



Time to Care:

Disabled and queer lived realities of care and time as forms of non-normative resistance

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Abstract

This research explores how care emerges and transfigures within queer and disabled contexts that diverge from a myriad of hegemonic ideals and ideas of normalcy, productivity, and independence. I pose the research questions: How might queer and disabled networks and practices of care change the lived understanding of care in conditions of Western neoliberal capitalism? How can acts of care be acts of resistance? How does queer and disabled subjects' exclusion from hegemonic chrononormativity challenge prevailing capitalist notions of linear progression and acceleration of time? How can care be re-thought and transformed by living in queer and crip temporalities? Answers to these questions are traced through in-depth conversations with queer and disabled people. My interlocutors' experiences of care expose and are contingent on the utilization of care as a biopolitical technique of governance under conditions of Western neoliberal capitalism. Under these conditions, care needs and capacities of marginalized subjects are systemically and intimately disregarded and disavowed. This caring research inserts itself as a project that scrutinizes and enriches the current normative understanding of care by figuring it through and in its complex and reciprocal entanglements with multi-layered facets of disability and queerness. Non-normative care offers productive grounds for resistance against harmful chrononormative prescriptions of productivity and progress, hegemonic standards of normativity that debilitate marginalized subjects, as well as systemic and personal uncaringness. I analyze care in relation to theoretical discourses within critical disability studies (Freeman, 2007, 2010; Kafer, 2013, 2021; McRuer, 2006; Samuels, 2021) and queer studies (Keeling, 2019; Muñoz, 2009, Halberstam, 2005; Edelman, 2004) that criticize life and care under conditions of systemic and interpersonal violence and oppression, by grappling with concepts such as interdependence (Clare, 2017; Piepzna-Samarasinha, 2018), debility (Shildrick, 2015), kinship (Hill Collins, 1995; Weston, 1997), resilience (Bracke, 2016; Butler, 2016) and resistance (Ahmed, 2014). Throughout this research, dominant understandings of care, time and resistance become enriched, unsettled, and transformed through their conflation.

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‘What does it mean to shift our ideas of access and care [...] from an individual chore, an unfortunate cost of having an unfortunate body, to a collective responsibility that’s maybe even deeply joyful? What does it mean for our movements? Our communities [and] fam[ilies]? Ourselves and our own lived experience of disability and [queerness]? What does it mean to wrestle with these ideas of softness and strength, vulnerability, pride, asking for help, and not—all of which are so deeply raced and classed and gendered?’

~ *Leah Lakshmi Piepzna-Samarasinha, 2018, p. 28*

Introduction

I started writing these pages lying in bed, my body feeling heavy and dull, throat and eyes burning, while I was trying to make sense of the thoughts spinning in my head. For me, the past year was shaped by viruses and sickness, Covid-19 and chronic migraines. This time unfolded as a debilitating rollercoaster of ups and downs. Throughout, I try to allow myself to feel sick while blaming myself for not doing enough and getting sick in the first place, feeling burdensome when accepting the help of friends and family, struggling through the conflict of rest and perfectionism, mad at myself for working despite the sickness, and directing disdain at myself for never functioning well enough. And while I am thinking about why it feels so wrong to simply rest, to be supported and helped, to be lovingly cared for and care for myself, I realize that this struggle with and over care lies at the heart of my health issues and internal conflicts for the past months. These are questions that follow me in work and life for years, that re-emerge and intensify in broader political and social contexts, questions that I would like to find answers to in this thesis.

In the past decades and years, governed by political turmoils, ever-increasing social and economic inequalities, and the Covid-19 pandemic, it was laid bare that the current system of care established under conditions of neoliberal capitalism is not sustainable and viable for many. The neoliberalist cutbacks of governmental support of care in Western welfare politics and implemented austerity politics create a social and economic vacuity of care, a care crisis (Dowling, 2021) that is characterized by a growing gap between care needs and resources supplied to meet these needs (Fraser, 2016). This systemic and universal undervaluation and neglect of care in all its facets is describes as a “world [...] in which carelessness reigns” in the book *The care manifesto: The politics of interdependence*, a manifesto collectively written that follows and responds to the recent events of the COVID-19 pandemic (Chatzidakis, Hakim, Litter & Rottenberg, 2020, p. 1). The neoliberal capitalist system that prevails in European countries, such as my home country Germany and the Netherlands, my current country of residence, imposes the “near-ubiquitous positioning of profit-making as the organizing principle of life” (Chatzidakis et al., 2020, p. 2) and undermines all structures and principles of care that “do not serve its agenda of profit extraction for the few” (Chatzidakis et al., 2020, p. 7).

Conditions of neoliberal capitalism induce and perpetuate austerity, scarcity, exploitation and a general crisis of care, time and care are regarded as mere resources that are scarce and unequally distributed among individuals and populations. This system values normative notions of linear progress and creates a dominant timeframe that is not just fast, but faster than most of us can keep up with without harming our mental and physical health. It feels like time is constantly accelerating, and most of us live, work and relate in ways that try to keep up with this acceleration, yet always lagging behind capitalist ideals of “productivity, capacity, self-sufficiency, independence, [and] achievement” (Samuels and Freeman, 2021, p. 251). Time, thus, is a factor by which our understanding of care and capacity to care is structured. The concept of chrononormativity, coined by Elizabeth Freeman (2010) describes this steering and organization of time that is utilized to push individuals and society towards maximum capitalist productivity and progress. This chrononormative order twines around all individuals in society, yet it is conflated with intersecting vectors of oppression such as class, race, ability, and gender and sexual identity, and grasps marginalized subjects especially tightly. Queer studies (Keeling, 2019; Muñoz, 2009, Halberstam, 2005; Edelman, 2004) and critical disability studies scholars (Freeman, 2007, 2010, 2021; Kafer, 2013, 2021; McRuer, 2006, 2018; Samuels, 2021) have directed attention to the entanglement of ableism, queerphobia, and heteronormativity with chrononormative techniques and structures of oppression and normality. Drawing on these insights, this research aims to contribute to and expand existing debates by exploring the reciprocal influence of experiences of time and care on one another within queer and disabled contexts.

In connection to the chrononormative force that impinges people’s capacities and options to spend time caring and be cared for, the influence that time wields on care raises questions such as: Who has time to care? How do we care in time, and who is excluded from our dominant order of care and time? The necessity to care differently and to relate differently has been a concern for social justice movements for many decades. Yet, in existing literature the necessity to care differently in time, since chrononormativity functions at the expense of and in tandem with the oppression of marginalized groups that do not adhere to the normative pacing of time, has not yet been regarded extensively. Disability might cause people to take more time when getting dressed, it might demand more breaks during work or make working impossible altogether. It might blur the rigid relational boundaries of neo-liberal independence and autonomy within care relationships. Queerness might mean shifting one’s understanding of caring relationships and kinship, since queer identities open alternative understandings of these

concepts, and because queer relationalities are not recognized sufficiently within many political and societal contexts. Under conditions of neoliberal capitalism that structure all aspects of life around work, productivity, and normative configurations of rest, care, and relationality, existing as queer and disabled people implicates being banished situationally or holistically from this hegemonic state-recognized and social order.

Alternative, community-based,¹ and self-organized networks of care² have argued for a need to change our appraisal of care and time, as so far primarily regarded as separate and independent concepts, for many decades. Therefore, this research generates new insights into how queer and disabled people whose reality of time does not correspond with chrononormative hegemony might transfigure understandings and practices of care that are inevitably entangled with their experience of and existence in time. My analysis displays how subjects' realities of care and time impede and transform each other. In a society that structures life and relationalities around heteronormative, cis-gender reproduction and family formations, within legal as well as social recognitions of these care formations, queer subjects are systematically cast out of chrononormative configurations of everyday and overall relational life. Similarly, disabled subjects oftentimes do not adhere to the chrononormative provisions that dictate how one must operate within everyday chores and occupational timeframes as well as within care relationalities and practices. Both queerness and disability are forces which transform and restructure figurations of relationalities and care, wherefore their interlacing interplay and junctions in regard to subjects' experiences of care and time are explored. By adopting an ethnographic research approach, I am able to elaborate on the interrelation of care with individuals' experiences of time and oppression by conducting conversations with queer and disabled interlocutors who discuss their lived experiences of care dynamics, practices, and temporalities in relation to their marginalized identities.

Time in a vector of power that influences and determines the hegemonic subject formation of the “entrepreneurial individual whose only relationship to other people is competitive self-

¹ While I use the term community, I want to draw attention to questions concerning the meaning and use of the term raised by Emma Downing in *The Care Crisis* (2021): “Who constitutes the community? Who is part of any given community and who is not? What norms and values govern a community? What relations of power inform its logics? Is there one community, or are communities multiple and even overlapping?” (p. 87) that I remain attentive and critical towards throughout this research.

² Throughout this research, the term “care network” encapsulates the interaction of different care practices and care relationships.

enhancement” (Chatzidakis et al., 2020, p. 3), a neoliberal and capitalist logic that discriminates against anyone who cannot preserve these principles of independence, competition with self and others, and productivity. State recognized systems of support have proven to be insufficient, and often harmful and discriminatory, means of providing and receiving care (Clare, 2017). Similarly, the traditional nuclear family and heteronormative³ ideals of reproduction and relating, oftentimes produce violent and hierarchical dynamics of care (hooks, 2001, pp. 1-29). While some realities of queerness “have been increasingly incorporated into the mainstream – on the condition that they reproduce the traditional [normative] nuclear-family model” (Chatzidakis et al., p. 11), I want to refer to queerness as a political and anti-(hetero)normative (Ahmed, 2014, p. 149) position and bearing that might have to potential to pose “a threat to the social ordering of life itself” (Ahmed, 2014, p.145) that unsettles, questions and resists hegemonic standards of reproduction, kinship, relating, and care.

I attend to disability to critique the ways in which the dominant order of time perpetuates compulsory able-bodiedness and able-mindedness and impedes our individual and collective understandings of care (Mc Ruer, 2006). Capitalist chrononormativity hurls people with disabilities out of the ordering of time and asserts a notion of disability “as lacking, sad and undesirable: a shortcoming at best, a tragedy at worst” (Mingus, 2011) as well as “futures of pain and isolation brought on by disability” (Kafer, 2013, p. 1). Crip time, therefore, is a conceptualization and lived reality that offers a new notion of time, one that is “detached from chrononormative capitalist structures and predicated [...] on the myriad realities of body-minds along a spectrum of abilities” (Samuels and Freeman, 2021, p. 251). Just as chrononormative capitalist frameworks of everyday rhythms and life exclude certain body-minds⁴ (Clare, 2017, p. 173), so does heteronormative, patriarchal society structure the course of life along the lines of nuclear family formations and reproduction, which is described by José Esteban Muñoz as “the autonaturalizing temporality that we might call straight time” (2009, p. 17). In this straight time, care is deeply and intricately entangled with heteronormative ideas of kinship, reproduction, and binary gender stereotypes (Edelman, 2004; Halberstam, 2005; Muñoz,

³ The concept of heteronormativity describes “the institutions, structures of understanding, and practical orientations that make heterosexuality seem [...] privileged. [...] its privilege can take several (sometimes contradictory) forms: unmarked, as the basic idiom of the personal and the social; or marked as a natural state; or projected as an ideal or moral accomplishment” (Berlant und Warner, 1998, p. 548).

⁴ In Clare’s words, the term body-minds (coined by Eli Clare and Margaret Price) is used “to resist the white, Western impulse” to conceive of the body and mind as distinct systems. “They are one tangled, complicated, complex, ambiguous, contradictory entity.” (Fordham News, April 15, 2019)

2009). Queerness has the potential to refuse this chrononormativity, to invoke alternative here and nows, to queer possibilities of reimagining relationalities and communities falling outside of compulsory reproductive timeframes.

Since queerness and disability have this capacity to transform normative understandings and realizations of care, I want to frame [queer and disability] understandings and acts of caring as forms of political resistance against the chrononormative, ableist, heteronormative hegemony of neoliberal capitalist uncaringness. I want to explore what resistance means in the context of care and how these concepts transform and shape one another. Based on the reflections and topics outlined above, this thesis traces the overarching questions:

How might queer and disabled networks and practices of care change the lived understanding of care in conditions of Western neoliberal capitalism? How can acts of care be acts of resistance?

Drawing on these radical potentialities of crip and queer time in the context of care, I want to pose the sub-questions:

How does queer and disabled subjects' exclusion from hegemonic chrononormativity challenge prevailing capitalist notions of linear progression and acceleration of time? How can care be re-thought and transformed by living in queer and crip temporalities?

To gain in-depth insights regarding these questions and contribute to a rich and situated understanding concerning the lived realities and experiences of care and time by queer and disabled subjects, this research is guided by the narratives of my interlocutors who share their individual heterogeneous realities concerning the multi-layered topics that have been broached in the research questions. This research approach arises out of the conviction that individuals are experts regarding their own lived experiences as a location of knowledge that should be respected and valued earnestly. Informed by my interlocutors' collective and individual experiences and knowledges, this thesis examines how disability as well as queer notions and practices of care provide alternatives to state recognized capitalist structures of care that are deficient and oppressive. I want to argue for an ethics of *promiscuous care*, a new notion of care that "that would enable us to *multiply* the numbers of people we can care for, about and with, thus permitting us to *experiment* with the ways that we care" (Chatzidakis et al., 2020, p. 21). I argue that caring for each other and for oneself as a marginalized person in a world that disregards care is resisting this uncaring world. This research explores how, in their aberrant potential to veer and transcend normative forms of care that reproduce heteronormative and

able-bodied understandings of time, productivity and life in general, alternative queer and disabled forms of care that disrupt these norms and might be understood as forms of resistance. As might be recognized in queer and disability communities, a world in which caring for one another is undervalued and underestimated, we need to create more sustainable, more capacious, more caring notions and practices of care. Care needs to become an organizing principle, a multilateral and collectively shared disposition for actions in all facets of life and society.

In analysis Chapter 1, I discuss my interlocutors' experiences of care within their disabled and queer care relations and practices. Guided by their multi-layered realities of disability and queerness, I delve into how people nurture and struggle with dynamics of care in interpersonal relationships as well as within personal care practices. The chapter expounds how care exists in a complicated entanglement with ideas of ability, normalcy, productivity, and independence within the neoliberal capitalist system and how queerness and disability influence and are influenced by these ideas, both in tandem and distinctly. Within this analysis, I point to the fluctuating manners in which these concepts play out in reciprocal as well as alternating dynamics with one another. This exploration shows how queerness and disability stipulate a constant and ever-shifting negotiation of care needs and capacities that break away and are simultaneously inextinguishably linked to hegemonic ideals of a neoliberal society that is inherently violent towards people that stray from the normative.

Adding the analysis of a further facet of queer and disabled non-normativity in relation to care, Chapter 2 traces my interlocutors' experiences of crip and queer time that exists in a complex interplay with the manners in which they practice care for self and others by slipping out of and back into chrononormativity. After raising the overarching issue that care needs to be appraised differently and demands more time than is normatively and systemically allocated, I attend to the manners in which care in interpersonal relationalities as well as practices of self-care is bound to and concomitantly hindered by normative ideas of time. This chapter provides a delineation of queer and disability scholars' existing work on and critique of chrononormativity which is conflated with my conversation partners' narratives of living and caring within queer, crip, and normative temporalities. Through tracing these insights and connections, I am able to point to the interactive relationship that experiences of care and time exist in for people living within neoliberal chrononormativity, and how queerness and disability

sway and change these dynamics, which is further expanded on in the final analysis chapter in its connection to resistance.

Chapter 3 focusses on the paradox of conceptualizing and practicing care as resistance within and against a system that perseveres and thrives precisely through the statal neglect of its duty to provide and enable care for its citizens. I explore which forms of care and self-care that exist in connection with and in neoliberal capitalism might carry political potentialities for resistance. In valuing my own principles of conducting caring research, I further chose to elaborate on the issue of care within the medical-industrial system that was brought up by my interlocutors. Tying this overarching location to the relationship between care and time, I identify how diagnosis and treatment within the medical-industrial system for queer and disabled people are oftentimes accompanied by chrononormative violence and systemic neglect and uncaringness. Finally, the chapter identifies potentialities of resistance that might be traced within the collective and individual understandings and realizations of queer and disabled care.

Throughout this research project, I do not intend to make any homogeneous and strict distinctions between what queer and disabled care is and is not, what the right way to live care in time and live in time is and is not, what disabled and queer care as resistance is and is not. Nor do I want to offer a one-size-fits-all solution that might solve personal, interpersonal, and systemic issues that arise in relation of care and the absence thereof. Rather, this exploration points to the ways in which realities of care, time, queerness, disability, and resistance influence each other and should be read and understood through and against one another. This thesis aims to expound on the multi-faceted and shifting interplays and tensions that the topic of care and its diverse materializations hold, how these mesh under conditions of Western neoliberal capitalism and within multi-layered identities of queerness and disability.

Theoretical Framework

Tracing my Understandings of Disability and Queerness

Before attending to the intricacies of the theoretical framework, it is important to clarify the operational definition and my personal understanding of disability and queerness as it is adopted throughout the research project. To begin, I would like to stress that “meanings of illness and disability are not [...] fixed or monolithic; [and that] multiple understandings of disability exist” (Kafer, 2013, p. 4). The definition that I offer, thus, cannot and must not be read as a claim to a universal understanding of disability. I found the notion of disability as *assemblage*, drawing upon Jasbir Puar’s framework, helpful, as the concept describes where “[c]ategories—race, gender, sexuality (and, I would add, disability)—are considered as events, actions, and encounters between bodies, rather than as simply entities and attributes of subjects” (Puar, 2009, as cited in Kafer, 2013).

In my use of this understanding within my thesis, disability becomes assembled, comprising multifaceted and shifting dimensions. This assemblage emerges not solely by and within a singular disabled subject but further arises within interactions and entanglements of [disabled] individuals, situations, and environments. Instead of following a fixed notion of disability, my analysis traces disability as an identity and lived reality that can exist in constant as well as halting assemblages of experiences and embodiments. Further, I my understanding of disability follows Alison Kafer’s development of the political/relational model of disability (2016, p. 9). This model locates “the problem of disability” (Kafer, 2013, p. 6) in environments, political decision-making, and social patterns that exclude, stigmatize, and oppress certain body-minds, instead of locating this issue in individual body-minds (Kafer, 2013, p. 6). It conceptualizes “[...] disability as a site of questions rather than firm definitions: Can it encompass all kinds of impairments—cognitive, psychiatric, sensory, and physical? Do people with chronic illnesses fit under the rubric of disability? Is someone who had cancer years ago but is now in remission disabled? [...]” (Kafer, 2013, p. 10). These and various other questions allow for a more holistic and opaque grasping of disability, rather than fixed definitions and clear-cut answers. This aligns best with my personal conceptualization and lived realities of disability that will guide my analysis in staying attentive to and valuing my interlocutors’ individual and unique experiences and narratives of disability.

In the past years, the common use of the term *queerness* as well as *queering* as a fashionable buzzword emerged, a casual, de-politicised approach to queerness that I want to distance myself from. To clarify my use of the term queerness, I want to refer to draw on Kara Keeling's and Jose Esteban Muñoz's work who understand queerness to signify a meaningful concept and important practice for political and social self-determination and non-normative resistance. Queerness is a way of relating, loving, thinking, acting, feeling, existing that resists heteronormativity. It becomes more of a doing than a static being. Connecting queerness to the concept of care, according to the sociologist Sasha Roseneil (2004, pp. 410-411) heteronormativity⁵ solidifies the nuclear family as the center of care: care is morally materially supported by marriage and family laws (Berlant and Warner, 1998, pp. 558-562). Hence, this moral and social appraisal of heteronormativity as the hegemonic ideal bleeds into the ways in which care is and can be practiced within queer people's interpersonal relationships. Queerness is frequently and systemically cast out of and simultaneously subversively wrests itself free from these normative scripts. It escapes prescriptions of how relationships of care and kinship can and should be established, recognized, and how they should unfold.

In contrast to the hegemony of heteronormativity, this radical potential of queerness can be recognized in Keeling's writing, as "in [her] usage of the term, "queer" is not an ontological category—it is not what one is; rather, it is an epistemological category—one that involves life and death questions of apprehension and value production. "Queer" involves how one signifies or how groups of living beings are made to signify within a given set of significations" (Keeling, 2019, p. 17). Keeling's hopeful and affective notion of queerness can further be recognized in her statement: "'Queer' is palpable, felt as affect. It is also not only an imposition but simultaneously a becoming. [...]" (2019, p. 18). Queerness is an ever-emerging ever-shifting identity, propelled by raptures of hope and a refusal of stifling and violent hegemonic orders and norms. Instead of lingering with resignation in present crushing realities of hegemonically enforced normativity, Muñoz formulates the prospect of a queer reality that we can manifest in educated hope for "concrete utopias [...]. Put another way, we are not yet queer. We may never touch queerness, but we can feel it as the warm illumination of a horizon imbued

⁵ In this research, I follow Berlant and Warner's (1998) definition of heteronormativity which delineates "the institutions, structures of understanding, and practical orientations that make heterosexuality seem [...] privileged. [...] Its privilege can take several (sometimes contradictory) forms: unmarked, as the basic idiom of the personal and the social; or marked as a natural state; or projected as an ideal or moral accomplishment."

with potentiality” (2009, p. 1). Hence, queerness is conceptualized as the rejection of heteronormativity and the collective orientation towards and affective enactment of queer potentiality that is not yet here. In line with this, in my analysis I approach queerness not as a fixed identity category but rather as a multivarious location of affect, knowledge and action from which relationalities and personhoods unfold and are negotiated in fluid and shifting ways. This understanding of queerness further informs my analysis of the interactive connection of queerness and care that in turn opens new perspectives and intricacies in current political and feminist debates about care.

Another conceptualization that diverges from Muñoz’ regard of queerness as potentiality that is “not yet here” (2009, p. 1) is in turn offered by Kara Keeling, as she stipulates queerness in its objection to and concurrent entrenchment of the normative (2019). Keeling conceives queerness as eluding normativity, while through this, in turn, reinscribing normativity, which she phrases: “Queer fluidly anchors and defines the normative” (2019, p. 18). I recognize this conceptualization of queerness juxtaposed with Robert McRuer’s conceptualization of compulsory able-bodiedness which he stipulates in imbrication to Rich’s concept of compulsory heterosexuality (1980), stating:

The “reality” of heterosexual identities is performatively constituted through an imitation that sets itself up as the origin and the ground of all imitations. In other words, heterosexuality is always in the process of imitating and approximating its own phantasmatic idealization of itself—and failing. Precisely because it is bound to fail, and yet endeavors to succeed, the project of heterosexual identity is propelled into an endless repetition of itself. (Butler, 1991 as cited in McRuer, 2006)

This delineation positions queerness and disability as eluding, subverting, transcending the norm while simultaneously rooting heteronormativity and able-bodiedness precisely through their opposition to it. This understanding of queerness and disability as that which defines the normative, through its opposition to the normative, informs my exploration of the realities of all concepts that are lived and experienced by my interlocutors in non-normative manners. These realities of care, relationality, disability, queerness and time are rendered not simply opposite to the norm but, precisely through their opposition, in turn deeply entangled and interwoven with the norm, never entirely separable but in constant shifting interplay and contradiction, perpetually informing one another.

