me and ignores our needs and wishes. It creates a lot of ambivalent feelings, especially when I feel like I should support Maya, but I really can't. Then I feel bad, but I'm afraid of what will happen the day that I am too exhausted. It's unfair because neither Maya nor I can choose how we want to live. There is such a big difference when the assistance works as it should, it is like night and day. (Lill)

As a parent, Lill often thinks this is the last time she will "work" as her daughter's PA. Lack of external PAs makes it difficult to set "healthy boundaries". Being able to choose each other's company rather than being forced to interact would strengthen the ability to create a more symmetrical relationship. When we cannot "choose each other", the levels of mutual frustration increase since we cannot leave each other and go home because we are already at home. We are still stuck in the same physical and emotional context.

5 Discussion and conclusion

In this article, the aim was to explore the emotion work around the navigation of emotional and epistemic injustice faced by disabled people and their family members, which is exemplified by utilizing our own experiences of living with PA in everyday life. Unequal distribution of social power is salient both in the process of applying for PA and the implementation of PA in everyday life. As Tremain (2017) pointed out, certain forms of unequal social power produce disciplinary norms about proper social behavior that shape public perceptions and authoritative epistemologies. A person's social position dictates how and to what extent they can express their emotions. If an individual fails to consider these social rules, they risk losing their credibility as an epistemic agent, which involves defining the reality of their own experiences. When assistance coordinators fail to acknowledge the lived experience of disability and have normative ideas of what the relationship between PAs and assistance users should entail, it leaves little room for developing an authentic relationship between the assistance user and individual PAs. Being dependent on maintaining a good relationship with PAs, social workers, or health care staff (see, for example, Hultman and Hultman, 2023) makes living with PA emotionally challenging.

Contrary to a nondisabled person the disabled person must navigate challenges related to crip time (Kafer, 2013). For example, there is a need for more time to accomplish tasks and duties that are usually easier and faster for non-disabled people. Lack of understanding the consequence of living in crip time, assistance users and their family members experience a need to perform emotion work both about external PAs and about the assistance coordinator. Previous experiences of non-disabled people's lack of understanding the consequences of living with crip time makes Maya inclined to justify her fluctuating assistance needs. To maintain a positive relationship and to protect herself from criticism and discomfort she tries to talk about it in a detached, unemotional way according to emotionally detached (normative understandings) of professional relationships.

The complexity of our everyday lives can make it difficult for professionals to consider the impact of linked lives (Elder, 1998) and the potential adverse outcomes. Due to the emotion work needed to assume different roles vis-á-vis each other, i.e., we are bound together by affection (as mother and daughter) and by necessity (as an assistance user and PA). Ambiguous roles can create conflicting needs and harm long-term health and wellbeing, as societal expectations and a shortage of external PAs pressure both assistance users and family members to assume the roles of PA and assistance user. Around the clock, different types of support are provided (attending assessment meetings regarding access to PA, health care meetings, collaborating with the assistance coordinator, working as a PA, providing emotional support), equal extended care. Care that goes beyond what one would expect as a mother due to professionals' expectations of mothers' moral commitment to take on a caring persona (Rogers, 2012). As a moral expectation, this requires linked lives (Elder, 1998), incompatible with the normative idea of independence and a need for separate lives.

Our sense of who we are and what we can achieve as epistemic agents is continually (re)shaped by how we feel (Davidson and Milligan, 2004). Having external PAs in one's home environment creates a sense of being unable to escape either emotionally or physically, which makes it important to develop authentic relations with external PAs and coordinators since the lack of authentic relations underscores the felt pressure of having to perform emotion work.

When emotion work fails because a tipping point has been reached, our positions as epistemic agents are questioned. It exemplifies emotional invalidation, the emotional counterpart to testimonial injustice. Being dismissed as "a knower" (Fricker, 2007) can create feelings of self-doubt, in which the assistance user values the opinions of non-disabled professionals more than lived experience. Not being validated and heard makes disabled people and allies (such as family members) more vulnerable to normative opinions about what is considered legitimate needs or an emotionally appropriate behavior. Epistemic injustice is often enacted in micro-meetings, such as relations between assistance users and PAs. However, these harmful actions often derive from epistemic practices which can be found on a structural level (Dunne, 2020).