The Meaning of Care

As my thesis grapples with the multifaceted concept of care, I offer a brief exploration of my use of the term care in this research. To do so, I draw upon Joan Tronto's widely known analysis of care in her books *An Ethic of Care* (1998) and *Moral boundaries: A political argument for an ethic of care* (2020) that aim to enable "alternative view of care that integrates practical, moral, and political aspects about the place of care in society" (2020, p. 102). Tronto, referring to Berenice Fisher definition, describes care as:

On the most general level, we suggest that caring be viewed as a *species activity that includes everything that we do to maintain, continue, and repair our 'world' so that we can live in it as well as possible*. That world includes our bodies, our selves, and our environment, all of which we seek to interweave in a complex, life-sustaining web. (p.103, emphasis in original)

This proposed conceptualization necessitates an *ethics of care* which suggest that life relies on receiving and giving care within a complex network of relationships and interdependencies (Tronto, 1998). Similar to Tronto's ethics of care, María Puig de La Bellacasa argues:" In worlds made of heterogeneous interdependent forms and processes of life and matter, to care about something, or for somebody, is inevitably to create relation" (La Bellacasa 2012, p.198). I use Tronto's and La Bellacasa's exploration and their appraisal of care as relational and life-sustaining in my project to re-think our understanding of care. By this, I point to the importance of shifting care as a virtue and action into the center of our political and everyday actions, seeing ourselves and others as connected and relational instead of independent.

Care exists on personal and societal levels (Tronto, 2015, p. 3–4). On a personal level, care takes place in relationships with others and self. Power imbalances persist between care givers and care recipients, but also in the questions of whose needs are taken seriously and how these are being attended to. Within this issue, my thesis raises questions such as: Whose needs are recognized as such? Is care for these needs presented as a matter of self-evidence, naturalness or as a burden? While current debates regarding these issues of care are informative and productive, my analysis enriches the prevailing conversation as it attends to how care and the systemic and personal appraisal and realization thereof is interlaced with factors of presumed body-mind normalcy and identity. On a structural level, power is intertwined with the circumstances and spaces in which care takes place: access to and decision-making power over

care resources are shaped by societal values, politics, and laws. Under conditions of Western capitalism, the survival and well-being of individuals and populations relies on the provision of unpaid domestic labour and undervalued and poorly remunerated care work, often carried out by women and/or people in lower social positionings (Gago, 2021).

This system perpetuates the ongoing neoliberal dismantling of care structures and, thus, contributes to and relies on the financial and mental straits of exploited, overworked and underpaid people who provide care work in institutional and informal settings (Dowling, 2021; Gago, 2021). This shift of responsibility onto certain individuals and the insufficient political and societal value that is put on care contributes to a prevailing private and global care crisis that is deeply and insidiously gendered, classed, raced and embroiled in multi-faceted intersections and geopolitical distributions of oppression and privilege. Of course, not all care structures within the capitalist neoliberal condition are destroyed; instead, capitalism relies on precisely the unpaid and exploitative care structures that are referred to above. Expounding the problematics of dominant prevailing conditions of care, I am interested in alternative forms and structures of care that are performed in interpersonal and private care networks that might enact alternative realities of receiving and providing care, existing outside of and yet entangled with capitalist neoliberal impositions of uncaringness and normativity.

Western states and prevailing conditions of neoliberal capitalism are built on the division of public sites of productive labour and the nuclear family as the private site of reproductive labour (Federici, 2004; Gago, 2021). By developing a genealogy of European (white) reproductive labor, as an Italian and American scholar and activist from the radical autonomist feminist Marxist tradition, Silvia Federici traces women's exclusion from waged labor and their constraint to the domestic space in the 15th to 17th century. In her work, she adds to Marxist theory by critiquing the assumption that reproduction of labour force is being accomplished entirely through commodity production (Federici, 2004, p.63, p.91). Instead, Federici alludes to the essential role of women's reproductive work and the patriarchal mass activation and deactivation of women's labor for the means of the capitalist system, which determined the reproduction of labor-power and social position of women, justifying the oppression of terror and political and social patriarchal despotism against them. Simultaneously, Federici analyses the devaluation of women's labor, stating: "[...] in the new organization of work *every woman (other than those privatized by bourgeois men) became a communal good*, for once women's activities were defined as non-work, women's labor began to appear as a natural resource,

available to all, no less than the air we breathe or the water we drink” (2004, p.97). I find Federici’s historical tracing of the emergence of patriarchal domestic labor and the created naturalization of women’s reproductive and care work (p. 75) to be productive for my own exploration of the societal and political positioning and problematics of care. In line with this, my own analysis will contribute to long-standing and ongoing debate concerning the importance of spaces and understandings of care that allow for interdependence, collectivity, and community under conditions of Western neoliberal capitalism.

Kinship and Relating in Care

Building on the importance of community and collectivity, I explore alternative ways of caring that refuse or transcend the individualistic notion of care that centers around the normative nuclear family structure. Patricia Hill Collins (1995) and Saidya Hartman (2016) delineate how the formation of a nuclear caring family structure has historically been denied to enslaved people within conditions of Western colonialism. In her book *Black Women and Motherhood* (1995), Patricia Hill Collins develops an Afrocentric feminist analysis of Black motherhood and kinship. According to Collins, in Black history as well as present realities, children might be considered a form of private property who are vulnerable to be subjected to arbitrariness and violence by parents and biological kin. In contrast, and oftentimes out of necessity due to systemic oppression of Black people, lacking time and lacking resources, children can be mothered and cared for by larger care networks that are able to care better for these children than the nuclear family can. The people implicated in these networks might be considered as other-mothers (Hill Collins, 1995, p. 178), who “work on behalf of the Black community by expressing ethics of caring and personal accountability.” Collins offers the concept of *fictive kin* (1995, p. 179), coined by Stanlie James, which describes kinship relations that are not established through biological relatedness or state-recognized kinship arrangements such as marriage or adoption but that emerge and subsist through social arrangements and practices of care.

I see this desire and project to find alternative ways of caring within kinship and other relationalities mirrored and reconfigured within queer and disabled care networks that aim to care differently outside of normative and hegemonic practices and understandings. Therefore, the concept of fictive kin, emerging within the Black and Afrocentric conceptualizations of relationships and care (Hill Collins, 1995) is used and transposed in my analysis of queer and

disabled care networks within conditions of Western neoliberal capitalism. At this point, I find it important to address that race itself did not emerge as a key vector of identity and oppression within my mostly white and European interlocutors' experiences of care. As my thesis heavily draws on my interlocutors' realities, race does not emerge as a prominent aspect of analysis as it did not in most conversations. Yet, this does not mean to suggest that race as a reality of power and oppression is not deeply influenced by hegemonic kinship norms and in turn affects lived experiences of care.

While Patricia Hill Collins recognizes a potential for caring relationships and Black care networks in the practices and roles of other-mothers and fictive kin, the British sociologist Jeffrey Weeks alludes to similar potentials of balanced, caring relationships in queer friendships since they are self-chosen and charged with fewer or different expectations than heteronormative relationships (Weeks, 2001, pp. 45-47). Queer care networks are oftentimes described using vocabulary associated with family relations. For example, particularly close friends are referred to as family and, therefore, are distinguished from other friendships (Lewis, 2020, p. 36; Weeks et al., 2001, p. 38). These relations are often described as “families of choice” or “chosen families”, a term coined by American anthropologist Kath Weston (1997) in her research on queers in San Francisco during the AIDS crisis. In my understanding, whilst emerging out of different forms of interpersonal and systemic oppressions, Collin's Black conceptualization of fictive kin and queer chosen families describe the creation and nurturing of relationships and care networks that aim to compensate for the violence, neglect, and disregard of care perpetrated by the state as well as by birth families (Levin, Kattari, Piellusch & Watson, 2020). My analysis alludes to these realities of care and relationality that are usually overlooked and ignored within prevailing discussions of interpersonal care. This discussion will hence offer a productive angle to dominant debates concerning care that are predominantly attached to normative frameworks and conceptualizations of family, relation, and personhood.

In line with this problematic, the book *The care manifesto: The politics of interdependence* (Chatzidakis et al., 2020) offers an extensive analysis of the prevailing global, statal, economic, and societal neglect of care and pursues a longstanding critique of the philosophical idea of the independent, autocratic subject and the neoliberal system. From the perspective of white

academia within the British context⁶, the authors argue for the need to establish alternative care arrangements in personal and interpersonal assemblages, communities, as well as within states and global politics. Andreas Chatzidakis and colleagues propose an ethics of promiscuous care “that would enable us to *multiply* the numbers of people we can care for, about and with, thus permitting us to *experiment* with the ways that we care” (Chatzidakis et al., 2020, p. 21, emphasis in original). In my reading, acting according to ethics of promiscuous care opens new possibilities to feel and enact care towards others and self in diverse and shifting contexts and assemblages, which I consider to be a fruitful conceptualization in my own analysis of alternative care networks. The book poses care as a proposed and ideal guiding principle and practice concerning moral and political actions and sentiments within personal, interpersonal, societal, and global contexts, an argumentation that I will continue to expand on throughout this project.

The prevailing crisis of care reinforces and puts dominant understandings “of who produces value and what modes of life deserve to be assisted, cared, and paid for [...]” (Gago, 2021) into question. Drawing on the above-mentioned scholars, my research critiques this devaluation and disregard of care and concomitant hegemonic understandings and practices of care and kinship. In line with this, I think through and with these critiques in my analysis of alternative care experiences that are realized in queer and disabled contexts. While drawing upon pre-existing debates concerning the theorizing and actualizing of normative and non-normative forms of care, this thesis expands and enriches these discussions and contributes to the further understanding of alternative care networks that concurrently are cast out of, exist in entanglement with, and resist current oppressive and uncaring conditions of enforced normalcy and Western neoliberal capitalism.

Non-normative Care

In exploring alternative understandings of care, this thesis draws on queer and disabled realities and conceptualizations of care that resist hegemonic prescriptions of normalcy. The term compulsory heterosexuality (Rich, 1980) delineates that heterosexuality is not only naturalized as a way of performing intimate relationships and sexuality but also as a main organizing

⁶ While the critiques and analyses offered within *The care manifesto: The politics of interdependence* (Chatzidakis et al., 2020) span diverse global and statal aspects and issues of care, it is important to account for the influence of the authors’ white and Western positionality that inevitably influences the focus, scope and insights of their work.

political structure for society and life as a whole. The same applies to the ordering and control of life and society concerning along lines and rules of able-bodiedness. Compulsory heterosexuality as well as compulsory able-bodiedness (McRuer, 2006) rely on the conceptualization of queerness and disability as the abject. In my analysis I take issue with this abjection and consider queerness and disability to carry the potential to destabilize the prevailing order that establish heterosexuality and ableism as naturalized and hegemonic norms. I explore disability and queerness as sites of productive theoretical and actualized inquiry and resistance that create alternative care networks that are not tied to normative prescriptions of relationality, ability, and (re)productivity (Berlant & Warner, 1998, p. 548).

Following and extending the work of disabled and queer scholars and activists, my research criticizes normative notions of care, which present care as a burden of pitiful care-providers, thereby forcing care recipients into the role of grateful and submissive dependents. The queer disabled writer and activist Leah Lakshmi Piepzna-Samarasinha regards care as a collectively shared responsibility, advocating for the necessity of care recipients to be able to decide about the care they need for themselves (2020, pp. 17-20). Giving care can be stressful and straining as well as joyful and fulfilling. In disability studies discourses about care, the artificial binary of caregivers and care-receivers is softened and blurred, and the affective dimensions of care practices and relationships are scrutinized. Care, a practice and disposition that affects all of us, takes place on personal and structural levels and is shaped by power relations within intimate settings and structures such as the health care systems and the nuclear heteronormative family. Breaking and leaking out of normative structures, queerness and disability necessitate and open up non-normative spaces for self-chosen and self-designed care relationships and practices. My analysis expands on these alternative potentials and materializations that can be traced in disabled and queer care and facilitates the critique of hegemonic debates about and appraisals of care that are oftentimes harmful towards, that disavow and despise the care needs and realities of marginalized subjects.

Care as Neoliberal Technique of Governance

This thesis in all its components and intricacies, including my own positionality, my interlocutors' realities of care, queerness and disability, care realities more generally, as well as all aspects of the research process and research scope exist within conditions of Western neoliberal capitalism. Neoliberalism is the ideological conglomeration of capitalist ideals that

elevates the call to progress and the priority of the individual over the collective onto an all-encompassing moral principle (Eagleton-Pierce, 2016). That neoliberalism is a deeply pro-capitalist political and societal ideology can be recognized when attending to the definition of capitalism, which is “an economic system characterized by private or corporate ownership of capital goods, by investments that are determined by private decision, and by prices, production, and the distribution of goods that are determined mainly by competition in a free market” (Merriam Webster, 2022). This definition of the capitalist system as rooted in privacy, individuality, and competition alludes to the entanglement of neoliberal and capitalist ideals and politics, ideologies based and kept alive by its very exploitation of and uncaringness towards the people that work and exist within the system. Similarly, in Joan C. Tronto’s proposal of a democratic politics of care, she describes these capitalist neoliberal logics of individuality and care as the following: “In this wide-open market, care can only mean “care for yourself and for your family. If all of this sounds familiar, so will the myth of personal responsibility. Our market-foremost democracy frames care as an individual problem” (2015, p. 23).

Under conditions of Western neoliberal capitalism, austerity politics and the dismantling of welfare politics privilege those who are autonomous, able-bodied and able-minded and adhere to the hegemonic norm (Ryan, 2019). These politics and ideological convictions rests on the belief that every single person can and should choose and govern their own lives in order to manifest desires and achieve success irrespective and independent of others - if we just try hard enough, we can and will eventually reach our dreams. The ideal of neoliberal individualism and independence presumes that our quality of our lives depend solely upon how much each of us is willing and able to take responsibility for ourselves. Consequently, marginalized subjects that cannot function, and compete autonomously and sufficiently according to neoliberal standards and ideals become targets of the concomitant debilitating repercussions that these neoliberal ideologies carry, as the moral and political order presumes them to deserve its harsh and precarious policies (McRuer, 2018; Ryan, 2019).

Neoliberalism actively produces certain ways of being disabled and debilitated that are conducive to its continued operation (Livingston, 2005; Puar, 2017; Shildrick, 2015, 2019). Disability is a central site in contesting and bring into question prevailing austerity politics and biopolitical strategies employed to make body-minds as productive as possible of the commodities valued and promoted within the current system (Mitchell and Snyder, 2019). By

challenging perpetuated hegemonic notions of normativity and alternative forms of “being-in-the-world” (Snyder and Mitchell, 2015, p. 3), by embodying and enacting alternatives to neoliberal ideals of productivity, production, and reproduction (Federici, 2019) that Mitchell and Snyder coined “capacities of incapacity” (2015, pp. 182), queerness and disability function as generative sites for contesting austerity politics and neoliberal moral and political convictions that systemically discriminate against marginalized subjects. Nevertheless, those who cannot produce and reproduce accordingly are oftentimes cast out of statal and moral support systems and targets of biopolitical and bio-medical (Clarke, Shim, Mamo, Fosket and Fishman, 2003) technologies, sanctions and violence (Barry, Osborne and Rose, 2013; Rabinow and Rose, 2003; Rose, 2001).

In this thesis, I want to contribute to the discussion of biopower within prevailing conditions of Western neoliberal capitalism by investigating care as a biopolitical technique of governance, control and oppression. Because disabled and queer subjects oftentimes do not produce and reproduce values and commodities valued in neoliberalism, care and the withdrawal and neglect thereof concerning minoritarian populations, is employed as a mechanism of biopower that “[...] exerts a positive influence on life, that endeavours to administer, optimize, and multiply it, subjecting it to precise controls and comprehensive regulations” (Foucault, 1998, p. 137). I consider queerness and disability to be generative embodied realities that have the potential to contest conditions of Western neoliberal capitalism and the deployment of care and the denial thereof as a means to debilitate, curtail, and destruct marginalized people’s rights, dignity, independence and quality of life. Further, within this discussion, disability and queerness, as well as their specific warping, defiance of and exclusion from chrononormativity will function as analytics through which to critique the prevailing spatio-temporalities of austerity, late capitalism, and the cultural logic of neoliberalism. Hence, in this research I regard care within queer and disabled contexts as a productive site to critique overarching and hegemonic logics and ideas of normality, care, independence, and productivity within Western neoliberal capitalism.

Methodology

In my research, I draw upon La Bellacasa's (2012) approach of thinking-with others (writers, interview partners, etc.) as a proposal to interact, relate and think with others in a caring manner, which offers a subversive alternative to the dominant practices of academic research being isolated and individualistic. La Bellacasa, thinking with and through Donna Haraway's work, expounds that to think with care and in collaboration with others means "to value a style of connected thinking and writing that troubles the predictable academic isolation of consecrated authors by gathering and explicitly valorizing the collective webs one thinks with, rather than using the thinking of others as a mere 'background' *against which* to foreground one's own" (La Bellacasa, 2012, p. 202). Caring, in this reading, is not simply an action directed towards others, it is also a different way of thinking- a tentacular stretching (Haraway, 2016) and entangling of positions, ideas, and actors in the narrative of this research. The way we think, we know, our thoughts about knowledge, the way we relate thoughts, and we relate to thoughts is deeply rooted in our position in the world and predetermines the worlds we are able to think. This situatedness of thinking and knowing (Haraway, 1993) requires care, care for the worlds we think through and in, care for the people we think about and with, care for the relations and consequences our thinking and knowing might have (De La Bellacasa, 2013, p. 198).

In this attempt to not only research care but also to research with care, I draw upon the "etymological acquaintance of care with curiosity, to revalue the latter as the care one takes of what exists and what might exist" (La Bellacasa, 2013, p. 212). Hence, to create a *caring research* project, I anchor my methodological approach in the notion of "radical curiosity" (Tsing, 2015, as quoted by Haraway, 2016, p. 37), remaining open and attentive to new ideas and perspectives that may arise during the course of the research, letting myself be guided by the input of my discussion partners. Therefore, I talk with queer people and people with disabilities about their own realities and experiences of time and their entanglement with experiences and practices of care. Following this line of thinking, I believe that collecting material in the form of conversations gives me the opportunity to gather more knowledge about these topics without superimposing my own position onto the conversations. I decided to have open conversations with my interlocutors following the idea that "[k]nowing is not about prediction and control but about remaining 'attentive to the unknown knocking at our door' (Deleuze, 1989, p. 193)." (La Bellacasa, 2012, p. 212). In enabling conversations in which my

research partners have relative control over the course of the conversations and the experiences and topics they want to address, the research is shaped by these unknown factors, by the opportunity to share freely and openly. Accordingly, I stay attentive to these new pieces and segments, I hope to incorporate the *unknown* in this research in whichever way it may reveal itself.

In this approach, I draw upon Haraway's understanding of feminist objectivity as being enabled by the acknowledgement of the limited and biased situatedness of the researcher (Haraway, 1998) to reflect on my own positionality in this research as well as my interactions with the subjects and my interpretation and analysis of their statements. The conversations aim to provide new insights into practices and realities of care that resist dominant capitalist timeframes and hegemonic norms of relating and caring. So, while past and present realities neglect and disregard care, while we are in the midst of a myriad of bigger and smaller care crises (Dowling, 2021), while "my knowledge and my understanding do not show the possibility of any acceptable development out of the present catastrophe" (Keeling, 2019, p. 13), this research aims to look for ways out of these precarious realities of care, to practices care as resistance in this uncaring world. In the midst of this care crisis, a "catastrophe, a word whose etymology stems from the Greek Kata (for "moving") and Strophein, (for "beyond"), is exactly the point where we "move beyond" the present and a new landscape is revealed. I do not see that landscape because my knowledge and my understanding are limited, and the limits of my language are the limits of my world." [...] So I must act "as if." (Keeling, 2019, p. 13). In line with this, I use the conversations as grounds to think up new, alternative ways of caring. To care, about the concept and our understanding of care and practices of care, might invoke a shift of care into our political and social conscience in order to move beyond the gloomy present realities of care, to resist the uncaring world, and to do so informed by queer and disability practices of care.

At this point I would like to sketch out the limitations of my research project and the limitations imposed by my own social and cultural positionality since I regarding myself as part of power systems in which I help to reproduce dominant values, even if this reproduction transpires unintentionally and unknowingly (La Bellacasa, 2012, p. 197). I am writing from the perspective of a young, White, and queer person who was socialized in Germany as a woman in an upper middle-class family, with a stable health insurance and a strong social support

network. While I am a TAB⁷ person, I suffered from chronic migraines for several months in the year 2021 which necessitated what Sami Schalk (2013) calls “coming to claim crip” during this time. This specific experience allowed me to gain personal insight into the porousness of identity categories and conceptualizations of disability and queerness. Felt in my own embodied experience, I realized the difficulties and tensions that exist in attempting to fix the boundaries of the identity category of disability.

This positioning influences the selection of my conversation partners, the choice of my literature, my research question, and my own perspective on my research topic (Ackerly and True, 2019, pp. 6–20). I engage with a Western notion of care, disability and queerness, speaking to international conversation partners, most of which are white and European, and refer mostly to literature in which Western White scholars engage with Western conceptions of care. At the same time, important concepts such as community care or mutual aid, which challenge heteronormative assumptions and practices of care, come from Western and non-Western BIPOC (Black, Indigenous, People of Color) communities (Piepzna-Samarasinha, 2018). My research project must be understood in this area of tension.

⁷ I prefer to use the term TAB over simply understanding myself as able-bodied and -minded, as, how Kafer phrases it: “the term is pedagogical: learn from its use. Intended to shake folks loose from their assumptions that bodies don’t change, the use of *temporarily* reminds us all that the abilities we take for granted today may disappear tomorrow, perhaps temporarily, perhaps not” (Kafer, 2021, p. 418).

Methods

To deploy these aforementioned methodological principles in my research, I facilitated one-on-one semi-structured conversations with people who are themselves queer and disabled to talk about their experiences of queer and crip time, queer and disabled networks of care, and care as resistance. By posting a small ad (Appendix 1) in the Utrecht University Gender Studies Students' WhatsApp Group as well as in the private feminist Facebook Group " AskAnnabel2.0: Utrecht's Gender Studies Collective!" that briefly outlined my research objective and asked queer and disabled people that might be interested in being part of the study to contact me, I recruited conversation partners.⁸ I decided to reach out to this specific pool of people as most of them might be familiar with topics such as queerness, care, and disability to different extents due to their engagement with these concepts in prior academic courses and broader feminist contexts. This pre-existing knowledge facilitates profound and extensive discussions concerning the topic of care, in which all conversational partners are aware of certain overarching feminist, disability and queer concepts that in turn can be used to further and deepen the discussion effortlessly. At the same time, this prior knowledge can render a closer critical examination of concepts and debates, that are firmly established and often remain unquestioned, possible.

While I gave people interested in participating the choice to either have conversations in a focus-group setting or in one-on-one conversations, all chose the latter option. Putting the methodological principles of a *caring research* into practice, I let the conversation partners decide individually whether they would feel most comfortable talking about their experiences and knowledge regarding queer and disabled care and time in person or in a Zoom meeting. Conversation partners that wanted to meet in person could further decide whether they wanted to meet in a private room in University, a Café or in my living room. By allowing my conversation partners to decide on these details, I hope to make them feel more comfortable and more involved as a coequal partner in our interactions. My interlocutors had total control over the duration of the conversation, as they were allowed to expand on topics, choose not to talk about certain topics, and end the conversation at any point. The conversations spanned from one and a half to three and a half hours. In line with this, I frame my interactions with my research partners as conversations instead of research interviews, because this description

⁸ The complete ad can be found in Appendix 1.

aligns most with my appraisal of the research as an open-ended, multilayered sense-making process for both, researcher and conversation partners.

By choosing to facilitate one-on-one conversations, I aim to enable a research environment that allows for open non-hierarchical discussions and in-depth explorations that “can make explicit meanings and realities that were previously hidden, thus promoting a new and greater understanding of [the participants’] social position” (Hesse-Biber, 2013, p. 331). I am aware that no such things as an entirely non-hierarchical environment exists anywhere, I am ultimately still a researcher working with people who I will write about. I aim to make these elements of power clear and have my conversation partners be as informed and as possible and allow for their biggest possible autonomy of decision within the framework of this research. The discussion of queerness, disability, and care as well as one’s own experiences in these lived realities can be quite personal and intimate. Hence, the “hierarchy-critical” choice of conversation setting and process is intended to make my conversation partners feel more at ease and enable a first sense of agency and trust. By preparing broad questions regarding topics of queer and disabled experiences of care and time, the research topics were discussed whilst allowing the conversation partners to share aspects and experiences that they find important.

In the one-on-one interviews, my interlocutors had the possibility to decide on the specific setting and the progression and thematic focus of the conversation. In choosing this research approach, my hope is to create a conversation setting in which the research partners can share openly and can have a determining influence on the course of the research. Further, in my research approach I am guided by Gloria E. Anzaldúa’s notion of *autohistoria-teoría*, (2015) a process which Mariana Ortega describes as “telling one’s story is part of a multilayered exercise that includes many facets: narrating one’s story in order to make sense of it, processing with ink and paper what one feels through the skin, providing narratives so that others like us can hear our stories, and developing accounts that have the potential for critical engagement with and resistance to dominant norms.” (Ortega, 2016, p. 8). While I did not ask my interview partner to engage with their sentiments and shared experiences through writing during the interview, I encouraged them to reflect on the topic of care in their life preparatory to the conversation. Therefore, I chose to introduce the topic of care by exploring my conversation partners’ personal care networks.

As an entry point to the topic of care and to enable a participatory start to the conversation, I gave my interview partners an exercise based on the concept of the *personal community*, coined by Spencer and Pahl (2018). In their research, Spencer and Pahl asked their interlocutors about people who are currently important to them and thereby filtered out relationships that are significant to my conversation partners. I use this approach as an analytical tool to visualize *personal care networks*. Directing the focus of the relationships onto care, I asked my interview partners before our conversation to think about approximately ten people who they currently *care for* and to arrange them on the map in the different circles according to their importance (Fig. 1). Persons of higher importance were located closer to the middle circle, which represents the interview partner themselves. This network is constantly changing wherefore any conversation about it must be considered a snapshot (Spencer and Pahl, 2018, pp. 43-45).

Figure 1



In the circles, please put the names of approximately 10 people that you care for at the moment.
People more important, are located close(r) to you/ the center.

By choosing the phrasing of “to care for”, I wanted to allude to the affective, emotional as well as physical, practical aspects of care that might arise differently depending on one’s individual understanding of care. Different understandings of *caring for* might entail immediate emotional and practical acts of care or the general feeling of care towards a person that might be predicated upon affective reciprocity or obligation. Deciding on this phrasing, I hoped to trigger a rich discussion concerning the concrete dynamics, relationalities, and practices within these care networks in the conversations. Using this personal care community map as a starting point, we then discussed the particular care practices and understandings that come into being in these specific relationship and kinship dynamics. The personal care network exercise allowed for the

normative relationship categories such as family, partner, friends to be avoided. Specifically, the care network map made it possible to not just ask about certain hegemonic relationship dynamics, overlooking the fact that most of the care work takes place in other types of relationships. At the same time, the binary between family and other relationships was partly reproduced through this concept, because these terms were used by me and the interviewees within the care network to define and differentiate relationships. The care network further reproduced individualistic understandings and differentiations between self and other that need to be explored and brought into question during the conversations. These points of friction and criticism will further be elaborated on in analysis chapter three. Despite these problematics, I consider the mapping of care relations using the personal community exercise to be a useful and productive entry point to the conversations.

In this interview process, my questions and subsequent analysis of the material are guided by the methodological principles of disability studies scholars and use their conceptualizations of care and disability as “[...] lens[es] to analyse the intersecting systems” (Schalk and Kim, 2020, p. 37) of oppression. Hence, considering multiple identity categories in their intersections with disability and queerness strengthens the understanding of how these multiple identities, experiences, and systems of normative power and oppression intertwine, redefine, and mutually constitute one another, as formulated in Crenshaw’s foundational work on intersectionality (1995). To analyze how different lived realities of ability, sexuality, gender identity, race, and class materialize and shape experiences of care and time, my research is guided by the methodological assumption that how “our many different lives and different experiences can provide the starting point for asking new, critical questions” (Harding, 2013, p.55). My conversation partners’ lived and learned understandings of care and their socialization into different care practices emerge from various national, social, and political contexts. Hence, I aim to further explore these differences in my conversations and enable my interlocutors to address aspects that they find particularly important in their lived reality of care.

Three of my conversation partners were unknown to me before the interview, while one was a close friend and the other two were acquaintances that I had briefly met in the context of our studies at Utrecht University. Based on the research insights by Ackerly and True (2010), Wekker (2006, p. 4), and Seeck (2021, p. 40), I need to take into account that that my situational disposition and overall personality, my behavior and my positionality inevitably influence my

conversations, my research partners' responses, and my interpretation and analysis of these interactions. To allow for a better understanding of the conversations I had with my six research partners and their respective positionality, I now want to briefly introduce them in their current experiences of queerness and disability⁹. The first person I talked to was Jasmine (she/they), a 26-year-old person from Pakistan who identifies as queer and experiences depression and anxiety. My next conversation partner was Mika (any pronouns), a 31-year-old queer person from the Netherlands who was diagnosed with Chronic Migraines, ADHD, PMDD, and Generalized Anxiety Disorder. Next, I talked to N. (he/him), a 25-year-old queer Dutch person with Generalized Anxiety Disorder, currently in the process of receiving a diagnosis for Autism. My next conversation was with Aomame (she/her), a German 23-year-old queer person who has a visual impairment. Further, I had a conversation with Ash (she/they) a 26-year-old Dutch person who identifies as queer and experiences fibromyalgia, a chronic pain disorder, and was diagnosed with irritable bowel syndrome. My last interview partner was Cody (they/them), a 23-year-old trans-masculine Dutch person who identifies as queer and experiences anxiety and is currently in the process of being diagnosed for ADHD. All conversation partners currently live in the Netherlands and have been or are currently studying or working in the field of Gender Studies. Therefore, all conversation partners were familiar with topics such as disability, queerness, queer and crip time, and interdependence to different degrees through the academic context.

An interesting observation that arose during my interviews was the distinction that my conversation partners placed between queerness and disability in the ways they referred to themselves. While all people I talked to “identify” as queer, most of them referred to themselves as “experiencing” disabilities. In this distinction, I recognize a certain hesitance to fully accept and embrace the label of disability. Many conversation partners identified as queer for many years already, while most of them are currently in the process of navigating and accepting their disabilities, struggling for official diagnoses. The lingering stigma surrounding the claiming of disability seeps into these self-identifications, and the hesitance thereof. At the same time, for some conversation partners, the “experience of disability” might entail that this identity holds more changes and fluctuations than queerness does. Queerness might be a more self-claimed and self-determined identity for some conversation partners, while disability is

⁹ To preserve their anonymity and make them feel safer and more open to share their experiences in our conversations, all interlocutors were asked to choose a name for themselves that I would use instead of their real name throughout my writing.

perceived as a reality that they experience, meaning that ableist and discriminating experiences “happen to them” (Ash) in their daily life; situations and realities that might hold shifting problematics and dynamics. In juxtaposition to the conceptualization of queerness as shifting and fluid identity and reality, my conversation partners deemed queerness a more “stable” (Ash) and “settled” (Cody) positionality in their lives, more fixed and determined in comparison to their identity as disabled persons.

I want to further point to a few other aspects that need to be considered in the following exploration of the interviews and the appraisal of care within them. One of such is the influence of my conversation partners’ disabilities on their care needs and wishes. The ranking of the severities of disability disagrees with me and feels deeply wrong; I do not wish to disparage anyone’s experiences of disability and the influence that disability has on their care realities. Yet, while all people I talked to are disabled, these disabilities do not require intensive care in everyday activities, most conversation partners still pursue gainful employment or their studies, do not need care workers to assist them, can live in independent housing arrangements. These factors indicate that the represented care realities, while emerging from disabilities and potentially fluctuating, cannot and should not be generalized or projected onto people with more and less severe disabilities and their interlacing realities of care. Further, all conversation partners are between 23 and 31 years old. At this point in time, all of them do not yet want to have children. Yet, some can imagine wanting to have children in the future, others do not want to ever have children themselves, which influences their personal ideas of kinship in their present and future life. All of them are in (more or less) close contact with their own biological family, sometimes due to obligation and pressure, financial dependence, or out of love and affection. Analyzing the realities and experiences of relationships and care they shared in our conversations, I want to clarify that these narratives can only ever be considered as snapshots taken at a very specific time in their lives, narratives that can shift, turn, and change at any point.

While this brief outline of my interview partners is helpful for you, the reader, to get a general overview concerning the positionality of my conversation partners and their realities of queerness and disability, I want to point to the discomfort that this condensed and reductive introduction of my conversation partners carries. Every single person I had the pleasure of talking to allowed me a glimpse into their multilayered, dynamic, and various experiences and understandings of care which are intricately entangled with their lived realities of queerness

and disability but can never be reduced to it or explained solely by the factors that I choose to focus on in the inevitably reductive analytical leaps of this research. I am well aware that, in the limited space of this thesis, I cannot possibly do justice to their deeply vulnerable and complex realities they allowed me to catch a brief glimpse of. Yet, I hope that my interview partners feel seen and cared for in our conversations as well as in my ensuing analysis.

In the following chapters, I will explore the conversations I had with my research partners about their personal experience and understanding of queer and disabled care. Each chapter traces one of the questions posed as the guiding inquiries of this research. While these chapters are an attempt at analyzing my conversation partner's realities of care following certain converging and over-arching issues and themes, this research does not intend to be a totalising or universalising claim to a generalized understanding of queer and disabled care. Further, I do not mean to suggest that disabled and queer experiences can be homogenised for a meta-theory of care and kinship that is a perfect fit for all. Instead, I explore the subtle sentiments and nuance glistening through multiple and eclectic understandings of care, inviting the messiness of contradictory and dynamic lived experiences into my analysis, understanding that what is accessible and real to some is simultaneously inapplicable to others, regardless as well as precisely because of certain realities of queerness and disability.

Chapter 1: Queer and Disabled Practices and Relations of Care

As alluded to previously, the prevailing care crisis penetrates and impedes on all aspects of work, relations, and life. This crisis however does not exacerbate the issues of care for all individuals in the same manner, irrespective of their identities and corporeal, social, socioeconomic, and geopolitical situatedness. Instead, the crisis and cutbacks of care affect marginalized subjects, people who fall out of, who cannot or refuse to adhere to hegemonic norms of work, efficiency, progress, and relationality, in especially insidious and detrimental ways. Within this precarious context, I will pay particular attention to the alternative ways in which marginalized, specifically queer and disabled, subjects deal with this austerity of care and find alternative ways of caring. In line with this, in this chapter I explore the research question: How might queer and disabled networks and practices of care change the lived understanding of care in conditions of Western neoliberal capitalism? Guided by the conversations with my research collaborators, I attend to how disability and queerness inform their understanding of care relationships and care practices. Firstly, I investigate how my interlocutors' disabled conceptualizations and practices of care are implicated in conditions of Western neoliberal capitalism. I then delve into the influence of disability on my interlocutors' experience of care, not only asking how care is understood and practiced in relation to others but also to oneself. Further, I analyze my interlocutor's queer and disabled reflections on the concept of family and a chosen family and their attempts to establish and nurture alternative relationalities of care. Throughout this chapter and informed by the knowledge and experiences of my research partners, I explore the influence and internalization of neoliberal and capitalist ideas of independence and individualism, normativity and ability, within queer and disabled people's understanding of care and their refusal thereof.

Caring In and Against Neoliberal Capitalism

To understand how queer and disabled individuals might create alternative ways of understanding, providing, and receiving care within the prevailing care crisis, I offer an analysis of how their realities of care are implicated in and emerge within the prevailing conditions of Western neoliberal capitalism that govern our collective and individual experiences of care. Although many people, especially those systematically oppressed by this system postulating social, political, or economic struggles as personal responsibility and failures, disagree and resist these neoliberal ideologies, it is hard to unravel and unlearn these internalized notions of independence and individualized success and process. Within Western

neoliberal capitalism, both disability and queerness are deemed hinderances and even preventions in the supposed universal ideality of becoming the most independent, productive, reproductive, self-reliant, and normatively conforming version of yourself that can possibly be achieved. Caught within systemic and social conditions of austerity, oppression and erasure, queer and disabled people suffer within the neoliberal condition that relies on norms of ablebodiedness, ablemindedness and heteronormative kinship.

Disabled people, amongst other systemically oppressed groups, are heavily impacted by this individualist system of independence that utilizes care and the denial thereof as a form of biopolitical state violence and governance. As Johanna Hevda describes it in her essay *Sick Woman Theory* (2016):

Capitalism cannot be responsible for our [, disabled people's,] care – its logic of exploitation requires that some of us die. “Sickness” as we speak of it today is a capitalist construct, as is its perceived binary opposite, “wellness.” The “well” person is the person well enough to go to work. The “sick” person is the one who can’t. What is so destructive about conceiving of wellness as the default, as the standard mode of existence, is that it *invents illness as temporary*. When being sick is an abhorrence to the norm, *it allows us to conceive of care and support in the same way*. (p. 12, emphases in original)

In a capitalist logic, hence, only certain people are worthy of being cared for, this care and support can only ever be provided temporarily, and a person’s sickness or disabling experience must necessarily be temporary. A similar understanding of neoliberal capitalism is offered by Chatzidakis and colleagues (2020) as they critique its “near-ubiquitous positioning of profit-making as the organising principle of life” (p. 2) as well as the “serious[...] undermin[ing of] all forms of care and caring that do not serve its agenda of profit extraction for the few” (p. 7). This neoliberal capitalist disregard of care oftentimes nips the possibility of liberating forms of interdependence, collaboration, and community in the bud.

Many of my conversation partners reflected on how their disability and their process of identifying as disabled provoked their critical engagement with neoliberal ideas of individual progress and independent achievement. For instance, for Cody, grappling with and adapting their own behavior and practices of care to their disability has changed their manner of viewing their own accomplishments and actions, which concerns everyday activities and chores as well as overarching expectations of productivity and academic accomplishments. They describe this realization as follows:

The disabling stuff in my head that keeps me from doing things that I'm expected to do—it forces me to be okay with the fact that I am maybe not going to accomplish things that I am supposed to accomplish. All my life, I've been really trying to push myself to still accomplish those things. Because that's what I'm supposed to. Like, I'm supposed to do my own grocery. I'm supposed to finish my studies in a certain time. (Cody)

For some conversation partners, the alienation from neoliberal capitalist ideals can be seen in their decision to take a break from or take more time in their academic education, detaching themselves from temporal predetermined frames and targets of occupational achievement and progress. Others locate their anti-capitalist care practices in the ways they (un)structure their daily rhythms and tasks, consciously resting and allowing themselves times of reprieve, which might span over hours, days, or weeks. This can be traced in Mika's practices of self-care, which they described as:

I used to really obsess over all of the things that I should be doing that I wasn't doing and that I really wanted to be doing, but just couldn't make myself do. And now I've just sort of accepted that sometimes I just can't do stuff, and that's very liberating in a way. So I'm just going to be on my phone for six hours playing a game in which I flip turtles around or build a sand castle. I'm just going to let myself do stupid shit, so that I can exist.

The various ways that disabled body-minds function and work – and are unable to perform normative level and frequency of “valued” productivity that is necessary for capitalist expansion – might deem their lived reality of work and life anti-capitalist (Hevda, 2016). In my conversations, I recognize a disabled, anti-capitalist approach to care, a disability justice perspective on self-preservation that understands and honors that our productivity according to capitalist values and ideals does not define our value, that we need to pace ourselves and allow rest and reprieve into our embodied experiences, individually and collectively, so that we can sustain ourselves long term. In this manner of care, I further catch a glimpse at an important aspect of anti-capitalist, disabled ways of caring: to care for oneself entails the subversion of presumed standards of how care and rest must be individually and collectively timed and limited to fit with the capitalist chrononormative scheduling of the everyday and our lifetime in which productivity and progress hegemonically occupy center stage. This temporal aspect of care will be elaborated on further in analysis chapter two.

Disability has been an important, if not defining, factor in how my interlocutors understand and practice care. I want to clarify at this point that grappling with their disability and its influence on their own productivity, ability, and achievement is by no means an easy and linear process. Instead, many research partners have expressed how distancing themselves from neoliberal ideals while still being implicated in the very system that they are trying to critically detach themselves from is difficult, at times painful, and never smooth or consummated. Due to internalized standards of independence, my conversation partners often hesitate to ask for support and feel guilty or needy when asking for care. In some cases, for instance in my conversation with Cody, it became apparent that disabling realities such as anxiety further prevent people from receiving the care they would need, which Cody describes as the following: “The ways I ask for - and oftentimes do not ask for - care is influenced by neoliberal ideas of individuality and the sense of ‘everyone cares for themselves’. I’m so influenced still by that, even though I am in queer networks. And this feeling of needing to be independent then works together with my anxiety, and in the end, I feel like I cannot ask anyone for help or support”. While my conversation partners are aware of the oppressions and violence that are perpetuated by the neoliberal capitalist thinking about care, it still is a difficult process to detach their own realities of care from these forces and internalizations of this uncaring system.

The way that ableist notions ooze into the collective understanding of care can be recognized in Aomame’s reflection on the conflation of the meaning of capacity and ability in the context of care:

Sometimes it seems to me that we understand capacity as just another resource, because sometimes when we talk about the capacity to care, this capacity just becomes ability. Care then is something you exchange, to care becomes this capitalist capacity to trade affection or support or time. But I don’t want to think about care as a trade. And then I wonder how capacity is different from ability, because sometimes we use capacity in order to hide that we actually talk about the ability to care, just to make it sound less ableist. Maybe there's a different way of trading that is not ableist.

This grappling with and challenging of ableist neoliberal traces of understandings of care is an important step in allowing oneself to care differently for self and others, to exist differently in the current uncaring system. While ideals of independence and individuality oftentimes hinder disabled and TAB people to reach out for help or call in the care they might desire or need, and neoliberal ideals are entrenched in our own understandings of productivity and care, for most

of my conversation partners, their practices of care were nevertheless interwoven with understandings of interdependence and collectivity. My interlocutors' experiences of care throw notions of independence into doubt while they concomitantly demonstrate that we need to attend to how care practices are shaped and determined by their emergence within conditions of neoliberal capitalism. Stemming from these reflections, I argue that care in disabled contexts can both affirm neoliberal notions of individual capacity while carrying potentials to become a site for collective support and interdependence.

In their stories about the diverse ways in which they provide and receive care, respecting and valuing others' situational needs as well as embodied experiences and multifaceted identities, I see Mia Mingus concept of access intimacy (2018) transformed into reality. Access intimacy describes the disabled possibility to embrace body-mind vulnerabilities while having needs understood and met without demanding an explanation or justification. In Mia Mingus words: "access [and care] for the sake of access or inclusion is not necessarily liberatory, but access done in the service of love, justice, connection and community is liberatory and has the power to transform" (2018). Access intimacy hence allows disabled body-minds to create community and care in relationship and interdependence, embracing solidarity and different positionalities. Within my analysis, these disabled ways of caring for one another and nurturing access intimacy (Mingus, 2018), respecting the embodied experiences and needs of others can subvert the prevailing oppressive and exploitative system of care since "[t]he most anti-capitalist protest is to care for another and to care for yourself. [...] To take seriously each other's vulnerability and fragility and precarity, and to support it, honor it, empower it. To protect each other, to enact and practice community. A radical kinship, an interdependent sociality, a politics of care [...] perhaps then, finally, capitalism will screech to its much-needed, long-overdue, and motherfucking glorious halt" (Hedva, 2016, p. 13).

In line with Hedva, I figure 'access intimacy' and disabled realizations of care to be important aspects in enabling the growing of community and relationships *through* an acknowledgement of different and changing needs, capacities, and abilities instead of *despite* them, which in my understanding carries deeply liberating and subversive potentials and resists neoliberal ideals. I consider these forms of care to hold the power to transform and resist uncaring neoliberal capitalist ideologies that are profoundly harmful and isolating for all, and especially violent towards people who cannot fully adhere to these normative ideals. These forms of care acknowledge the challenges of our dependence and differences, they nurture skills and

resources necessary to promote the capabilities and needs of everyone, whether as care providers or care recipients, noting the frequent reciprocity of these positions.