The felt need to perform "balanced emotions" (surface acting) (Hochschild, 1979) could be seen as an attempt to convince the assistance coordinator and external PAs of the legitimacy of expressed needs and wishes. All three themes exemplify the presupposed binary between rationality and emotionality, where both Maya and Lill are exposed to an emotional double bind where they either must redirect energy to the regulation of intense emotions to have a better chance of being heard, and risk, emotional dissonance and depersonalization, or express their authentic emotions while speaking on a personal experience of oppression and risk being dismissed as overreacting.

This emotion-regulation double bind is reflected in Bailey's (2018) work on silencing spirals. As Bailey (2018) notes, these silencing spirals are a "closed hermeneutical system" in which the speaker suffers a double epistemic injustice—neither the testimony nor the authentic emotions are validated. This occurrence of both epistemic and emotional injustice builds with each layer of demands from people in "dominantly situated positions," such as assistance coordinators and external PAs. When assistance coordinators or external PAs require certain emotions to be removed from the experience of assistance users or family members, for it to be seen as credible, they fail to recognize the value of epistemically relevant information about a situation. Silencing people with lived experience creates a situation where people with insight into an injustice are those most likely to become emotional while talking about it, and therefore more likely to have their relevant first-hand knowledge dismissed (Whalley, 2022). With this silencing cycle, those systems of oppression and dismissal continue, and the instances of epistemic injustice remain intact. By defining and analyzing this emotion-specific form of epistemic injustice, we can begin to value emotions as a powerful resource for real social and political change.

Data availability statement

The datasets presented in this article are not readily available because the study is based on personal narratives that are already included in the manuscript.

Ethics statement

Ethical approval was not provided for this study on human participants because this study is a collaborative autoethnography which implies that the researchers analyze their own experiences. In relation to the subject matter we have followed ethical guidelines and been careful in anonymzing other people and places. Written informed consent was not required for this study in accordance with the national legislation and the institutional requirements.

Author contributions

LH: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Resources, Supervision, Validation, Visualization, Writing – original draft, Writing – review & editing. MH: Conceptualization, Formal analysis, Methodology, Validation, Visualization, Writing – original draft, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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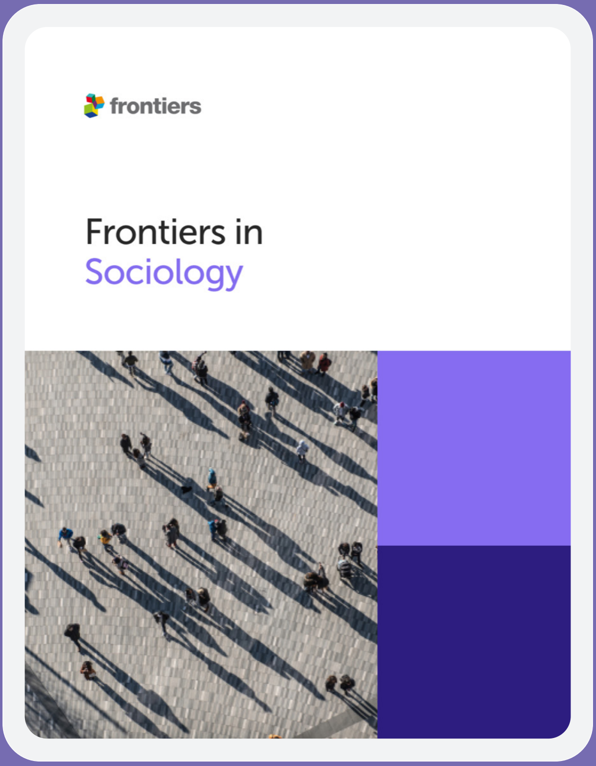

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