For my conversation partners, care exists in a complicated and fluctuating entanglement in embracing disabled care out of necessity, simply because the ableist and capitalist notions of care do not account and allow for disabled lived realities, while at times experiencing the liberating and empowering facets of this imposed divergence from normative, able-bodied and -minded care. This contradictory grappling with care can be recognized in Cody's account, as they state: "Embracing more of this stuff in my head would also be embracing the fact that I may be not as productive as other people are ... or I'm productive in different ways. And I think most of all, it would really force me to care for myself instead of trying to bully myself into doing things." Their phrasing "[embracing disability] would really force me to care for myself" caused me to reflect on the contradictions and conflicts that arise in disabled care realities within capitalist neoliberal conditions. To care for oneself and insist on the importance of care might be experienced as just as straining and difficult than simply forcing oneself into the structures and objective that are prescribed by the hegemonic norm.

Existing within these norms and standards as a disabled person however might be equally or more draining than resisting them by caring for oneself. Within a system that condemns care and is fundamentally based on the disavowal of manners of care that exceed or differ from normative standards, the physical and mental exhaustion caused by a lack of care for oneself needs to be traded off against the exertions that care demands. This sub-chapter brings to the fore these multi-layered and conflicting realities of disabled care that often go unnoticed or are not allowed sufficient space within dominant discourses about care. My analysis illuminates and scrutinizes how, under conditions of Western neoliberal capitalism, the potential that disability carries to care differently and more fully for oneself and others, respecting and embracing individuals' embodied experience, goes hand in hand with frustrations and afflictions of existing in a system that poses these disabled care practices and needs as unproductive, deficient, and even morally reprehensible. Yet, this section also traces how, existing against these individualist ideals of independence and progress, my conversation partners are implicated in the disability-informed perpetual process of adjusting and expanding care so that it values the situational and embodied experience of their own and other people's body-minds, with all its joys and pain, ebbs and flows.

Disabled Care Practices

The necessity and benefit of adjusting and expanding care to respect and value peoples' individual needs, wishes, capacities became particularly apparent in my interlocutors' reflections on their own care practices, informed by their embodied realities of disability. Disabilities, no matter if physically or mentally disabling, neuro-divergent or chronically ill, influence how people living with them can practice care for themselves and others and affect the manners that disabled people want and can be cared for. Aomame, a person with a visual disability might require more physical care, while Cody and N. who experience anxiety, might wish for more emotional care and frequent caring interactions. Care for Ash and Mika who have chronic pain disorders, might include more rest and alone-time, while other conversation partners felt most cared for when spending time with others. In the stories that my conversation partners shared I felt the potential to change our understanding of care, what it means and can feel like to care for and be cared for, shimmer through these realities of disabled care relationships and care within them. My interlocutors' individual care needs and experiences illustrate that there is no not a singular perfect model of care, not one homogenous understanding of what care should look and feel like- disability and body-mind differences disrupt this unrealistic possibility.

Nevertheless, disabilities do not necessarily solely denote a sensed reality of lack or difficulties. Instead, they should be understood as allowing for more flexibility, more compassion, ways to enrich and expand care. In the following, I would like to use the concept of *crip emotional intelligence*, coined by Leah Lakshmi Piepzna-Samarasinha (2018, pp. 60-63) to inform my exploration of how disability opens alternative modes of understanding and practicing care. My conversation partners experienced that creating care practices that respect the varying and various ways disabilities can affect care might radically alter the dynamics of the people involved. Inviting disabled notions of care into these practices allow for more understanding and forgiveness, more space to want closeness and distance in specific situations or times, for support that feel right for all people involved in the care interactions. Ash describes these considerate understandings of care practices and needs as follows:

The care that I give my friends is through knowing who they are and knowing how they respond to things and knowing their issues, their problems, what they're dealing with and the care that I give them is unique to them. The way I interact with a person is unique to them because I keep in mind what's going on with them. And I feel like the same thing

is happening to me when other people provide me care that I enjoy or that I appreciate where people keep in mind who I am, how I identify, what I struggle with.

This understanding of care is deeply entangled with the practice of *crip emotional intelligence*, which means “[...] not assuming. Anything. It’s always asking: if you can touch, what you call your body or your sick, what you need, if you even want suggestions for your issue or if you just want listening. It’s understanding that each disabled person is the expert on their own body/mind. [*Crip emotional intelligence* ...] is offering what you can. Is asking if you can offer. Is saying when you can’t” (Piepzna-Samarasinha, 2018, p. 63). Care, here, is understood as attending to each person’s embodied experience, respecting limits and boundaries in receiving and providing care, while accepting and embracing the fluctuations and shifts in care relationships. Thinking and experiencing care through disability challenges the normative ideas of care that are tailored to a presumed subject that adheres to unalterable yet unachievable body-mind standards. Alternative manners of care open spaces for care to exist in shifting reciprocity with multi-layered assemblages of experience and identity, to inform and influence each other so that care serves most body-minds, not just a few. This analysis points to the importance of valuing differences in care needs and capacities instead of casting non-normative individuals into the undesirable counterpart image of the utopic ideal- an aspiration of the hegemonic many, fully achievable by nobody.

One way that disability allows for alternative ways of caring concerns the approach to “closeness and distance” (Aomame) in care relations. My conversation partners mentioned that people involved in their care relationships often show more understanding when plans are being changed, postponed or cancelled. Mika, for instance, mentioned that due to their disabilities and medication, they cannot meet friends frequently and often need to call of plans at short notice, sometimes because they suffer under the side-effects of a new medication or oftentimes because they simply do not have the energy. Mika described this in the following: “I cancel plans with people I am in care relations with all the time. Well, not all the time because I don't have that many plans. For example, I was supposed to meet a friend for drinks the other day, but I just started a new medication and it made me fall asleep all the time. So I have no problem telling people: It's not going to happen today, I need to sleep.” The relationships Mika has nurtured and sustained during their disability do not put pressure onto them to interact frequently. This sentiment was shared by the other conversation partners: current relationships in which they feel cared for and care for others adjust to people’s fluctuating conditions,

acknowledge and respect that some days are harder than others, allow for vulnerability and changes in the ways that relations and care are lived. In this understanding of care, I recognize crip emotional intelligence in the way that care is practiced while “not taking it personally when someone cancels and continuing to invite them to things. [It means] to not forget them” (Piepzna-Samarasinha, 2018, p. 61).

Yet, some conversation partners also experience close proximity and frequent availability as pivotal to their experience of care relationships. These people described that their disabilities, such as experiences of anxiety or ADHD, cause them to easily feel disconnected or forget about people. Alluding to the influence of their anxiety and ADHD on their care interactions, Cody mentions: “physical distance and frequency influence how I can be caring for and be cared for by people. Because of my anxiety, I don't like traveling. I need to live close to people and see them often to feel a lot of care in our relationship.” Due to their disabilities, in care relations that are infrequent or not established in their everyday life, some interlocutors cannot provide or receive care in a way that feels sufficient and right for them, which has caused these relationships to drift apart or to end entirely. At this point, I again want to point to how ways of caring varied vastly between conversation partners. Ash for example, due to their experiences of chronic pain and fatigue, often interacts with friends online, stating: “my whole system of care is based in a queer community that occurred online”. When they occasionally meet friends offline this requires clear communication and planning of the setting, transportation, activities, and location beforehand as well as a period of rest afterwards, which might sometimes take several days. Jasmine, on the other hand, felt most cared for by a friend that she has not seen in person for several years and interacts with very infrequently online, because a shared understandings of personal histories and experiences growing up within the Pakistani culture, being able to relate intimately to each other, makes Jasmine feel deeply seen, understood, and cared for in this relationship. This synopsis of my interview partners' needs and wants regarding the frequency and proximity in care relations delineates how different these experiences are within a group of people with disabilities, showing once again, how realities of care cannot be generalized and must not be framed as a single condensed claim to disabled care. Instead, every relationship and practice of care is unique and has to be seen in the specific and fluctuating dynamics and conditions in which it unfolds.

My interlocutors described a similar dealing with the shifts and flows of care that might exist in specific situations or over time. They shared a disabled understanding of care, dreaming to

understanding any care relationship as reciprocal and coequal, even if asymmetries in care activities exist, while not strictly weighing care actions against one another. In our conversation, Aomame described this feeling within care practices as: “I understand care so that when I care a lot for someone, they don’t necessarily need to give me the same amount of attention and care back at that time, or at any given time.” My conversation partners further alluded to the influence of certain stages of disability and their disabling realities on this flux in care relationship and practices. This variation in “closeness and distance” (Aomame) in care practices oftentimes changes; “sometimes people move closer or drift away when they are becoming disabled, need more support or more space, and of course people experience their disabilities differently at different points in time, those rhythms can be hourly, daily or even span over years” (Ash). In this reflection on the shifting nature of care dynamics, the disabled subject challenges the illusion of invariant and unalterable co-equal relationality that is aspired within neoliberal assumptions of linear progression and achievement that leaks into and permeates our collective and individual understandings of care relationships. Disabled practices of care oppose these rigid standards of relationality that are hegemonically presumed and embrace the fluctuations that are inevitable and simultaneously pivotal to establish an alternative understanding of care that values and respects all subjects involved.

This regard for the changes in needs and wants depending on a specific experience of disability reminds me of the concept of “crip doulas [who are] other disabled people who help bring you into disability community or into a different kind of disability than you may have experienced before” (Piepzna-Samarasinha, 2018, p. 132). All conversation partners practiced care for others adapting to these shifts, scooching closer to others when needed, holding each other tight, or loosening the grip at times, because care also means to allow for distance and “room to wiggle” (Ash). In my conversation partners’ understanding of care, I recognize a budding potential of ways to care for and with “people contributing as they can, not necessarily “equally” or “always” (Piepzna-Samarasinha, 2018, p. 55). Yet, all research partners also mentioned that this way of caring and understanding care can be nurtured more easily in their relationships with people with a disability, while their relations of care with TAB¹⁰ people

¹⁰ While my interlocutors did not use this term in our conversations, I decided to use the word TAB regardless in my analysis, as it is “[i]ntended to shake folks loose from their assumptions that bodies don’t change, the use of *temporarily* reminds us all that the abilities we take for granted today may disappear tomorrow, perhaps temporarily, perhaps not” (Kafer, 2021, p. 418).

oftentimes harbor frustrations and experiences of overt and covert ableism, pressure, and sadly a general lack of understanding for disabled care needs and realities.

In my analysis of the dynamics between TAB people and disabled people, care becomes a site where identities are being negotiated and boundaries are defined or unsettled. The very distinction between temporary able-bodiedness and disability contradicts the way I approach disability in this analysis, as an embodied and structural reality of assemblage and severing of individual and collective body-minds and spaces into distinct and fluctuating arrangements of ability and impairment. Within my own analysis of disability as assemblage, care interactions then themselves might be understood as interpersonal amalgamation in which disability is negotiated, consolidated as well as repudiated. Within these assemblages, my interlocutors pointed to the difficulties and distinct struggles they encountered in attempting to help people currently experiencing temporary able-bodiedness understand individual care needs and wishes that are oftentimes closely related to their experience of disability.

In our conversations, it became painfully clear that most of the disabled people I talked to had experienced or still experience interpersonal acts and sentiments of ableism in their care relations with TAB friends, romantic partners, and family members. Care relations between TAB people and disabled people frequently emerged as a location of friction, struggle, and disavowal. While most conversation partners experienced their current care relations as loving and genuine, many pointed to a certain discomfort and hierarchy in these care practices, in which the person with a disability who might require more care or help in certain situations is perceived as inferior to the person providing care. Aomame mentioned that these hierarchies often replicate the stereotypical dynamics that are present in parent-child relationships in which the parents hold more power and knowledge than the child, stating: “Some of my friends tell me that they feel like being my mom when they assist or guide me because of my visual disability. That makes me feel inferior and pitied sometimes. So, for them there is this hierarchy in our care relationships, even though for me being cared for isn’t a bad thing and wouldn’t have to mean that I am inferior”. In this statement is recognize Tronto’s appeal to caring differently by “[beginning] to think about caregivers and care-receivers in more complex relationships, [so that] we can easily break down any lingering assumptions that care is necessarily hierarchical” (Tronto, 2015, p. 35). While Aomame herself does not perceive dependence and needing to be helped as necessarily negative, she did criticize the condescending understanding that some of her friends adopt in their supportive practices. TAB people not being able or willing to reflect on their own understandings of relationality and care

here arises as a moment of assemblage in which ableism gets reproduced and the necessity to deconstruct these internalized ideals of independence and autonomy becomes apparent.

My conversation partners expressed their sadness and frustrations not only regarding systemic and interpersonal experiences of ableism. They further acknowledged the weight and pressure these care relations with TAB people put on them to perpetually educate them on these issues without being too assertive so that the relationship would not be compromised. Especially invisible and mental disabilities as well as disabilities whose severity and impairment might fluctuate situationally and periodically were reported to cause TAB people in my interlocutors' surroundings to display disbelief and a lack of understanding and empathy concerning the disabled person's care needs and experiences. Some conversation partners mentioned that these issues led them to distance themselves from many TAB friends and family members over time or end relationships entirely.

In their work on disabled care webs as networks of providing and receiving care, Piepznar-Samarasinha points to the complicated positionality and role of TAB people in care relations:

They need to understand that [...] the problems [disabled people are] facing aren't individual ones but systemic struggles that face all crips and need collective solutions. They need to ask themselves why they have systematically refused to value or take in what disabled folks around them have been and are saying. They need to listen and learn from the care work and skills disability communities have been doing for years—and maybe offer some compensation for that knowledge. Or at least say thank you. (2018, p. 45)

The interdependent relationships between disabled people and TAB people are often messy and fraught with power imbalances (Clare, 2017, p. 136). And while this is a frustrating reality, it can by no means be accepted. Despite the conflicting and difficult care relations and interactions that my conversation partners have with TAB people in their lives, they remained willing to nurture these relationships. Care relationships unfold more naturally and with less conflicts or disappointments with other people with disabilities. Yet, care relations of people with disabilities and TAB people are not impossible, they simply require more consideration and reflection by the TAB individual.

TAB people often struggle to understand or relate to lived disabled realities, wherefore vigilance and reflection by the TAB person are necessary to enable an alternative manner of

care that serves all people involved, irrespective and precisely because of different lived degrees of temporary able-bodiedness and disability. Mika explained their struggles within care relationships with TAB individuals as follows: “I’m not saying that relationships are impossible between people who have different experiences of being or not being disabled. But I think that it takes effort and it takes work and well... it takes care to be able to be vigilant about ableism and forms of discrimination. Of course, you don’t have to be perfect as a care partner of somebody with a disability. But you have to acknowledge that you you’re going to fuck up, that you are going to be ableist sometimes. And when you are - apologize to the disabled person, take them seriously in their experiences and needs, and then work against that ableism”.

And while TAB people can try to understand the experiences of disabled people and the ableist system they deeply entangled with better, they need to become “comfortable with the discomfort” (Mika) of messing up, being ignorant or reproducing ableism in these care relations- even without intending to. Clare points to these complicated dynamics as he states: “[...] Interdependence exists whether it’s laced with easy banter and mutuality or with struggle, hierarchy, and exploitation” (Clare, 2017, p. 136). Disabled care might then mean to work against these frictions and struggles within care relationships, to open space to change and learn personal and collective ideas of how care should be practiced and understood.¹¹ Returning to the concept of crip emotional intelligence (Piepzna-Samarasinha, 2018, p. 61), in my understanding, caring for each other in alternative ways that respect and value all people involved in these dynamics means dismantling normative hierarchies within care relations, deconstructing ableist ideas of interdependence and asymmetry in care practices being negative.

To reflect on the principles and practices that are enabled by crip emotional intelligence, to internalize these understandings of disabled care, to attend to the own implication seriously and intently in an ableist and oppressive system, to work towards care together while not forgetting about body-mind differences that are existing with and between all of us would benefit all care practices between diverse body-minds in diverse care relations. In my understanding there is no such thing as the perfect TAB care partner, firstly, because such thing

¹¹ I want to clarify that, while a TAB consideration of individual body-mind experiences and our collective implication in a deeply oppressive and ableist system is important, these reflections and discussions need to be furthered and taken seriously in all forms and dynamics of care relationships and practices.

as perfect does not exist and, secondly, because this way of thinking and idealizing feeds into the problematic projection of neoliberal, capitalist ideals of excellence and achievement within the context of care. My conversations brought to the fore that there is not one perfect-fit-for-all recipe for care. To care for and be cared for somebody carries many facets and layers of actions, interactions, and relations that interweave and independently influence the reality of care. Care practices and care relations are irrefutably connected and interlaced, build on and embody one another; relations conflate and condense practices, practices delineate and constitute relations. My analysis illustrates how care exists as a site of assemblage and negotiation in which different identities, diverse body-mind experiences and realities, care wishes, needs and capacities meet- how they at times dovetail and clash. The conversations brought to the fore the individual and collective need to rethink the meaning and enactment of care, acknowledging and valuing body-mind differences instead of forcing the care we give and receive into prefabricated molds of harmful ideas of clean-cut timing, stark hierarchies, and unachievable ideals independence and autonomy.

Reflecting on the conversations, I noticed how my interlocutors more often connected disability with more specific actions and practices of care, while queerness had a more significant influence not on the practices of care themselves, but on their general understanding of care relationships. This distinction does not mean to foreclose the connection and entanglement of care relations and practices, nor will I attempt to strictly divide these two aspects of care in the current analysis. Rather, I am attempting to guide the reader through this artificial disentangling and layering of care practices and relations that was mirrored in my conversations. De La Bellacasa argues:” In worlds made of heterogeneous interdependent forms and processes of life and matter, to care about something, or for somebody, is inevitably to create relation” (2012, p.198). These relations consist of interactions and practices, yet they also imply affective and relational dimensions that are less easily traceable or reducible to concrete actions. Care is at once situational and immediate while eluding these concretizations, permeating relations and realities elusively and manifoldly. In my analysis, I want to trace the materializations of care in practices and relations following the patterns that emerged in my conversations, disability being more easily connected to specific care practices while queerness influenced care relations more broadly. Therefore, after focussing the exploration of care on the influence of disability on care practices and vice versa, I now want to move into an analysis attending to queerness and its influence on care relations and vice versa.

Queer Care Relationships

In my research, it was fascinating to observe that for many of my conversation partners, queerness allowed for relationship dynamics and labels to unfold more freely. For instance, stepping away from heteronormative ideas of friendship and relationships, Cody mentioned that they are close friends with past lovers, a shift in relationship dynamics which many people adhering to heteronormative relational scripts could maybe not imagine. In the queering of care relations, I found it especially insightful to attend to the ways that my conversation partners understand kinship relations, who exists within their frames of family and kinship, and how this ultimately influences the realities of care within these interpersonal connections. Generally, my conversation partners shared the sentiment that their queerness opens up alternative non-normative ways of relating and caring, similarly to how living with disabilities allows for more fluid and varied ways of caring. Yet, it also became apparent that kinship is a relationship construct in which normative ideas of connection and care are particularly hard to shake, despite conscious queer disidentifications from such norms.

At this point, I would like to attend in more detail to one part of the conversation I had with Jasmine in which she talked about her understanding of queerness and queer romantic relationality growing up in Pakistan and now living a queer life in the Netherlands. In this short segment, the intersecting forces of different identity fragments on the reality and understanding of relations and care comes to the fore, unveiling how our cultural and social norms and upbringing imprint on us and pose to be hard if not impossible to ever fully leave behind. For Jasmine, her understanding of queerness hovers in a complicated dynamic with the pathologizing and rejection of queerness in her home country Pakistan. In the Pakistani context, a country in which queerness is pathologized, sanctioned and prohibited, not having the option to have a public relationship, queer people embody different forms of loving and being within their relationships.

She described these difficulties of being queer and living queer love in Pakistan as the following:

It meant seeing how you can make room for somebody in your life and in structures where you have to exist in the crevices of the loopholes. And it was exciting. It was painful. It was very confusing. Because it really did bring to light just how little room there was for any form of queer love. Because if you did not make a deliberate, conscious

effort to be together it was so easy to not be with somebody. It was so easy to not have a queer relationship.

Back in Pakistan she craved the mundane. She craved things that seem to be just given in queer relationships in the Netherlands, like moving in together or holding your queer lover's hand in the street. Mundane acts of care and affection became grand and meaningful. Now, living in the Netherlands and being romantically involved with Dutch people, Jasmine mentioned that Pakistani societal standards and confinements of queer love persist in her experience of current relationships even though she had hoped to be able to leave these internalized norms behind, which often leads her to feel disconnected or alienated from her lovers. She often feels that her partners don't realize how important small acts of care and affection are for her. This account illustrates how Jasmine's Pakistani societal upbringing and experience of queerness shape her present understanding of and feeling of care within queer romantic relationships. For Jasmine, experiences of care are determined by Pakistani prohibitions of queerness and her queer identity within these conditions, her experience of Pakistani culture is influenced by her queerness, whereas the manner in which she experiences and expresses her queerness is impeded by Pakistani culture and norms that are projected onto care relationships. Societal norms and provisions, queerness and care exist within a tension in which all aspects of this enmeshment complicate and impede one another in complex manners. On a similar note, Mika mentioned that internalized queerphobia kept them from reaching out to queer networks, in the fear that someone from their hometown might recognize them in these communities. These two examples draw attention to the intersecting powers of multi-faceted identities that each of us holds and internalized norms that all people carry within them, which wield individual and interlaced influences on how we understand and live relationalities and care.

In my analysis of the experiences my conversation partners shared regarding queerness in their relationships, it quickly became apparent that even though the queering of caring romantic relations and friendships was common, this bending and twisting of relations and norms transpired to be difficult in kinship relations. For all of my conversation partners, their parents and siblings were important constituents of their current care relations. Even though they are critical towards the notion of normative kinship as "heterosexual, state-recognized, tied to gender identity and certain cultural and biological dynamics" (Freeman, 2007, p. 295) and are trying to build alternative care relations outside of these norms, the normative idea of the biological family as an important unit with the role to provide care persisted in most of them.

Reflecting on family relations in their own life, Mika ponders: “I’m thinking to myself, well, what does family mean? What is the point of family? If I’m going to call my friends my family, what difference does that make? It’s just sort of a relationship that is mutually caring. And I have the same thing with some of my friends and with my mother and sister. I also have other family relationships that went sour. So, the family label doesn’t really mean much to me to be honest.” And while the notion family is oftentimes stretched and transformed in queer relations, for instance in queer understandings of “families of choice” (Weston, 1997), how come that kinship is so hard to queer? And how do queerness and disability interweave in people’s understandings of relation, kinship, and care?

Caring Kinship and Families of Choice

Care with biological and chosen family relations sway within complicated and shifting feelings of love, closeness, obligation, conditional acceptance, and unconditional affection. For some conversation partners, relations and interactions within their biological family are connected to feelings of unconditional care. Their family relations allow for a relational space in which they are held and feel comfortable to be vulnerable and take a break from “everyday performativity” (Mika). Care in family relations signifies practical availability in situations in which they need support; care relations with their parents often hover in the background of their everyday life, available when care, support, or guidance is needed. Several conversation partners also pointed out that their relations of care with family members who experience disabilities themselves are guided by their mutual understanding and practices of care. Therefore, these disabled ways of providing and receiving of care within the family follow ideals of “crip emotional intelligence” that might not be self-evident or come naturally to other TAB family members.

In these caring kinship relations, I recognize the practice of care as a pivotal part of the practice of kinship as renewal (Freeman, 2007), which can “be viewed as the process by which bodies and the potential for physical and emotional attachment are created, transformed, and sustained over time” (Freeman, 2007, p. 298). These caring kinship relations might further render space possible that embraces other ways of living and relating non-normatively. Hence, the mutual care and understanding that is enabled through experiences of disability might also open a possibility for my interlocutors’ queerness to be understood and accepted by family members more openly and caringly. Yet, disability might also pose an important factor in conjunction to the question: How come that kinship is so hard to queer? If, as previously established, care

relationships are structured tightly around heteronormative kinship and family norms, my queer disabled interlocutor's care needs might cause them to hesitate and struggle to distance themselves from these kinship structures.

While some conversation partners consciously distanced themselves from their biological family, also regarding aspects of care in everyday life, still every person I spoke to would, in situations of extreme distress or emergencies, reach out to their biological family, mainly to their mother. It also became clear that my conversation partners' family relations reproduced patriarchal and gendered distribution of care responsibilities in which the women in the family, especially mothers, took on most of the emotional and reproductive care work (Federici, 2020, Dowling, 2021). These experiences within their biological family reproduce the normative dynamics in which "[t]he traditional nuclear family still provides the prototype for care and for contemporary notions of kinship, all stemming from the mythic ramifications of the first 'maternal bond'" (Chatzidakis et al., 2020, p. 17). For two conversation partners, the parent-child dynamics unfolded less hierarchical or even reversed at times, so that the child had to provide most care for the mother. Yet, this interesting shift in care dynamics might largely be stemming from the father being absent, so that the mother cannot not receive care in the parents' relationship. Due to the death of her father, Jasmine's relationship with her mother shifted from this moment on. In order to process and live with this shift in mother-child dynamics, Jasmine needed to abandon "myths of what a mother should do, can do, what they look like, what I could expect from a mother." This painful realization and the ongoing process of navigating this relationship is characterized by love and disappointment, closeness and dislodgement, a liberating and painful bargain with the idea of care, home and family.

Jasmine as well as other conversation partners nurtured relationships in which they could feel understood, held, and care for outside of their kinship relations, a painful and conflict-ridden process in which many of them had to consciously detach themselves from the idea of the biological family as the sole most important care structure that exists. "In state-centered societies, kinship consists of the social policies that recognize some forms of lived relationality – those extending from the heterosexual couple and the parent–child unit – with financial and other benefits; these policies in turn demand certain responsibilities between recognized relatives" (Freeman, 2007, p. 295). In line with Freeman's understanding of kinship, while unconditional kinship relations might feel reassuring and caring for some, three conversation partners talked about their struggles with these predicated, unalterable kinship bonds and

practices, with the pressures and responsibilities that kinship carries. Jasmine shares: “For me, family implies an inescapability. It implies that you could not leave. It implies a trappedness, which I don't associate with the relationships that I have or that I'm trying to build separate from my biological family. I want relationships in which people feel that you are here because you want to be and having the option of leaving if it doesn't serve you anymore. For me, family implies very much so no option of leaving”.

The vastly different realities of care, and the lack thereof, within kinship relations brings to the fore how, while figured as natural, unshakable, normative care relationships, “[k]inship delineates the caretaking activities that have not been socialized as services for purchase or as state entitlements – or, more accurately, the kinds of nurture to which, despite their having been socialized so that they are available outside the household, people have unequal access. Kinship is private, unevenly distributed social security” (Freeman, 2007, p. 298). I read social security here as not only tied to the official recognition and support of certain relationalities by society and state within neoliberalism but also as intimately connected to the feelings care and security that one might experience within these relations - and the lack thereof. Kinship holds many potentials for care, understanding, and affection which exist in complex and imbricated dynamics with realities of obligation, pain, and carelessness. Especially for queer and disabled people, care within normative kinship structures is oftentimes entangled with painful experiences of ignorance, violence, and discrimination (Mika; Clare, 2015, 2017). Many of my interlocutors however decided to stay within these dynamics, which points to a lingering sense of inescapability regarding one’s kin that is mirrored in Jasmine’s narrative. I am wondering, despite the conflicting realities of caring and relating, how might the concept of kinship and family be refigured and transformed by queer and disabled people in the creation of their care relationships?

In her ethnographic study of lesbian and gay non-marital kinship relations, Kath Weston (1997) “posit[s] “families of choice” against a background of “biological family,” such that gay kinship is neither an imitation nor entirely independent of the latter” (Freeman, 2007, p. 304). This holds true for some of my conversation partners for whom understanding certain care relations with friends and lovers as queer chosen families offer a way to conceptualize these connections as more significant. For Aomame, her queer family fulfills needs that her biological family cannot meet, because she feels cared for and accepted in her queerness and can live this part of her identity freely and openly, which is sadly not possible within her

biological kinships. The term “chosen family” entails that she creates her own social networks and is able to nurture care relations outside of the family structures that are predicated. Cody expressed: “In my queer family, I don't really need to explain much to because they understand me, they see me and who I am, they are always there and care- as I do for each and every one of them.” In their statements I trace a potential of caring promiscuously within queer families, of creating relations “that would enable us to multiply the numbers of people we can care for, about and with, thus permitting us to experiment with the ways that we care” (Chatzidakis et al., 2020, p. 26).

This lived understanding of queer chosen family overlaps with its potential to “appropriate [...] and transform [...] the terminology of “straight” kinship, emphasizing the elements of freedom, creativity, and flexibility – and thereby shifting the discourse on “straight” kinship as well” (Chatzidakis et al., 2020, p. 26). For Cody and Aomame, having a chosen family and framing these people in their lives as such describes the sense of agency and deliberate and free choice of these relations. Sara Ahmed describes this reality of queer chosen families and the joy and possibilities these relations hold as “[t]he ‘non-fitting’ or discomfort opens up possibilities, an opening up which can be difficult and exciting.” (2014, p. 154) In this lived understanding of queer chosen families, in the act of claiming the label as well as claiming queer acts of care and relationality, I recognize the “suggestion that kinship is a kind of doing, one that does not reflect a prior structure, but which can only be understood as an enacted practice” (Butler, 2002, p. 34). Are establishing and nurturing queer caring relations and queer family then manners to practice care differently?

Yet, others are hesitant and critical of the concept of queer family. For Jasmine, friendships and non-familial relationships of care cannot be framed as a form of “family” because, for her, the concept of family carries a feeling of obligation and inescapability which she does not experience in her other care relationships. The concept of queer *chosen* family is further critiqued by Freeman in its presupposition of choice: ““chosen family” is a peculiarly queer-unfriendly model, however friendly it may be to bourgeois lesbians and gays” (2008, p. 304). In my reading, Jasmine and Freeman point to different aspects of the issue of *choice* that notions and realities of biological and queer families might entail. The notion of chosen family further presupposes the striving for individuality and independence entrenched in neoliberal ideals. To understand the family of choice as such, necessarily, even if unwittingly, reproduced neoliberal ideologies which this research is trying to refute. Further there are relations and

connections that (disabled and queer) people cannot freely reject or enter, such as with biological kin or in relation to state-controlled or institutionalized relations (Clare, 2007; Freeman, 2007). “‘Choice’ is an individualistic and, if you will, bourgeois notion that focuses on the subjective power of an ‘I’ to formulate relationships to people and things, untrammelled by worldly constraints” (Freeman, 2007, p. 304). So, while I acknowledge the affirmative potential that the interpretation of queer care relationalities as chosen family might carry, I want to draw attention to this tension and contradiction that this framing holds.

While in their intellectual engagement with the notion of family, my interlocutors esteemed the importance of people within lived experiences of care as independent of the relationship categories these people sit it, most conversation partners positioned their biological family and romantic partners as most important to their realities of care. In this dissonance, I faintly recognize Butler’s critique of kinship and queer attempts to alter kinship understandings and relations, stating: “The hypostatized heterosexuality, construed by some to be symbolic rather than social and so to operate as a structure that founds the field of kinship itself—and that informs social arrangements no matter how they appear, no matter what they do—has been the basis of the claim that kinship is always already heterosexual. [...] The social variability of kinship has little or no efficacy in rewriting the founding and pervasive symbolic law” (2002, p. 34). The creation of queer kinship and care relations in the absence of normative scripts can be liberating and exciting (Ahmed, 2014, p.154; Weston, 1997). Yet, my conversations made me wonder if nurturing relationships of care that do not necessarily, even if unintended, mirror and reproduce dynamics and understandings of heterosexual kinship are ever fully possible.

This first analysis chapter is guided by the overarching question: How might queer and disabled networks and practices of care change the lived understanding of care in conditions of Western neoliberal capitalism? The chapter reveals the complexities that the conceptualization and practices of care hold as they are understood in connection to and through identities of queerness and disability. Attending to the non-normative ways care is understood and practiced by queer and disabled people offers an alternative lens of the concept of care, which opens up a richer, multifarious analysis of care as it is concatenated and conflated with and understood through a myriad of layers of identities and experiences. My analysis sheds light on the potential that disability and queerness carry to care differently and more fully for oneself and others, respecting and embracing individual embodied experiences and celebrating differences. This non-normative potential goes hand in hand with frustrations and afflictions of existing in

a system that poses certain queer and disabled care practices, needs and relationalities as unproductive, deficient, and even morally reprehensible. Offering novel appraisals of care raised and reinforced by my interlocutors' narratives, this chapter enriches pre-existing literature and theoretical debates on care as it identifies care, and the withdrawal and lack thereof, as a technique of governance and biopolitical control within neoliberal capitalism.

In this chapter, I critique normative and simplified conceptualizations of care as it demonstrates how care can only ever be rudimentarily comprehended as resembling lived realities of care: it needs to read through facets and layers of identity, situatedness and multi-faceted characteristics and experiences of relationality, kinship, and various body-mind differences and forms of oppression. This analysis holds space for the ways queer and disabled people experiences care within conditions that render adequate and non-normative care onerous or impossible. Existing within and against individualist ideals of independence and progress, realities of heteronormativity, ableism, and other oppressions, my conversation partners are implicated in the disability-informed and queer perpetual and fluctuating process of adjusting and expanding care so that it values the situational and embodied experience of their own and other people's body-minds, with all its joys and pain, ebbs and flows. This exploration shows how queerness and disability stipulate a constant and ever-shifting negotiation of care needs and capacities that break away and are simultaneously inextinguishably linked to hegemonic ideals of a neoliberal society that is inherently violent towards people that stray from the normative. After offering an analysis of queer and disabled care practices and relations and their connection to and divergence from normative ideals and standards of care within conditions of Western neoliberal capitalism, in the second analysis chapter I will explore the figuration of time itself within these care realities.

Chapter 2: Caring in Time

In her book *Matters of Care. Speculative Ethics in More than Human Worlds* (2017) Maria Puig de La Bellacasa explores alternative temporalities of care, by focusing on “different modes of “making time” by concentrating on experiences that are obscured or marginalized as “unproductive” in the dominant futuristic drive” (p. 177). In this quote, I recognize not only a critique of prevailing hegemonic appraisals of care but also a critique of the passing and acceleration of time itself within conditions of Western neoliberal capitalism. Attending to the need to care in time differently, to make time for care in a framework that resists capitalist productivity ideologies, this chapter investigates how care is influenced by our realities of time and how crip and queer time might carry a radical potential to care differently. I trace the questions: How does queer and disabled subjects’ exclusion from hegemonic chrononormativity challenge prevailing capitalist notions of linear progression and acceleration of time? How can care be re-thought and transformed by living in queer and crip temporalities?

Falling out of Chrononormativity

“I live and care in crip time. But only because it was necessary. And I think crip time is a very interesting concept as well, but I think that it can also be very estranging, because it's not really how the world operates.” (N.)

In this statement, the force with which time imbues and controls our reality of care and life percolates through the contradictory sense of necessity and impossibility that become incongruously conjoined in N.’s experience of time. In line with this, the concepts of crip time (Samuels, 2017; Kafer, 2013) and queer time (Edelman 2004; Halberstam 2005; Muñoz 2009) describe how disabled people are not only pushed out of hegemonic notions of reproductive and body-mind normalcy but also out of normative frameworks and rhythms of time itself. As a way of resisting chrononormativity and conceptualizing their reality of time, crip time expresses the feeling of always being out of time, always being late, always being slow. Crip time is a concept and lived reality that is “paradoxically both liberating and confining, because it breaks open rigid socioeconomic structures of time and affords others, and because that breaking is not a choice but a necessity, an enforcement issued by the physical and mental structures of the crip body-mind” (Samuels and Freeman, 2021, p. 249).

Time is a vector of power that structures not only our every daily activity, encounters, and actions, but also encroaches on the overarching course of life. The impact that time has on us in all facets and scales of life is conceptualized by Freeman in her book *Time Binds* (2010), in which the author wittily emphasizes the critique of temporality and history as crucial to queer politics. Freeman describes the force of chrononormativity as “the use of time to organize individual human bodies toward maximum productivity. [Through chrononormativity] people are bound to one another, engrouped, made to feel coherently collective, through particular orchestrations of time” (Freeman, 2010, p. 3). Luciano (2007) localized this administration of time as a technique to regulate processes of life and bodies on individual and population levels in the concept of chronobiopolitics, which temporally aligns as well as alienates people in relation to collective experiences of life and time. It delineates the “[o]rchestration of time through which people come to feel part of a collective” (Kreisel, 2018, p. 237). Chrononormativity and chronobiopolitics, then, signify the manner in which time structures our very idea of life and existence along capitalist and neoliberal agendas of progress and productivity, a reality that controls each and every one of us individually as well as the entirety of societies and nation-states.

Chrononormativity and chronobiopolitics presume a linear progression of life from a dependent childhood to an independent adulthood that is structured around work, marriage, and reproduction. Similarly, everyday rhythms of activity and rest are bound to chrononormative rules. In my conversation with Ash, it became apparent how their experience of time drastically diverged from the imposed hegemonic chrononormativity: “I go from activity to activity instead of from day-to-day. I'm very bad at keeping track of the days because I don't structure them as a day, I structure them as periods of time where I can do things. And whether that happens at night or during the day, for example, if a party is at night, then that is one activity, but it also means that the two days surrounding that activity are empty.” Ash detaches themselves from the prescribed manners in which hours and days, days and nights, activity and inactivity are timed, how every day and everyday are normatively structured and lived. This statement contradicts and diverges from the normative ordering of time that serves capitalist interests of production and reproduction (Freeman, 2010). So, if life is understood as merely the accumulation of a “sequence of socioeconomically “productive” moments” (Freeman, 2010, p. 5), what does it mean to escape this temporality, even just temporarily? While every person is implicated in the power of chrononormativity, queerness and disability might offer a

reality of time that slips out and is wrested out of the normative organization of time, detached from hegemonic ideas of how days, weeks and lifetimes should be organized and clocked.

The intersections and overlaps of queer studies and disability studies raises a critique of the chrononormative order that excludes and discriminates against queer and disabled people in everyday contexts and in overarching appraisals of life. The normative pacing of time become difficult or impossible to follow for disabled people, as disabilities cause daily rhythms and activities such as getting dressed, working (Ash, Mika), going for groceries (Cody) to become warped- sometimes slowed down, sometimes sped up, and sometimes simply impossible to perform. Chrononormativity is marked by overarching measures of time throughout life that normatively orient themselves according to hegemonic milestones such as marriage, raising a family, caring for one's offspring and, later in life, being cared for by them in turn. In opposition to and perpetrated by the exclusion from these life-governing rhythms of chrononormativity, queer and disabled people "[...] will and do opt to live outside of reproductive and familial time as well as on the edges of logics of labor and production. By doing so, they also often live outside the logic of capital accumulation" (Kafer, 2016, p. 39). In crip and queer time, I trace a potential not only to enable disabled and queer modes of living in time, but also to create an alternative mode of caring for self and others outside of chrononormative and capitalist standards of productivity and relationality.

Care often takes place in private and intimate settings. Regarded as non-work (Federici, 2004) and affective relationality, care is normatively theorized and understood to exist as the counterpart of everyday and overarching rhythms of work and productivity. I take issue with this figuration of care as existing outside of the chrononormative order of "imaginative life schedules" (Halberstam, 2005, p. 1), and in line with critiques formulated within the discourse of social reproduction theory (Federici, 2019), raise the question: How could care be positioned outside of these rhythms if care practices and affective realities of care permeate these rhythms in a myriad of ways, while care is the premise that allows for these schedules to persist and be realized by people in the first place (Federici, 2019; Kafer, 2013, p. 38)? How exactly is care influenced by temporal rhythms and limitations? And how are these temporal experiences of care set within non-normative queer and disabled realities of time? Hence, in conversation with my research partners, I explore the various ways that care is understood and practiced differently by living in queer and crip time. How do lived realities of queer and crip time influence care? And, in turn, what is the role of care when living in queer and crip time?

Time To Care

In my conversation with N., he reflected on his struggles with anxiety that demanded him to step out of chrononormative demands of academic work and the liberating potential that this necessary decision, enforced by his disability, carries. He states:

I do think that the way I structure my days and experience care for myself and others is informed by my disability, because my anxiety makes rest important in my everyday life and in my relationship. For me, care in crip time means not putting pressure on each other in terms of having to do certain activities that are actually not caring but overwhelming for the other person or for myself, like going out. That's something that I used to do a lot before I identified as disabled. So, I live and care in crip time. But only because it was necessary. And I think crip time is a very interesting concept as well, but I think that it can also be very estranging, because it's not really how the world operates. I think I would like to live in crip time forever. I think it is a very different way of viewing and experiencing time. But I am looking for a way to maybe... half live in crip time and the other half live in regular time, which has to do with the reality that at some point I will have to find a job and re-enter that capitalist system.

The necessary shift in our individual and collective appraisal of care and the time we spend caring can be traced in Tronto's book *Who cares? How to reshape a democratic politics* (2015), in which she states: "A "caring-with" alternative would require everyone to work less or spend a certain amount of time every day caring. Of course, to really effect this change would require us to revolutionize how we think about our time, the place of work [and care] in our lives [...]" (p. 31). While caring differently for himself is a necessity, N. also experiences the anticipatory pressures that chrononormative capitalist standards of productivity and work carry, feeling that crip time can only ever be a temporary reality of reprieve before entering chrononormativity again. Yet, in my analysis of his statement, I notice that while he deems the return to a chrononormative schedule of work and productivity inevitable, the changes in care practices with other people feel be more established and realizable perpetually.

In N.'s statement, I recognize the difficulties as well as freeing potentials that living in crip time involves. By refusing to fit the Western, capitalist notions of productivity, pace, and progression, which can be acknowledged as a political form of resistance as well as a necessary way to conceptualize the lived temporal realities of people with disabilities, crip time does not

“bend disabled bodies and minds to meet the clock, [but instead] crip time bends the clock to meet disabled bodies and minds” (Kafer, 2013, p. 27). Living in crip and queer time means experiencing an ambivalent and conflicting reality of time. This experience is “paradoxically both liberating and confining, because it breaks open rigid socioeconomic structures of time and affords others, and because that breaking is not a choice but a necessity [...]” (Samuels and Freeman, 2021, p. 249). While refusing and defying chrononormativity is draining and exhausting, often arising out of precarity, hardship and necessity, crip time opens spaces to care differently, to adopt alternative understandings of the signification and manifestation of care in one’s life. Reinforced by my interlocutors’ reflections, I argue that crip time carries liberating and empowering possibilities that allow for individuals to structure care relations and practices according to their individual and unique body-mind care needs and capacities. This figuration of crip time facilitates a more flexible and understanding approach to care not only regarding oneself but also in interpersonal contexts, which will be expounded in the paragraph regarding temporalities of care relationships experienced by Mika.

The inescapability of a chrononormative work reality can further be recognized in my conversation with Mika. Mika explained that in their neurodivergent experience, “time is like an oval or an orbit. So, I have these really, really fast periods and then I have these very slow periods of time. So it's not like a constant linear progression. Time can feel faster or slower based on whatever part of the cycle you're in.” In their position as a PhD student, this orbital flow of time causes their work schedule to unfold in “waves”, some weeks not being able to do any work and then again doing weeks’ worth of work within a day. And while they work according to these flows, this reality of work time is only realizable and accepted by their employer because they never miss a deadline or reduce their workload. In this institutional acceptance of crip time, conditional on the completion of the prescribed amount of work within a predetermined time frame, I recognize the capitalist construction and co-optation/misappropriation of crip time as “a way of increasing productivity rather than refusing such values altogether; offering extra time on tests rather than doing away with timed tests; allowing us to work on our own time as long as the same amount of work gets done” (Kafer, 2021, p. 421).

Mika’s experience of time as progressing in bursts and ruptures influences not only their reality of work but also of care relationships. Regarding their experiences as crip time in care relations, Mika mentioned:

I've had friendships before where there's a lot of pressure to perform in a certain way and to always be checking in every day, but that just doesn't work for me. I'm more drawn to people who have the same kind of perception of time, because there's usually less of this pressure. So, I have had close friendships that have sort of gone astray because, um, I seem to not care enough or not reach out enough. But, in reality, time was just passing very quickly. And for me it was passing very slowly. I have a lot of object permanence issues, so when people are far away, it's not like I forget they exist, but it doesn't feel as urgent to like keep in contact, because time flows in a strange way. And I don't feel like it's been so long just because I haven't talked to them.

In this statement, it can be traced how care unfolds within disabled temporalities, influencing and in turn influenced by the way time is experienced by the people in a care relationship. A similar experience of crip time and chrononormativity can facilitate care. To care for each other within disabled contexts however might imply a reciprocal, if only temporary and alternating, adjustment to each other's experiences of crip time and chrononormativity. This way, care interactions can be facilitated that do not force one party to discard or discredit their experience of time entirely. Disabled care signifies attending to the ways in which time flows, ripples, and stagnates differently for different people.

Interestingly, Ash who is also neurodivergent and experiences a chronic pain disorder, mentioned that for them people disappear quickly from their mind. In contrast to how this reality of time manifests in Mika's care relations, this causes Ash to seek frequent contact with these people. Ash describes this in the following:

Frequently interacting with someone will bring them to the forefront of my attention. So, if I don't talk to someone for like a week, it's difficult to remember them., It's like they disappear from my mind. The people that I care for and feel cared for by are people that I talk to frequently.

So, while Mika and Ash have a similar experience of time and disability, their manners of creating and sustaining care relationships within these crip temporal realities is vastly different. This example brings to the fore how disability and crip time influence the proximity and frequency of care connections. In contrast to Mika's experience of crip time in care relations, Cody and N., both experiencing anxiety, mentioned that they need to be in close and frequent contact with people to feel cared for and supported. These different temporal care needs

addressed by my conversation partners allude to the heterogeneity that exists among disabled people in their experiences of crip time. Hence, while I am tracing overlaps of anti-chrononormative realities of care, I once again want to point to the complexity that these embodied temporalities hold.

The influence of chrononormativity on my conversation partners realities of care also became apparent in their experiences of queer care relations. Chrononormativity structures the course of life and manifestations of affection and care along the lines of heteronormative reproduction (Edelman, 2004; Halberstam, 2005; Muñoz, 2009). Muñoz counters this chrononormativity and alludes to a hopeful notion of queerness that evokes invigorating and subversive potentials by existing within, outside, and across time, never ever fully definable and detainable. However, in my conversation with Jasmine it became explicit how her experience of queerness is constrained and arrested within heteronormative chrononormativity, how straight time penetrates the ways queer affection and care can be, and are prohibited to be, expressed. Jasmine reflected on the influence of temporal norms, oozing with queerphobia and heteronormativity, on queer care relations in her home country Pakistan, voicing: “When you are queer and exploring queer romantic relationships of care, you must set different milestones for yourself because you can't get married to your partner. You can and will never be openly caring or loving towards one another.” To have a queer relationship in Pakistan, you must learn to live with this arrest of time in the progression of relationships, that there will be no official and recognized future in which you can care and love openly.

Muñoz alludes to the queer potentiality and hope that might lie in enforced queer alternative realities of relating and caring that might be nurtured precisely because queerness must exist in the crevices and loopholes of the norm. Yet, while Muñoz propels: “[w]e must strive, in the face of the here and now's totalizing rendering of reality, to think and feel a *then and there*” (Muñoz, 2009, p. 1, emphasis in original). What lingers after my conversation with Jasmine was the impossibility of this supposed queer hope to escape “the here and now's totalizing rendering of reality” (Muñoz, 2009, p. 1) that she experienced in her experience of queerness in Pakistan. In our conversation, I came to understand how difficult it is to practice queer relationalities and care in spaces that render the open and free expression of queerness and concomitant queer care relations impossible. For Jasmine, being violently cast out of chrononormativity and normative structures of life, in spaces in which the here and now is dangerous and crushing, a then and there becomes unthinkable.

I would like to further expand on a snippet of Muñoz' formulation of queer temporalities that I found especially difficult to understand in relation to temporalities of care, namely: "We have never been queer, yet queerness exists for us as an ideality that can be distilled from the past and used to imagine a future" (Muñoz, 2009, p. 1). How might this queer layering and entanglement of temporal planes be understood in relation to care? How can the past nurture and influence care presently?

I found traces of this temporal layering and spilling in queer care in my conversation with Jasmine. Talking about the care relationship she had with her ex-girlfriend, Jasmine explained:

Even though I have not received any form of care from her in a year now, she is someone who has not only seen me struggle with depression, but she also stuck around afterwards. And for me, even if we're not on good terms anymore, I feel like I can still sometimes exist off of that feeling of being held and heard in the past, that reserve of energy of care and love that I can still sometimes tap into.

Care reaches from the past and creates a feeling of warmth and fondness in the present. So, while it is oftentimes assumed that care is constituted of more or less urgent activities and practices directed towards immediate and current care needs, this queer understanding of care figures it as an affective relationality that spans different timeframes without necessarily being bound to certain active care practices or hetero/homonormative relationships structures.

While Jasmine's experience of queer care in Pakistan showcased the difficulties of queer potentialities in certain spaces, queerness can allow for relationships of care to unfold and shift more freely, allowing all people involved to invite new dynamics and relations of care into the relationship in other spaces. This liberating potential interlaces with the influence of disability on care relationships, which Ash alluded to by stating:

My queerness and my queer relations leaves a lot of space for other non-normative things to be introduced, including disabled experiences of rest and work, and non-normative experience of caring for one another, because the people that care for me and that I care for are already accustomed to the fact that not everything fits into neat little boxes. There is a lot of room to wiggle.

This room to wiggle, to experiment with the ways that people connect and care for each other, to respect and appreciate each other's embodied experiences and realities of care, to stretch and

flex the time one takes to care and be cared for, can be recognized both in disabled and queer understandings of care.

Cody mentioned a similar flexibility of care in their own experiences of being trans, saying:

Queerness for me and my girlfriend sets different time points in our relationship. Being trans, everything is slowed down to a sense. My gender identity and sexuality take time to develop over the years. So it can take a lot of time until I get to a point of feeling much more comfortable with myself in the world. So, the way we care for each other changes and shifts often and that feels good, because we care for each other by caring for and respecting our individual and shared trajectories of relations and identities.

Their queerness allows their relationship to unfold within fluid temporalities, it opens up different possibilities to explore identities and desires, ways to hold and know each other. While queerness influences the manner that care is practiced and understood, the ways that people take time to care and understand care in time, care is in turn a pivotal part of creating and nurturing queer relationalities.

Time for Self-Care

The ways in which disabled and queer people break out of chrono-normative timeframes can also be recognized in my conversation partners' statements regarding their experiences of self-care. In her conceptualization of *crip time*, Kafer states: "For those who live with chronic fatigue or pain, for example, the present moment must often be measured against the moment to come [...]. This idea of conserving energy, of anticipating, can be read as queer in that it bucks American ideals of productivity at all costs, of sacrificing one's body for work." (2013, p. 39) The importance of taking time to care for oneself was addressed in all conversations, yet I want to draw closer attention to the manner that Ash described their realities of self-care and its entanglement with non-normative figurations of time. Talking about the activities they would describe as a way of caring for themselves and the influence of their disabilities in these practices, Ash mentioned: "Going to events is taking care of myself, because I really enjoy spending time with other people and doing things like karaoke and going to parties. But at the same time, the intensity of the experience just makes it simultaneously very difficult for me. It's never casual for me. But doing these things is caring for myself. And then to rest and not do anything for two days after an event is also a form of self-care ironically." This excerpt of

our conversation illustrates how, for Ash, both rest and activity can become a source of self-care.

Yet, these practices do not happen according to normative able-bodied standards of casualness or timing. As quoted above, Ash's care practices do not follow strict daily rhythms; their experience of care is detached from notions of linear temporal progression or chronological order. They practice care for themselves within queer and crip temporal rhythms and leaps. In my interpretation, while Ash organizes care practices against chrononormative standards, it is not possible for them to escape these normative timeframes entirely, since their chronic fatigue demands rigorous planning of activities beforehand. So, while Ash's self-care practices elude "'hidden rhythms,' forms of temporal experience that seem natural to those whom they privilege" (Freeman, 2010, p. 3), Ash does make use of materializations of these rhythms that take the form of schedules, calendars, and wristwatches (Freeman, 2010, p. 3) since their care practices need to be aligned to their rhythms of rest and activity.

Not only the planning and timing of my conversation partners' care practices escapes chrononormative standards. In my reading, my conversation partners practiced care and self-care in non-normative anti-chrononormative manners by allow for "different modes of "making time" by concentrating on experiences that are obscured or marginalized as "unproductive" in the dominant futuristic drive" (de La Bellacasa 2017, p. 177). All research partners mentioned that caring practices with others always include periods of rest and reprieve, ways of being together while allowing each other space to recuperate from other activities, from strains that ableist and queerphobic experiences and barriers inflict on them constantly. Practicing care in these connections invites space to be yourself, be with yourself, while being with others. These caring interactions and self-care practices embody crip and queer time by stepping out of "a capitalist and heterosexist economy" (Freeman, 2010, p. 54). For instance, N. opened up regarding his experience of taking a break from his studies and work for a year in order to improve his mental health and receive support concerning his disability. While he shared that this break was simultaneously necessary and alleviating, he also expressed his intent to return to his studies once his mental health improved. Within the discussion of the neoliberal capitalist penetration and austerity of care, N. raised the topic of care as a form of resistance within this neoliberal capitalist condition by stating: "Care is a form of resistance. Because if you rest, you can't work." This possibility of care to resist the prevailing hegemonic system and its ideologies

of independence and productivity that go hand in hand with uncaringness and oppression will be explored in the final analysis chapter.

Within my interlocutors' experiences, I detect the tentative beginnings of living care in "time [that] can be described as the potential for a domain of nonwork dedicated to the production of new subject-positions and new figurations of personhood" (Freeman, 2010, p. 54). The people I spoke with described practices and understandings of care that move within my understanding of crip time as "flex time" (Kafer, 2013, p. 27). Caring is practiced towards self and others without demanding strict schedules of how extensive this care time might be. And while planning caring activities so that they are compatible with the involved people's needs and energy at that time is important, I recognize a "challenge to normative and normalizing expectations of pace and scheduling [in those care practices]. Rather than bend disabled bodies and minds to meet the clock, crip time bends the clock to meet disabled bodies and minds" (Kafer, 2013, p. 27). A caring interaction or activity can last a few minutes or days, but in this care time people are allowed to care and be cared for however feels best for them, and are not pressured to return to capitalist agendas and activities by their care relations. In this practice and understandings, I see that care in crip time "is flex time not just expanded but exploded; it requires reimagining our notions of what can and should happen in time or recognizing how expectations of "how long things take" are based on very particular minds and bodies" (Kafer, 2013, p. 27).

While some conversation partners offered crip and queer approaches to resisting chrononormative demands, the persistent influence of capitalist and ableist ideals and standards on non-normative understanding of self-care and care time came to the fore in my conversation with Aomame. In her reflection on crip time, Alice Kafer states: "I am trying to understand *crip time*—like *crip kin*, like *crip affiliation*, like all the other terms moving through my brain—as potential tools for thinking otherwise, as tools for mobilizing against ableism, white supremacy, patriarchy. But such moves will require us to insist on crip time's multiple temporalities, *slowness* already being rapidly devoured by capitalism, whiteness, and the neo-liberal university's attention to 'self-care'" (2010, p. 420). Capitalism and neoliberalism penetrate care by framing it as an inconvenient yet necessary step to maintain productivity and progress. In this conceptualization, care for self and others exists as an indispensable break within every day and overall life that should pursue the final goal to be able to return to work and hegemonic standards of productivity and activity as soon as possible.

This consumption of care by capitalist and ableist ideals can further be recognized in Aomame's statement:

To care for myself is often something that I feel obligated to. Care then simply is a way to become as able-bodied and productive as possible outside of that care time. So, self-care for me is connected to a lot of pressure. And I think that is because I internalized that ideal of productivity and a lot of ableism in my upbringing. Taking it slow, resting, taking a break, then, becomes nothing more than an interim stage from which one should emerge more productive, able-bodied, adherent to predicated norms than how one entered that care time. Our conversation made it painfully clear that, even within crip and queer temporalities, even while consciously refusing to adhere to able-bodied- and -minded and queer norms, capitalist standards of productivity and progress permeate care practices and self-care practices constantly and relentlessly.

This chapter presents a productive entanglement of existing literature and my interlocutors' narratives regarding chrononormativity, chronobiopolitics as well as crip and queer time. My analysis offers new insights into the reciprocal connection and influence of the realities of time and care that are exemplified through my conversation partners' experiences. These insights point to the complexity that this alternating and interactive relationship of time and care holds, how these two facets vary and shift and are in turn interwoven with various aspects of identity and situatedness under conditions of Western neoliberal capitalism. In this chapter, I argue that living in crip and queer time can carry a potential for alternative and non-normative care that is nurtured and sustained within and slipping outside the chrononormative system. The overarching issue of time within contexts of care is frequently addressed in debates concerning care within the hegemonic neoliberal capitalist system by feminist thinkers as well as critical disability and queer scholars and activists. My research expands and reifies this preexisting debate as it elucidates on concrete lived realities of time and care experienced by marginalized subjects. This expansion enriches the understanding of the ways care in interpersonal relationalities as well as practices of self-care bound to and concomitantly hindered by normative ideas of time. Through tracing these insights and connections, I was able to point to the interactive relationship that experiences of care and time exist in for people living within neoliberal chrononormativity, and how queerness and disability sway and change these dynamics, providing fertile grounds to care in time differently. While this chapter suggests subversive ways in which queer and disabled subjects transfigure realities of care in the context

of chrononormativity, in the following chapter I will inquire into ways my queer and disabled interlocutors transform and resist hegemonic normative ideas and realities of care in more detail.

Chapter 3: Care as Resistance

The first and second analysis chapters of this research point to ways in which queer and disabled subjects live care differently within realities of care practices, relationality, and time. Building on these insights, in this chapter I zoom in on the potential that this non-normativity might wield as a form of resistance against hegemonic ideas and realities of care. Hence, I explore the overarching question: How can acts of care be acts of resistance? In doing so, I will draw attention to the interplay of conflicting systemic and interpersonal dimensions in considering care as resistance, pointing to the importance of acknowledging capitalist and neoliberal appropriations and absorption of care and remaining critical of the violence that might manifest in care. I will allude to the conceptual difference between resistance and resilience, by tracing the question: What exactly is meant by resistance in the context of care? I will point to my conversation partners' experiences of care- and the lack thereof- within the medical-industrial system. Disabled people need to navigate an uncaring health care system that they are simultaneously relying on, in which their disabled body-minds exist in a complicated paradox of dependence and repulsion. Regarding this, how might resistance in the medical-industrial system be practiced? Lastly, by attending to my interlocutors' realities of queer and disabled community care and self-care, I will offer a glimpse of the resistant and subversive potentialities that disabled and queer care carry and address the need to rethink our understanding of how care as resistance might manifest. Rather than providing a clear-cut answer to the paradoxical relation of care and resistance, this chapter is asking how the conditions that my interlocutors move through change and inflect our understanding of the relationship between care and resistance.

No Opting Out of Care

Feminist acts to resist systemic oppressions and injustices can be recognized in various manifestations of revolt against these circumstances, in collectively and individually working against – or the refusal to work in- these realities. This resistance often takes form in public protests and strikes, in resistance against a part of discriminating systems (Gago, 2018; Spade, 2020). In some contexts, while always carrying risks, strikes and refusal are feasible and effective options for making injustices visible and fighting against them. Yet, in the context of care, this option becomes more difficult to realize, if not impracticable. Reflecting on this issue, Cody mentioned: “It's like the state is holding you hostage. For example, the healthcare system is so completely fucked that, if it were any other system, people would go and strike. But within

care work you cannot strike because if you refuse to care, people will die.” Within private care provisions as well as in the occupational field of care work, the neoliberal capitalist system sustains itself by allowing care to exist in a reality of underpayment, underappreciation, and undervaluation. The system is grounded in and flourishes precisely on the backs of people who need to counterbalance its uncaringness. Care cannot collectively be refused, neither by care providers nor care receivers. Care and care work are essential for people’s survival. Therefore, resistance in the context of care needs to be understood as alternative to dominant notions of political resistance; new conceptualizations of resistance need to be developed that make the potential of care as a form of political resistance visible and intelligible.

At this point, I want to point to Verónica Gago’s analysis of the contradiction that arises in labeling care work “essential work”. Gago states:

It is a complex twist that leads to the recognition of these tasks through their baptism as “essential.” To a large degree, it has been done by codifying them in a register of self-sacrifice, heroism, and gender mandates. Thus, this forecloses the feminist recognition of that work, which was achieved through these years of mobilization, debate, and organization [...] A strong paradox is condensed in essential work: it names a renaturalization of those tasks and the bodies dedicated to them, who now receive applause but not sufficient remuneration; valued but re-instated in a quasi-philanthropic imaginary (with church support). This produces a strange pirouette: they speak of labor, but by classifying it as essential, it seems to stop being labor. Its value is recognized, but it seems to be of a fundamentally symbolic and emergency value. (2018, p. 27)

So, while I decided to use the term *essential* to describe the irrefutable necessity of care, I do want to take issue with the phrasing of care work as “essential labor” and point to the aforementioned paradox. In this example, I see the vicious ability of the dominant system to absorb feminist caring resistance, which in this case manifests in the insistence to acknowledge care activities and work as important forms of labor, and turn it against the revolting group, reflected. Grappling with these paradoxes and contradictions, I came to wonder: How then can we resist an uncaring system when care is something we cannot simply opt out of? And what counts as resistance in the context of care?

Resisting Resilience and the Politics of Self-Care

In debates about political subversive actions, the concept of resilience has been established as a common buzzword in the context of feminist and political struggles since the “1980s or the beginning of the hegemony of neoliberalism” (Bracke, 2016). In the following segment of the analysis, I would like to briefly point to my understanding of care as resistance, aiming to distance myself from notions and aspirations of resilience oftentimes adopted within “neoliberal ‘leadership-feminism’” (McRobbie, 2020, p. 44) discourses. As pointed out in the previous analysis of neoliberal and capitalist influences on care, the current system presents ideal and desirable personhood in an “autonomous, entrepreneurial, and endlessly resilient, [...] self-sufficient figure whose active promotion helped to justify the dismantling of the welfare state and the unravelling of democratic institutions and civic engagement” (Chatzidakis et al., 2020). The ideal of individualized resilience, then, becomes a welcome justification for the dismantling of collective and state-funded care structures and governments’ disavowal of care responsibilities on the part of the state. Resemblant to the mechanism that reverts the feminist insistence of care practices as a form of “essential” labor into a disavowal of said care work, the concept of “resilience” is another example of a feminist critique of society being absorbed so as to renew or replenish the capitalist economy (McRobbie, 2020, p. 52).

The concept of resilience does not only operate to deflect care accountability of macro structures such as states and governments, but it also simultaneously permeates notions of individuality and personal care practices and dynamics. Sara Bracke describes this twisted proliferation of neoliberal uncaring ideals through the concept of resilience in the following: “Resilience, in short, is a powerful idea whose deployment spans the macro-level of ecological and economic systems to the micro level of selves, and the complex circuits of power that connect and constitute these different levels of social reality” (2016, p. 54). Resilience, then, is a concept that projects the obligation to care for oneself and presupposes a universal “capability of a strained body to recover its size and shape after deformation caused by compressive stress.” (Bracke, 2016, p. 54). In my understanding, resilience serves as a concept that forces all body-minds into a predetermined and simultaneously unachievable ideal of personhood and ability that forecloses the collective acknowledgment and embrace of individual and shared struggles, vulnerability (Butler, 2016), and the need for support and solidarity.

Within the context of resilience, a concept that is often addressed to point to individuals' need for rest and care in order to remain resilient and functioning is the concept of "self-care". Throughout the past decades in which neoliberal capitalist ideals of progress and independence flourished, ideas and projects of community care and social welfare have been discarded and replaced with "individualized notions of resilience, wellness and self-improvement, promoted through a ballooning 'selfcare' industry which relegates care to something we are supposed to buy for ourselves on a personal basis" (Chatzidakis et al., 2020, pp. 6). In her essay *Selfcare as Warfare* (2014), Sara Ahmed draws on the work of Black feminist writer and activist Audre Lorde in describing this neoliberal undermining of care:

Audre Lorde, who is with us today through the words she left for us, gave us a strong critique of neoliberalism, even if she did not use that term. Her work is full of insight into how structural inequalities are deflected by being made the responsibility of individuals (who in being given the capacity to overcome structures are assumed to fail when they do not overcome them). Her work explores how self-care can become a technique of governance: the duty to care for one's self often written as a duty to care for one's own happiness, flourishing, well-being. (p. 3)

In this segment, I recognize the principle of resilience that lingers in neoliberal understandings of self-care. These conceptualizations pose well-being and care as an individual responsibility within a system that supports and fosters the existence only of those who can adhere to individualized ideals of care and sustain themselves independently - those who prove to be resilient in the uncaring system. Within the context of mainstream feminism, self-care then becomes adopted as a vehicle to achieve "white woman's upward mobility" (Ahmed, 2016, p. 2), a means to promote and boost oneself while striving toward the neoliberal glass ceiling. While these adoptions of self-care play into capitalist and individualized ideals of care that I would like to distance myself from, later in this chapter, I still want to allude to the possibility of self-care as a practice of resistance within this capitalist framework.

The Violence of Care

Before exploring the resistant potential that queer and disabled care might hold, I want to point to the problematics and possible violence that is lurking in all contexts and manifestations of care, as well - and sometimes especially- within queer and disabled experiences. While queer and disabled contexts might allow people to nurture care relationships and practices eluding

and transcending normative scripts, queer and disabled care is not necessarily liberatory or resistant. Practices of care always bear the danger of violence and harm being caused willingly as well as unintentionally. Exploring the role of interdependence in disabled care relationships, Clare states:

The interdependent relationships between disabled people and the people who provide care for us are often messy and fraught with power imbalances rooted in racism, sexism, homophobia, transphobia, ableism, and capitalism. [...] And yet interdependence exists whether it's laced with easy banter and mutuality or with struggle, hierarchy, and exploitation. (2017, p. 136)

Care, oftentimes emerges within complex interpersonal and systemic hierarchies and positionalities and is streaked with possibilities for violence and harm to arise. Alluding to this issue, Mika opened up about their experience of being in a “toxic” romantic relationship with a TAB woman who often showed little understanding of Mika’s disabilities and weaponized her care actions toward Mika. Mika reflected the manner that queerness and disability play into care relations, as they pondered:

I mean, there are a lot of really shitty queer people. This is a reality that I also struggle with a lot when I talk about queerness as *resistance* or *queerness is the future*. I don't think that there's anything inherently liberatory or alternative or resistant about queerness itself. Yes, by definition, it's not *normal*, but there can be just as much oppression and violence within queerness as there is outside of it. Also, for disabled queer people, you're more vulnerable to manipulation, to violence, to oppression from the outside world, but also by other queer people.

Simply framing something as queer or disabled care doesn't free it from violence. Care dynamics within the various realities of queerness and disability can be laden with pressure, ableism, queerphobia, and abuse (Bonomi, Nichols, Kammes & Green, 2018; Chen, Dulani & Piepzna-Samarasinha, 2011; Mitra & Mouradian, 2014; Simplican, 2015; Smith, 2008).

To attend to more subtle and insidious manifestations of violence within the context of care, the relational formation of marriage serves as an illustration of such covert oppression and violence that care bears for marginalized subjects. While my interlocutors did not specifically address the topic of marriage in their reflections on their care relations, in the following segment, I choose to attend to the ideology and relationship construct of marriage as it is exemplary of how certain care relationships are framed as desirable and caring whilst they in

fact reproduce interpersonal and structural violence and oppression. Muñoz (2009) and Ahmed (2016) both point to the enmeshment of allegedly queer and feminist care practices and relations within normative oppressive dynamics and ideals, as is manifested in the kinship institution of marriage. In his book *Cruising Utopia: The Then and There of Queer Futurity* (2009), Muñoz critiques marriage as a relationship ideal that is positioned as an aspirational ideal within “assimilationist gay politics [that] posits an “all” that is in fact a few: queers with enough access to capital to imagine a life integrated within North American capitalist culture” (Muñoz, 2009, p. 20). In this argumentation, I read a call for the refusal of queerness to adhere to prescribed relationship norms, such as “the flawed and toxic ideological formation known as marriage” (Muñoz, 2009, p. 21). Yet, as Ahmed points out, marriage is a form of social and relational privilege that can operate as an “elaborate support system” within prevailing compulsory heterosexuality (Ahmed, 2016, p. 2). Within heteronormative contexts, social and legal security and care can be established and corroborated within the formation of marriage more easily, since it plays into the hegemony of “[...] how some relationships are nurtured and valued, becoming a means of organising not just one’s own time, but a way of sharing time and significance [...]” (Ahmed, 2016, p. 2).

I argue that marriage and other normative, state-supported forms of kinship and relating oftentimes carry dangerous potentials for harm and violence, within them as well as by means of exclusion. State-recognized queer and disabled romantic and “fictive kinship” (Collins, 1995) relations would enable care and support within these relationships to unfold and be nurtured with fewer legal and social obstacles and need for justification. But while people with disabilities in most cases are not prohibited to marry, marriage often is an excuse for the state to withdraw government subsidies that might be existential for the medical and social well-being of disabled people, causing serious and life-threatening financial and medical disadvantages (Jones, 2017). In this abuse of state-recognized relationship formations to discriminate and oppress people with disabilities, factors of ableism, classism, racism, and queerphobia often entwine and coincide. As mentioned by Muñoz in relation to queerness and the ideological formation of marriage (2009, pp. 20-21), some queer and disabled people cannot enter certain relationship recognitions as these are not permitted and even penalized, as can be understood in the example that Jasmine offered concerning queer relationships in Pakistan.

Simultaneously, for some disabled people, the financial and medical disadvantages that formal relationship recognitions contain hinder them from entering these legally protected and authorized formations. Within heteronormative TAB contexts, marriage is often considered the ideality of how kinship and care relationships can take shape. By the example of marriage, an established normative relationship structure that enables care to be recognized and nurtured within its boundaries, it becomes apparent that all manifestations of care carry possible exclusions, harm, and hurt within them. Experiences of queerphobic and ableist violence within their care relationships were shared by all conversation partners. Our conversation also brought to the fore that violence and harm within care relationships and interactions are caused by individuals in vastly different care dynamics to my interlocutors, ranging from doctors (Ash, Cody, Mika) to friends (Aomame, N.), romantic partners (Mika, Jasmine), relatives (Mika, Jasmine) and parents (Cody, Jasmine). Care within any form of relationship is never exempt from possible violence, regardless of the political and social positioning, gender identity, sexuality, or degree of disability of the people involved in the care dynamics (hooks, 2001; Chen, Dulani & Piepzna-Samarasinha, 2011). Bringing these heavy aspects of care to light, fraught with problems and pain, offers an important change in and critique of the general appraisal of care: Care does not exist as a utopian and paradisiacal practice and disposition that invariably exudes positive affect, hope, and support. Instead, care must be understood through and as the assemblage of shifting and often unjust power dynamics that entangle its subjects in a complicated web and conflict of dependence and agency, violence and care.

Motivated by my interlocutors' and disability scholars' (Clare, 2001, 2015, 2017; Mingus, 2018, Shildrick, 2015; Simplican, 2015; Smith, 2008) reflections on the enmeshment of violence, care, and resistance, I want to attend to the issue of care and cure in the medical-industrial complex¹². In doing so, I flesh out the ambivalent relationship of my conversation partners with care in their navigation of the medical system and in interactions with medical professionals. During our conversations, my research partners shared their experiences and concerns regarding the issue of care- and the lack thereof- within their experiences of treatment and diagnosis within the medical-industrial complex. While these aspects of care were initially

¹² I chose to use the term "medical-industrial system" (coined by Eli Clare, 2017) instead of health care system to point to the system's interest in advocating for the validity and truth of specific medical assertions concerning diagnosis and cure. The medical-industrial system is critiqued, as a site of physical and epistemic violence in which medical and biopolitical mechanisms are employed with the aim to categorize certain body-minds as abnormal and in need of repair and cure, by various trans and disability studies scholars.

not attended to in my research design, in complying with my methodological principles of conducting caring research that earnestly values the unique knowledge and experiences of my research partners, I would like to allow space for this topic to be explored in the following sections. Their reflections on the struggles and conflicts that the navigation of the medical-industrial complex carries, their refusal to accept uncaring diagnoses and treatments that exists in complicated entanglement with the unalterable necessity to receive medical support and care, enrichen my analysis and exploration of what resistance might entail and delineate within the context of care.

In his book *Brilliant Imperfections* (2017), Eli Clare offers an exploration of the deep-seated ableist notion that disabled body-minds need to be cured. This belief motivates medical practices that simultaneously hurt disabled people and change experiences of illness and disability positively, even save lives. Ash described the conflict they experience in respect of the medical-industrial system and care provided within it in the following: “There is absolutely a place for doctors and medicine, obviously they are doing amazing and important work. But the assumption that comes with this system is the problem.” The assumption alluded to here is the ableist belief that all body-minds can and should be *fixed* by eradicating disabilities. In Ash’s statement, I see Clare’s reflection on this conflicting, necessary yet harmful, concept of cure mirrored that pervades collective appraisals of medical support and care. Wanting to improve one’s corporeal lived reality, for instance easing one’s experience of chronic pain or fatigue and other afflictions and disabilities, is understandable. Yet, aiming at optimizing and curing body-minds redounds upon disabled people and feeds back into capitalist and normative ideals of perfectibility and progress, dividing society into people who live, work, and function under capitalism and those that cannot participate and exist in the same way. Care and work are administered so populations are cut into groups who function corresponding to the norm, and those who are debile and disabled, whose realities of debility and disability are being exacerbated through the hegemonic absence and restriction of appropriate care towards those who are not deemed worthy to be adequately cared for in the eyes of Western capitalism.

The term debility within disability studies was first explored by the American historian Julie Livingston in her book *Debility and the Moral Imagination in Botswana* (2005) in which the influence of colonialism, independence, industrialization, and development on bodily life and perceptions of health, illness, and debility within the African context is being scrutinized. Debility was then further adopted by Jasbir K. Puar: in her book *The Right to Maim: Debility,*

Capacity, Disability (2017) the concept describes corporeal injury and social exclusion brought on by economic and political factors as a technique of governance and control. Critical disability studies scholar Margrit Shildrick critiques the division of populations and body-minds into these binary categories of ability to work and flourish and the lack thereof, by arguing for a shared, universal condition of existence and debility (2019, p. 600) within the gears of neoliberal capitalism: most people, irrespective and precisely because of their specific embodied experiences, sexuality, gender identity and sociopolitical positionality, will never achieve the imagined “promise of happiness” (Berlant, 2011) and flourishing. This condition of debility “indicates that living on is always measured against an impossible sense of fulfilment, a fantasy of full capacity that is ever beyond reach. It invokes both an underlying ontological anxiety and a futile desire to resolve that anxiety through strategies of self-realisation directed towards happiness—a privileged trope of Western neoliberalism (Ferguson, 2007; Ahmed, 2010; Kingfisher, 2013) —and, more generally, well-being” (Shildrick, 2015, p. 14).

We work and care and exist under the dreamlike promise of cure and happiness that dictates us to direct our energy, thoughts and aspirations towards “happy objects” (Ahmed, 2010, p. 21) that are shaped by and within dominant societal norms, such as compulsory heterosexuality, able-bodiedness and able-mindedness, globalized capitalism, productivity and progress. This projection of neoliberal capitalist ideals of achievement and future aspirations bleeds into the way our debilitated body-minds are cared for within the medical-industrial system. So, while medical care can be helpful and supportive at times, the promise of cure and recovery inexorably casts disabled people into the hegemony of able-bodiedness and various regimes of enhancement and correction. In the next section, the consolidation of this multilayered conflict within the provision of medical care will be traced further.

While the harm caused by care within the medical-industrial system as well as in other interpersonal settings might arise inadvertently, violence within care dynamics can also be perpetrated willingly. Looking back at their past relationship, Mika mentioned:

At some point I realized that my ex was not able to give the care that I need. She was somebody who is stressed out and frustrated by my health all the time and made me feel horrible about myself. Because of that, care didn't feel like I was restoring myself so that I can be the person that I want. Instead, you are trying to make yourself fit into this mold that she expects.

In this statement, I recognize the hurt that care can cause when it is practiced without respecting and acknowledging the specific needs and circumstances of the person receiving care. My reading of the ableist care provided by Mika's ex interleaves with the issue that Eli Clare takes with the current ableist understanding of disabled body-minds generally, with institutions as well as other individuals trying to cast disabled people into molds of able-bodied and able-minded conformity and emulating the promise of cure (Clare, 2017).

Resisting the Medical-industrial Complex

In our conversations, the complex and conflicting process of diagnosis was addressed by all conversation partners as a key aspect in their experiences of care within the medical-industrial system. While some conversation partners have already gone through the long and strenuous process of receiving support and legitimization through medical authorities, others are still new to the reality of disability and the navigation thereof in the medical-industrial system. Care within this system of recognition and dismissal often occurs indirectly through the professional acknowledgment of their disabling experiences and the validity of these medical judgments in turn grant the reality of the disabilities. Aomame describes this as needing a medical “diagnosis in order to show other people, especially those without disabilities, that you need help and maybe a bit more care with certain things.” Similarly, sharing experiences from their past “toxic” (Mika) romantic relationship with a TAB woman, Mika explains: “In the relationship that I was in, I needed an excuse on paper to show my partner: this is why I am the way I am. This is why I respond differently to things than others might. This is why I might have different care needs. The diagnoses were somehow needed to help her understand these things and respect me in my disability.” Receiving a medical diagnosis might then not only help the own understanding of one's disability, but it mostly aids the understanding of one's disability by other people.

At the same time, in my conversation with Cody about their experiences of anxiety and ADHD symptoms, not yet having received an official diagnosis, they shared: “When I was younger and I struggled with anxiety, my dad always gave me the feeling that he either does believe me or he simply didn't understand. He would simply tell me to get over it. So, I think a diagnosis would give me a sense of calmness so that I don't have to prove myself anymore.” The diagnosis here is not a promise of cure but of relief, not only from symptoms of disability due to treatment and medication, but also relief from feeling misunderstood and misjudged (Clare, 2017).

Yet, in my conversation with Aomame, I also saw emerging the potential for further harm and discrimination that the process and conclusion of a particular medical diagnosis might hold.

Aomame mentioned:

Regarding my vision, I can say that I have, in a medical way, 10% of the vision of a normal person. In this, I am only defined by my lack of vision. And I think that is something that I sadly internalized. It required an emancipatory act to go beyond and resist the terminology- because I'm more than just a lack of vision. Now I would describe my vision as blurred but also, through that, very smooth. And that's actually a very beautiful thing. My visual reality is now somewhat a spiritual experience because I also see different forms floating around and everything is sparkling a little bit. It's a very cool way of seeing actually. For me, my vision is a location of knowledge through which I perceive the world differently. I feel like there's so much capacity in my disability that I didn't see or that I wasn't aware of before, because I was defined by that lack of vision. For a long time, I did not realize how much this medical terminology harmed me. But even while I criticized the medical system and my diagnosis, that doesn't mean that I am not also really grateful for the medical care that I received. Things like glasses and contact lenses allow me to, for example, read books and be in university.

In this reflection of her reality of diagnosis, living with and beyond the medical assessment, I feel the multiple and shifting dynamics and realities of diagnosis concur. A diagnosis is oftentimes prerequisite for receiving medical care and adequate treatment and medication. At the same time, care in the context of diagnoses in the medical-industrial complex might mean to distance oneself from a diagnosis, care might then mean to disidentify or look beyond the very medical frame that granted your disabling experience tangibility which was acknowledged and respected by others. In our conversations, these conflicting realities of the journeys to and through diagnoses came to the fore.

In Aomame's touching statement I also see Eli Clare's thoughts on the eclectic nature of diagnoses in the medical-industrial complex mirrored, as he writes:

I want to read diagnosis as a source of knowledge, sometimes trustworthy and other times suspect. As a tool and a weapon shaped by particular belief systems, useful and dangerous by turns. As a furious storm, exerting pressure in many directions. Simply put, diagnosis wields immense power. It can provide us access to vital medical technology or shame us,

reveal a path toward less pain or get us locked up. It opens doors and slams them shut. Diagnosis names the conditions in our body-minds, charts the connections between them. It holds knowledge. It organizes visceral realities. [...] It legitimizes some pain as real; it identifies other pain as psychosomatic or malingering (2017, p. 41).

While care in the medical-industrial complex might be practiced through the process of diagnosing and respective medical support, I want to draw further attention to the violence and harm implicated in the treatment within the medical-industrial complex through the chronobiopolitical (Luciano, 2007) determination of diagnoses.

The process of diagnosis is an important part of existing within the medical-industrial system that compounds systemic, temporal, and interpersonal problematics of care. The neoliberal capitalist striving for unattainable standards of efficiency of care interactions that are supported by state subsidies and funding becomes apparent in my conversation partner's reflections on their experiences of diagnosis. Mika took issue with the current diagnosis and treatment procedures, voicing:

It can take months and years to receive the diagnosis that you need to be treated. And even then, the government allows you to do these programs that are six to 10 weeks, where they basically diagnose you with something and then they give you 10 weeks of therapy. They are funneling people with very complex mental health issues into these programs that are way too simplistic. And it's very dismissive from what I've seen. I've had a lot of backlash from different professionals when I express my experience... they basically have this idea of: it has been studied that this approach works best for most people. Why do you think you're special?

Within this dismissive and insufficient experience of care throughout the process of diagnosis, I also recognize discrepancies between different coinciding temporalities of care that collapse within the navigation of the medical-industrial system. Until adequate medical care can be received, people often have to wait many weeks, months and, in some cases, for instance in Cody's process of transitioning, even years until the system grants them the needed medical support. Their condition becomes arrested in time. This debilitating administration of time dovetails with Foucault's description of the biopolitical regulation of processes of life and bodies on individual and population levels, which Luciano (2007) localized in the concept of chronobiopolitics that temporally align and alienate people in relation to collective experiences of life and time. In the biopolitical objective "to ensure, sustain, and multiply life, to put this

life in order” (Foucault, 1998, p. 138) certain people who fall out of normative hegemony and fall out of and transcend the prescribed order of life are not deemed worthy of timely care. Visibly upset and frustrated, Ash firmly criticized this detrimental temporality of diagnosis, as they uttered: “There's tons of nonbinary people around me, tons of genderqueer people around me, who need medical care and assistance but simply are being told to wait for months and years. Literally trying not to kill themselves while they're waiting for medical help because the system would rather see them die than invest a single euro or speed up their process of diagnosis and treatment.” The issue taken by Ash with the current reality of diagnosis further becomes apparent in the structural functioning of biopower that comes into operation through the governmental allocation of resources, and the insufficiency thereof within the medical-industrial system and care work.

Concomitantly, the time in which medical support is taking place is oftentimes brief and does not allow for the patient’s situation and complaints to be attended to holistically. Medical care is skimped in the neoliberal capitalist system that counterposes all interactions of care that transcend the normatively approved amount of time and resources. Cody describes this uncaring temporality of interactions within the medical-industrial system in the following: “the influence that neoliberal policies have on the healthcare system become apparent, for example, when I had to fill out these lists before a medical appointment because doctors can only spend so much time per patient. Everything feels rushed and a bit sloppy.” The process of diagnosis is being cast into the insufficient chrononormative hegemony of how temporalities of care are meant to emerge and exist, turning it into an experience in which a feeling of uncaringness prevails. Within the medical-industrial system, temporalities of care are twisted and turned so that time creeps slowly where care should be immediate, while time becomes scarce in interactions which would require time to slow and stretch to make the patient feel safe and seen.

The only trace of a possible resistance against this uncaring system that I recognized within our conversations was expressed by Mika, who claimed: “I would say that most of my resistance comes from directly resisting institutional healthcare and self-advocating within it.” This care for themselves by resisting medical authorities and trusting their own embodied knowledge demonstrates how political self-care can be a manner of empowerment that interleaves with realities of self-care as a burden and struggle. Self-care, also within the medical-industrial system, is an indispensable mechanism of self-preservation (Ahmed, 2016).

To insist on the reality of one's personal embodied experience can be a form of care, a form of resistance that defies the hegemonic belief that disabled and queer body-minds need to be fixed and brought into line with normative standards of personhood and ability. The exploration of my interlocutors' experiences of care, and the lack thereof, within the medical-industrial system brings to the fore the conflict and seeming impossibilities that resistance holds when it is directed against structures one fundamentally relies on.

My analysis sheds light on this complex and paradoxical manifestation of resistance within the context of life-sustaining care. Within conditions that make expressions of resistance dangerous and even life-threatening, subversiveness and resistance must be appraised following different standards of performativity. Attending to the conflicting reality of diagnosis and uncaringness within the medical-industrial system, my analysis insinuates how care, disability and resistance need to be read against and through each other, how these realities exist in a complicated entanglement that alters and imprints on each other in phantasmagoric and multi-layered manners. Resistance in the context of care means to oppose and defy normative care, it means to insist on care for all body-minds, it means to accept and allow care by a system that you fundamentally take issue with, if this care allows you to persevere within systems that makes other forms of care impossible. Care as resistance is simultaneously impossible and inexhaustible, it encompasses a myriad of manifestations and acts of care and resistance while its subversiveness is systemically foreclosed. This seeming paradox of resistance within the context of care will be investigated and complicated in the following sub-chapters of the analysis which will attend to the possibility of resistance and the meaning thereof within other queer and disabled manifestations and conditions of care.

Queer and Disabled Care Networks

What I'm struggling with in thinking about care is that, on the one hand, I think we should have community care and care that happens away from state institutions. But on the other hand, I also feel like the state should be taking care of this. For example, I see queer and trans people sharing GoFundMe's for top surgery, this call then circulates in the community... but the people in the community are also the ones who need care, who don't have money. So I am thinking we should take care into the community and care for each other. But shouldn't we change the state so that the state takes care of its citizens?
(Cody)

As in this quote, in our conversations, my research partners pointed to the very paradox that I am grappling with throughout the process of this thesis: people need to care, people need to be cared for; yet the very formation, existence and preservation of well-functioning care networks tosses the responsibility of care onto already debilitated and weary shoulders (Spade, 2020). The system continues to push its uncaring capitalist neoliberal agenda on the costs of and precisely enabled through private care networks that are most often sustained by the marginalized people hit hardest by the prevailing care crisis (Dowling, 2022). To preserve oneself in the prevailing system, the “creation of community, fragile communities, assembled out of the experiences of being shattered” is necessary (Ahmed, 2016, p. 5). In Cody’s case, such caring community built by trans and queer people provided them with support group meetings- a space to share openly with other trans people who would understand and empathize with their struggles as a trans person. This group allowed for a space in which Cody’s narratives and experiences were not questioned or investigated, but instead, the people in this group care for each other by “listening in good faith” (Cody) and intimately understanding and relating to the realities and pain that are shared. In Cody’s experience, I see the call for “cooperative communities: communities that are co-produced, that enable us to connect, to deliberate and to debate, to find joy and to flourish, and to support each other’s needs amidst the complexities of our mutual dependencies” brought to life. The feeling of being cared for by a community that deeply values and understands your experiences and positionality is manifested in the creation of such a support group, a caring space in which people uphold each other, oftentimes “by just being there” (Cody). Tying the topic of community care back to the issue of care as possible resistance, similarly to Ahmed’s (2016) understanding of self-care as warfare, which is inevitably reciprocal with and mutually dependent on communal and collective care, I propose an understanding of care within communities of queer and disabled people as resistance.

While Cody’s positive experience of care communities in the queer context was shared by Mika, Ash, and N. who found caring communities of either queer or disabled people online, our conversations brought to the fore that, while caring communities take on important care responsibilities, for many marginalized people the access to such communities is sadly nowhere near given. Sharing his frustrations in the ongoing search for caring communities that are inclusive and tailored to both disability and queerness, N. voiced:

I was looking for safe spaces, spaces that allow me to be cared for and care for others. And I don't think they really exist offline, or maybe they do but I was never able to find them. It's either a queer space, that is very inaccessible for disabled people, or it's a disabled space that's not queer-friendly. And that's something that I struggle with a lot. Because when I first came out as gay and queer, I was glad to have these spaces that were accepting of queer people. Looking back, these communities fit my queer identity, but they weren't disability-inclusive which made them very overwhelming and exhausting for me.

The frustration that was shared by my conversation partners concerning their search for care communities that value and support the intersecting multi-faceted realities of queerness and disability points to the lack of such care networks and the urgent need for the creation of such spaces. The scarceness of already established queer and crip care communities reveals that “[t]he community is not a magic utopia, just like our families weren't, and we don't all just magically love each other, or even like each other, let alone agree on every political issue” (Piepzna-Samarasinha, 2018, p. 53). Even within care communities that are established to allow for a caring space of connectedness, communities that aim to acknowledge and respect each member's individual embodied identity, experiences, and realities, care is not untainted by the risks of exclusion, discrimination, and violence. how “[o]nly once we acknowledge the challenges of our shared dependence, along with our irreducible differences, can we fully value the skills and resources necessary to promote the capabilities of everyone [...]” (Chatzidakis et al., 2020, p. 25). So, while some marginalized people might find care and support within their communities, the difficulties of my conversation partners to find and be part of these communities that value and dovetail with their own body-mind experiences and identities illustrate the urgent need for caring networks and communities.

The topic of collective and community care takes up the issue of the disregard of care on behalf of the state in the Dutch context. Ash addressed the contradiction that arises when pushing community care initiatives while the state's violence enacted through the dismantling of the social welfare state as an explicit technique of governance, which becomes blatant in the Dutch governmental idea of “participation society” (Knijn & Hopman, 2015), remains unchallenged, as they stated contemptuously: “The system can benefit from the work that people are doing privately and they can rely on that and continue to operate as it does because people are picking up the slack, but what else are you supposed to do? Because there's no choice. That's the

problem. It's the same with whether care can be resistant if it's always like complying with the state, if it's always helping the state remain violent. But there is no other option.” To realize the radical potential of care, the current political status quo that disparages care and lies heavily on the commitment of private people and communities to care for one another needs to be subverted and fundamentally changed.

This concern is echoed in the critique of the Western idea of the autocratic individual and neoliberalism by the authors of *The care manifesto: The politics of interdependence*, who proclaim: “what ‘caring communities’ does not mean is using people’s spare time to plug the caring gaps left wide open by neoliberalism. It means ending neoliberalism in order to expand people’s capacities to care” (Chatzidakis et al., 2020, p. 42). The practice of building deeply caring communities and caring promiscuously (Chatzidakis et al., 2020) needs to be connected to the collective endeavor to place care in the center of political and economic life, to care against capitalism and neoliberalism. Tronto describes this private and political endeavour in the following: “But suppose we could adjust our political institutions to support a different culture. Suppose we could live in a culture of care where we can reliably expect to be cared for when we find ourselves—and our loved ones—in need. Thinking about reallocating caring responsibilities is a start: but we need to go from thinking about changing care to actually changing the Politics and politics of care” (Tronto, 2015, p. 33). At the same time, it is important to recognize that care practiced by marginalized people should not be framed as a solely political act. This would weaponize care and force the responsibility to transform care onto the people who already bear the brunt of the prevailing care crisis. To impose the obligation to care onto individuals instead of concomitantly aiming for wider systemic changes regarding the appraisal and deemed importance of care would deflect the grander political issue that underlies the prevailing uncaringness, “structural inequalities would be deflected by being made the responsibility of individuals” (Ahmed, 2016, p. 3).

The ambition to care differently for each other, to defy chrononormative and hegemonic impositions of time and independence within conditions of neoliberal capitalism, and to care in collaborative, collective and promiscuous manners would insinuate the possibility of locating care as a collective emotional and practical objective within queer and crip communities and society at large. Living in crip and queer time can carry a liberating potential to practice care and relations escaping normative standards of time, affection, and connection. This slippage in and out of time however bares challenges for establishing caring connections.

The various and shifting ways in which my interlocutors experience time and care oftentimes pose difficulties in creating care networks. Mika describes this in the following:

The way I experience care is always in flux, never stable, and always changing. Because of that constant changing nature of the relationships that I have, it's really difficult to establish a network of care. When things are always changing, regardless of the multiple ways that I'm cared for by multiple kinds of people and the multiple people that I care for, the idea of a care community doesn't sit well.

While ebbs and flows, shifts and changes, can be helpful and freeing in care relations, this inconsistency might lead to people feeling less secure and supported. Similarly, Aomame lamented: "I miss a more communal sense of support and care. And I think that's also connected to my disability because I felt so like lonely and isolated in able-bodied institutions. I feel like I am always missing just like a disabled support network, a community of people who have similar experiences to yours." Even within the small group of people that I talked to for this research, it quickly became apparent how vastly different people's needs for frequency and proximity within care relations between and within certain disabilities. And while all these differences should be embraced, these divergent realities of care time might impede the possibilities to create care relations in community settings with a group of queer and disabled people involved, instead of one-on-one care interactions in which care time can more easily be stipulated and altered.

In her proposal for a new, democratic understanding of care, Tronto states that "[...] a new caring vision would recognize everyone—young, old, infirm, and other—as part of an ongoing system of caring acts in which we're sometimes on an extreme end of the giving-receiving scale, and sometimes in the middle" (2015, p. 16). Despite the shifts and fluctuations in care relations and practices embraced by my conversation partners, I still noticed that this welcoming of changing care dynamics was rather difficult for most of them to accept. Jasmine, for example, pointed out "I can't understand care as a *network*, like when walking on tightropes and then there's a safety net at the bottom of it. Instead of lying in that net, it's more something to bounce back off of. It's not a place to stay. It's not a place to be engulfed - it's not a hammock moment. It's definitely a trampoline moment, something enough to have your foot beyond it to bounce back." In this reflection on her understanding of care *networks*, I recognize a certain hesitation and discomfort with being explicitly cared for by others for too long. Not feeling able to receive care and be engulfed by a care network over an extended amount of time might also

arise due to ableist and capitalist notions of independence and progress as the normative ideal. Internalized ableist and chrononormative standards influence how much time and space disabled and queer people feel comfortable taking up on the extreme end of the care-receiving spectrum, which in turn undermines possibilities of nurturing care networks detached from these temporal limitations and concomitantly prescribed expectations. This is reflected in my interlocutor's difficulties to establish and allow embodied experience of collaboration and community in queer and crip care that might defy normative impositions of time, autonomy, and independence.

Disabled and Queer Resistant Care

In the final segment of this chapter, I would like to explore how disabled and queer forms of care might carry potential for resistance against the dominant ascendancy of uncaringness. "I think existing as a marginalized person is a form of resistance in itself, a form of resistant care for oneself", Cody voiced in our discussion about the possible political potentials of self-care. Care then becomes refusing to not exist or refusing to be erased. This declaration closely resembles Ahmed's rendering of Lorde, who claims: "self-care is not self-indulgence but self-preservation" (2016, p. 2). Similarly, Ash alluded to the resistant possibilities that are entangled in the reality of queer and disabled existence and care as they pointed out:

Merely existing as queer and disabled is a form of resistance because everything, every power that exists, is trying to either get rid of the disability by treating you or killing you ... or trying to get rid of the queerness by, it used to be killing, but I think now it's assimilating or ignoring it. So I think just openly and unapologetically existing as a queer disabled person in itself is a form of resistance. And at the same time, practicing care in queer and disabled ways is. There are so many problems that I have with the normative idea of care of how to care for someone. The very act of thinking about somebody else's needs before your own or in addition to your own, is the opposite of what individualism neoliberalism wants us to do, right? I think that in itself is a queer thing or a resistant thing to do.

To position care for self and others as a central concern in one's life, to embrace one's queerness and disability and respect others' and personal embodied experiences and needs within care dynamics, to distance oneself from norms and prescriptions of how and how much one should care for others and be cared for, in my opinion, is a form of resistance. Resistant

care is not just about doing or refusing to do care, but about how care is being understood and practiced in non-normative ways.

Such a non-normative understanding of care can be recognized in Mariana Ortega's Latina feminist work (2016), in which she engages in an epistemological de-centering of the self, arguing that the subject is formed through a multiplicity of the self. This multiplicitous selfhood is described as being-in-between while simultaneously being-in worlds (Ortega, 2016, p. 202), which, I argue, can be read in parallel to the paradoxical desire and need of marginalized subjects to change and escape conditions of oppression and uncaringness while simultaneously being deeply implicated and unavoidably dependent on certain forms of systemic and state-recognized care and support. In this conceptualization, I sense the legitimacy of the desire to belong while it alludes to the impossibility to locate and integrate the "multiplicitous self" (Ortega, 2016) fully into a given environment or reality, which becomes palpable and tangible in the queer and disabled people's conflictual and contradictory embodied reality of care. Ortega, thus, offers the notion of hometactics, which describes "practices that allow for a sense of familiarity with and a particular sense of "belonging" to a place, space, group, or world while avoiding the restrictive, exclusive elements that a notion of belonging might carry with it" (Ortega, 2016, p. 194). I understand hometactics as specific practices of care that allow oneself to feel like oneself in a specific mental, physical and interpersonal space. In this context, hometactics can be a subversive response to how particular circumstances and structures thwart care, a playful form of caring for and centering oneself within conditions of care that systemically disregard and discard individual non-normative realities of care.

This non-normative appraisal of self-care as a sense of caring for the own multilayered eclectic existence and experience might be manifested in the creation of mental and physical spaces and practices that allow the multiplicitous self to immerse itself in ways of receiving and giving care that experience ease, familiarity, and reprieve (Ortega, 2016). Similarly, the political importance of self-care practiced by marginalized people is addressed by Ahmed throughout her work (2014, p. 5). I read Ortega's hometactics as practices to satisfy the desire to feel belonging and care within a specific social and physical location, which exists in juxtaposition with the impossibility to conclusively locate and consolidate all facets of the multiplicitous self, I further trace the inevitable flaws and imperfection inherent in care and belonging, the impossibility to consummately care and be cared for perfectly.

Ahmed's and Ortega's analysis, while emerging from different geopolitical contexts and within different feminist strands of thought, both emphasize the centrality of the marginalized person's self within the context of care. Nevertheless, I want to point to the aspect of community and connectedness in the context of care. Community is vital when talking about self-care because both are mutually constituting each other. We all have a finite capacity to care (Aomame), which in turn creates a sense of interdependence and multifaceted connectedness with others. We need the care and support of others and of our communities to be able to care for ourselves and make space for self-care, which Federici phrases as "cooperation, and a responsibility to each other" (2016, p.386). Self-care and care within communities are mutually dependent and exist in shifting reciprocity, as "self-care is about the creation of community, fragile communities, assembled out of the experiences of being shattered" (Ahmed, 2016, p. 2) And while "caregiving and dependency are risky situations as our vulnerability to one another always opens us to wounding one another" (Simplican, 2015, p. 231), I offer an exploration of disabled and queer understandings of interdependence and care as possible relationalities of caring resistance. This argument points to a potentiality of queerness and disability that transfigures and compounds new facets of what care and resistance mean and entail- how they shape one another. In my argumentation, I open an alternative way of understanding resistance and care that is not valued or regarded in dominant political discourses and debates by looking at these concepts through the lens of disability and queerness.

Care as resistance might entail the shift of the notions of individuality and independence towards a more communal, connective, and interdependent reality of care. In our conversations, I noticed that all research partners stepped away from the hegemonic individualized notion of care in which one person, for instance, your romantic partner, must be able to provide all forms of care that you need. Instead, they leaned into and embraced various forms and dynamics of giving and receiving care with different people and the established care relationships, which Ash described in the following: "there's kind of this assumption that one person has to provide all the care. But all of these people in the diagram provide me with the different kinds of care, and I can have a different kind of relationship of care with all of them." They illustrate how it is possible to create dynamics of care that embrace interdependence and promiscuous care which means to start "caring more and in ways that remain experimental and extensive by current standards" (Chatzidakis et al., 2020, p. 31).

It was insightful to observe the discrepancy between my conversation partners' reflections on the problematics of the hegemonic notion of individualized care, and the actual realization of this critique within their own lives. They took issue with the reality of care within the individualized neoliberal system in which the subject is constructed as an independent and autonomous subject, expressing that they "wouldn't necessarily and consistently place [themselves] in the center [of their own personal care network]" (Cody). Further, as alluded to previously, all conversation partners criticized dynamics of care that are anchored in heteronormative ideas and defaults of relationality. Yet, in the completion of the "personal care network" exercise, people who were currently in a romantic relationship placed their partner close to the center of the diagram. Similarly, at least a few members of their biological family, oftentimes their parents, were located in a place of higher care importance by all conversation partners.

As previously established, queer and disabled care carries liberating and resistant potentials if it acknowledges and respects the individual embodied experiences and needs of the people involved in a specific care interaction, and if care practices can be modified and adjusted based on situational and varying care needs and capabilities. In their reflection concerning the "personal care networks" exercise, my conversation partners critiqued the hierarchical thinking that was predetermined by the separate network circles. Most of them had great difficulties placing people into the rigid levels that were given and instead placed people on the verges of the different circles or found it important to explain their care dynamics in more detail to oppose the simplistic categorization imposed by the exercise. The discussion of my interlocutors' understanding of individuality and connection within the context of care brings normative appraisals of separated and fixed understandings of self and other within care dynamics into question. This reflection can be read as an impersonated and intellectual resistance against neoliberal ideals and prescriptions of individuality, autonomy, and interpersonal separability. It further offers methodological criticism regarding the manner in which qualitative research ordinarily approaches the mapping of care relationships, forcing them into discrete and separate hierarchies and relations. This methodological contestation facilitates a broader theoretical critique of the way care is simplified and constrained within research contexts, which becomes visible in the restricted and artificial classification of interpersonal manifestations of care that seems to be out of touch with the lived reality of queer and disabled care relations. Consequently, this reflection on the "personal care networks" exercise and the concomitant exploration of queer and disabled care dynamics furthers an understanding of care as entangled

and collective practice and condition that holds various and shifting intensities, importance, and compositions of interpersonal relationalities.

My interlocutors pointed to the importance of feeling flux and changes in their care relations that are free to shift, come closer and retract at any given point, they “wrestle[d] with these ideas of softness and strength, vulnerability, pride, asking for help, and not” (Piepzn-Samarasinha, 2018, p. 28). Further, the fluctuation in dynamics of care giving and receiving revealed the consideration of “[...] distinct needs, whether as carers or cared for, noting the frequent reciprocity of these positions” (Chatzidakis et al., 2020, p. 25). In this attention to and embrace of shifting care dynamics and relationalities, the potential for care outside of the hegemony of normative rigid standards and rules can be conjectured. Mika reflected on the resistant potential of this way of caring, pondering out loud: “I don't think any care, disabled or queer, is intrinsically resistance just on the basis of being called care. But I do think that care itself, when done in a mutually understanding way, in a way that people are being empathetic and considering who they're caring for, can be resistance for sure.” For care then to realize its potential to become a resistant intervention, it needs to acknowledge the different meanings and facets of care and self-care according to different experiences of oppression and marginalization.

This final analysis chapter offered an exploration of the way queer and disabled care might be understood as forms of resistance. By caring for marginalized body-minds and by doing so within non-normative practices and constellations, by taking time to care and possibly defying temporal frameworks that systemically exclude certain individuals and their realities of life, non-normative care as resistance pushes back against the dominant notions of care in prevailing conditions of Western neoliberal capitalism. Much feminist literature and activism have alluded to the radical subversive potential and possibilities for resistance against this system by advocating for the refusal to take on certain (care) work (Federici, 2020; Gago, 2018). And while I agree with these feminist subversive tactics in certain contexts, I argue that resistance in relation to care cannot simply take recourse to these strategies. Care cannot simply be refused without serious repercussions - we mustn't not care. This realization became obvious in the discussion of my interlocutors' experience of care within the medical-industrial system and in the expressed need for alternative care networks for marginalized subjects. Yet, if the care is taken on by individuals out of necessity, despite adverse circumstances and lacking resources and governmental support, this is not necessarily subversive but rather allows the current

uncaring system to persist. In this chapter, I overarchingly grapple with this paradoxical reality of care as a possible form of resistance.

For this exploration, I distinguish two forms of care: certain forms of care reproduce heteronormative and able-bodied understandings of time, productivity, individualism and corporeality, others change and resist these understandings. Ideally, care as resistance means to establish alternative non-normative understandings of care as a collective and communal responsibility and joy, as an affective practice and disposition that values and appreciates individuals' body-mind differences, and with this, differences in care needs, wishes and capacities. In conversation with my queer and disabled interlocutors, I argue that resistance in the context of care means to oppose and defy normative care, it means to insist on care for all body-minds, it means to accept and allow care by a system that you fundamentally take issue with, if this temporary care allows you to persevere. Care as resistance is simultaneously impossible and inexhaustible. Its subversiveness is systemically foreclosed while it encompasses a myriad of manifestations and acts of care and resistance that defy chrononormative, hetero-normative, and ableist body-mind ideals, that resist precarious uncaringness and the systemic dismissal and hindrance of non-normative care that carries subversive and resistant potentials to escape and exceed these hegemonic standards.

Conclusion

This research project was initially motivated by my own experience and struggles with the internalized and systemic uncaringness within the Western neo-liberal society, its erratic and relentless uncaring nature becoming laid bare throughout the private, local, and global care struggles within the Covid-19 pandemic. I wanted to critique this devaluation and disregard of care in the capitalist, neoliberal system and the concomitant hegemonic notions of care and kinship that deem certain realities of relationality, embodiment, ability, and life in general undeserving of adequate care. State recognized systems of support have proven to be insufficient, oftentimes harmful and discriminatory, means of providing and receiving care, especially for oppressed and marginalized people. Specifically, queer and disabled individuals are categorically cast out of the hegemony of care that prevails in neoliberal, capitalist, heteronormative and ableist normativity. The concept of care in this study was fleshed out through developments in classic feminist theory as well disability studies, disability activism, and queer studies. In conversation with and informed by the lived realities of queer and disabled people, this research explored the networks of care within disabled and queer contexts, as the traditional nuclear family and the heteronormative ideals of reproduction and relating oftentimes produce violent and hierarchical dynamics of care. Further, attending to the need to care differently, time as a vector of power determines the capacities and rhythms that are allowed for care on individual and population levels. Exploring care within frameworks of crip and queer time, this research provides an insight into alternative modes of caring for self and others that resists capitalist productivity ideologies. Hence, I explore how care is influenced by our realities of time and how crip and queer time carry a radical potential to care differently.

I created a caring research project which allowed me to remain open and attentive to new ideas and perspectives that arose throughout the research process, letting myself be guided by the input of my interlocutors. My inquiry into queer and disabled non-normative experiences and understandings of care was realized by engaging in in-depth conversations with six queer and disabled persons between the age of 23 and 31 that were willing to share their own lived reality of care vulnerably and openly. These conversations were planned and held with the intent to make my interlocutors feel seen and cared for and to give them the biggest possible autonomy of decisions within the design of the conversation setting as well as throughout the course of the conversation. This research allowed for my interlocutors to address aspects of care that had not crossed my mind yet; these conversations deeply influenced the themes analyzed in this research. These methods have helped provide a new exploration of care within queer and

disabled contexts that adds to what has been previously theorized, while letting new facets of the general topic of care emerge by compounding and enriching the concept through its understanding in entanglement and tension with aspects of disability, queerness, time and resistance.

Throughout the research, it came to the fore that my interlocutor's various identities of queerness and disability enabled them to step into relations and practices of care that diverge from the hegemonic normativity of uncaringness prevailing under conditions of Western neoliberal capitalism. The explored disabled and queer reconsiderations and changes in practices and relationships of care hold vast potentials to rethink and understand differently the dynamics and nature of interpersonal care. Yet, it is important to consider that grappling with disability, ability, and queerness is by no means a linear or smooth process, but instead holds ongoing as well as ever-changing struggles, contradictions, and joys. For most of my conversation partners, their practices of care were interwoven with understandings of interdependence and community, while still realizing their need for rest and reprieve in and outside of these moments of connectedness. Further, based on theoretical sources and my interlocutors' narratives, I argue that disabled understandings of care offer subversive potentials for the understanding of care within neoliberal, capitalist societies, as they resist pressures in care relationships and individual care practices.

This study foregrounds the ways in which care is sustained under the uncaringness that existing heteronormative, ableist and neoliberal structures have particularly imposed upon queer and disabled people. All conversation partners shared the understanding that care should be uniquely shaped to fit the overall and situational needs, wishes, and circumstances of the person that is receiving care while not overwhelming the care-providing person. In disabled and queer realities of care, the strict hierarchies and separation of certain positionalities within care hierarchies are oftentimes rejected and blurred. Instead of weighing each care practice against one another, my conversation partners understand care as attending to each person's embodied experience, respecting limits and boundaries in receiving and providing care, while accepting and embracing the fluctuations and shifts in care relationships. My research further portends the importance of a new understanding of interdependence and collectivity that materializes in the nurturing of (queer and disabled) care communities. The held conversations point to a lack of and the urgent need for the flourishing of such communities that should be attended to in future research.

The methods employed within my *caring research* approach allowed my interlocutors to open up about issues concerning the lack of care within the medical-industrial system that my conversation partners had experienced and suffered from, which would have initially not been a focal point of my inquiry. Within this elucidation, issues of systemic violence, interpersonal uncaringness, and chrononormative conflicts in the time spent on care within interactions with medical professionals came to the fore. While I am glad that these topics, central to my interlocutor's overall experience of care and disability, could be addressed in this research, future studies on the topic of care should consider putting a stronger emphasis on the importance of scrutinizing and fundamentally revolutionizing the role of care within the medical-industrial system and overall state-recognized institutions of care. A clear limitation of this research is that no concrete political directives or extensive critiques detailing current local and national political decision-making and governing processes were formulated. Hence, it would be productive to locate the issue of care more firmly and decisively within specific political and geopolitical debates and events in future projects. Further, more attention needs to be paid in future research to how the divisions of who can care and has the capacity to care are influenced by aspects race and class, issues that were not yet regarded in the current research project.

What lingers at the end of this research project is the feeling that disabled and queer care resists seeming paradoxes, defies normative expectations of achievement and productivity, expectations of how to receive and give care, how to live in a caring manner, expectations concerning independence and relationality that society and our social surroundings project onto us -all, while allowing yourself to slip back into normative frames and dynamics if these serve your reality of care at a certain point in time. Trying to challenge these and other expectations while allowing for slip-ups and stumbles, disabled and queer care means resisting uncaringness and allowing and embracing the ebb and flow of care. This research project highlighted the systemic and private obstacles, issues, and impediments that my interlocutors encountered in their lived realities of care. Yet, this study has further pointed to the resistant and subversive potential that queer and disabled practices and understandings of time, interdependence, and care carry. My analysis brings into question and challenges the current hegemonically prevailing reality of care within a system that is fraught with and rests on intersecting and multifaceted vectors of oppression and injustice. Entailing and exceeding all areas of personal and political life, this research shows that as well as how care must become a systemic and

individual guiding principle and disposition in our collective endeavor to resist prevailing conditions of precarity, oppression, and violence under which uncaringness reigns.

This thesis has been driven by my desire to think through and with critiques of normativity and hegemonic notions of care to offer an analysis of care and alternative visions and practices thereof. These offer potentials for resistance against the prevailing neoliberal oppressive system which employs care and the withdrawal thereof as a biopolitical technique of governance and disciplinary power. Reflecting on the topic of care as resistance, I came to grapple with the seeming paradox of acts of caring being acts of political resistance; care does not challenge the neoliberal capitalist system but rather, out of necessity and a systemic disregard of care, takes on care responsibilities which in turn allowing the uncaring system to persist. My analysis brought to the fore how resistance needs to be understood as expressing itself in different manifestations within the context of care than is presumed in prevalent feminist thought and discourses. The uncaring system cannot simply be resisted in renouncing manners if it is the very system one needs to rely on for care, care that can determine well-being and survival. Instead, my analysis suggests that caring for self and others for marginalized subjects can be a form of resistance, as a way to insist on one's value and validity detached from capitalist ideals of production, a way to respect and appreciate body-mind differences and nurture collective alliances and communities that can be weaved through the embracing of precisely these differences. I figure that to remain caring towards self and others despite adverse circumstances and painful struggles is a way of resisting the prevailing conditions that weaponize care, it is a way to nurture alternative foundations for care within, despite, and beyond these circumstances.

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Appendix 1

Hello lovely people,

for my Gender Studies Master's thesis, I am researching queer and disabled understandings and practices of care, time, and kinship. Therefore, I am looking for people who identify as queer and/or disabled who want to talk to me about these themes in either an interview setting or in focus group meetings. Things like the duration and location of the meeting, drinks and snacks, and other details will be decided on together, as I would want you to feel as comfortable as possible in the conversation.

If you're interested, feel free to reach out via e-mail ... or WhatsApp ...

I am excited to hear from you!