

Doing “gendered exit”: Work, care and the moral practices of disabled persons

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Abstract

Previous research into the exclusion of disabled persons from paid work tends to compartmentalize them into a stable and undifferentiated category of “cared-for” subjects. This fixation implicitly approves the ethics of work as the exclusive source of their dignity and citizenship. Drawing on in-depth interviews with Myasthenia Gravis patients and their families, this paper argues that a subscription to the logic of interdependence that organizes the ethics of care enables our participants to transcend the conventional carer/cared-for dichotomy. However, the patriarchal structures in which the agency of our participants finds expression create a gendered distribution of care. By delimiting the possibilities of social membership for disabled persons, this paper embraces the care ethics as an alternative to that of work. It nevertheless circumscribes care by bringing into relief its differential and contingent qualities.

KEYWORDS

care, disability, ethics, exit from work, gender

1 | INTRODUCTION

Work regulates processes of identity, dignity and citizenship (Grint, 2005). Owing to their perceived inability to perform the role of economic agents, disabled persons have often been seen to pre-maturely exit from the labor market, as marginalized and even morally inferior (Abberley, 2018; Van Rijn et al., 2014). What unites most scholarly and policy discussions on disabled “productivity” is their preoccupation with facilitating the integration of disabled persons into the labor market (Barnes & Mercer, 2005; Hyde, 1996). By entertaining the premise that disabled

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persons are capable of cultivating themselves as valuable and moral entities following their exit from the labor market, there has been the suggestion that they are pioneers of the enactment of a “counter-hegemonic imagination” that marshals an alternative ethics regardless of their “productivity” (Graby, 2015, p. 152). This paper partakes in this imaginative effort to explore how disabled persons derive their sense of self-worth from cultural scripts alternative to the overbearing paradigm of work.

While disabled persons are often found in a stable and undifferentiated category of “cared-for” subjects (Morris, 1993), previous research shows that they can be enmeshed in a diversity of care relationships by way of their domestic and voluntary activities (Taylor, 2004). These endeavors constitute an epicenter for the unsettling and re-construction of their subjectivities (Chattoo & Ahmad, 2008). Care, as is conventionally broached by a variety of disciplines, is diffuse, not definable in any simple way and widely unstable (Han, 2012). Faithful to the Gilligan (1993) tradition that the care ethics represents a form of moral reasoning that values inter-dependence and relationality among human relationships, however, this paper probes the availability of care to the life-worlds of disabled persons. We argue that the efforts of our participants to make meaningful sense of their lives transcend the carer/cared-for dichotomy. While they powerfully contest the monolithic category of the “jobless disabled” by bringing to the fore questions of gender and age that coalesce with their disabled attributes, these identitive intersections they experience nevertheless both create and prohibit the possibilities of the ethics of care to propagate effective transactions of moral recognition.

We begin with a theoretical interrogation of the significance of the exit from work and of the alternative ethics of care for disabled persons. After fleshing out our research methods, we go on to elaborate how our female and male participants encounter the ethics of care. Their differential access results from the operation of patriarchal structures: while our female participants are presented with ample opportunities to perform care activities, they do not necessarily enjoy more freedom than their male counterparts in the existing labor regime. In connection with the essentializing and exclusionary nature of the “female carer role,” the contradiction is that care is not always available for appropriation. Overall, care is offered in contra-distinction to the orthodox principles of autonomy and self-reliance in neo-liberal personhood (Gibbs, 2018; Gilligan, 1993). Meanwhile, however, we are not oblivious to care as a contested territory that invokes often irreconcilable agendas, stigmatizing practices and other vexing consequences (Fine & Glendinning, 2005; Mik-Meyer, 2016; Morris, 1993). Our rendition of care as an alternative to work is therefore scarcely total.

2 | WORK, ETHICS AND THE “SICK ROLE”

Central to this paper is the concern with the significance of “exit” as a pivotal life transition from full-time employment, not least where a transition of this nature may be structured in gender-specific ways. The idea of exit is frequently engendered by social norms surrounding a particular age threshold, sustained in turn by the institutional arrangements that prescribe the temporal order of biographical events (Radl, 2012). Early exit is adversely perceived as a derogation from the normative age paradigm and in association with undesirable conditions of work (Solem & Mykletun, 1997), work-family conflicts (Xue et al., 2020) and health issues (Kouwenhoven-Pasmooij et al., 2016). Pathways such as disability pensions, unemployment or early retirement also contribute to shaping a disabled person's decision to exit employment early (Van Rijn et al., 2014). While risk predictors of exit from work among disabled persons have been extensively examined (Milner et al., 2018; Riphahn, 1997), what happens during their transition into post-work lives has received much less scholarly attention (Radl, 2012).

It has been argued that the symbolic role “exit” plays revolves around the morality of the disabled person as filling the “sick role” (Parsons, 1951). While the “sick role” is justified in their exemption from work obligations, the justification is temporally limited insofar as there is an expectation that they would return to “normality” and resume their engagement with work within a short length of time (Varul, 2010). Even for those experiencing long-term illness, the expectation is that they would do so by re-prioritizing their different endeavors (Parsons, 1975). Pervasive discussions on the ethics of work treat work as constitutive of one's identity (Abberley, 2018). Engagement with work mandates it as a pre-eminent condition for one's full membership in civil society (Barnes & Mercer, 2005), and participation in it has often been promulgated as an indication of the passage to adulthood (Frayne, 2015). We become

through work worthy and responsible family members, as well as disciplined and governable subjects in the extensive social and political modes of cooperation (Weeks, 2011). What is more, paid work is valued above other modal possibilities of work. It establishes the sense of independence required to harvest aspects of social life to which we affix value (Barnes & Mercer, 2005).

Disabled persons are therefore not free to exit the labor market in a morally upstanding manner, but instead find themselves under the imperative to move off welfare and into the workforce (Frayne, 2015). Public policies enable this imperative with the provision of vocational education and training initiatives designed with the interests of disabled persons in mind. Mainstream political agendas that uncritically dismiss the possibility of leading varied lives outside of work are unsurprisingly ubiquitous (Frayne, 2015). In China, a number of workability-driven policies have been enacted to promote market employment for disabled persons, including the introduction of tax-reduction schemes that encourage enterprises to train and hire disabled workers (Qu, 2020). All the while, state discourses anchored in the theme of self-reliance have accompanied the state's reduced commitment to welfare provision since the late 1970's (Liao & Luo, 2010). These moves tend to refashion disabled persons into individuals who would be "attractive" to the labor market (Barnes & Mercer, 2005, p. 535), even if this is often achieved at the expense of broadening the scope of their life choices.

If employment can never be the be-all-end-all for persons with impairments, however, we echo the argument that "full integration of impaired people in social production can never constitute the future to which we as a movement aspire" (Abberley, 2018, p. 77). In this spirit we are concerned with the "exit" of disabled persons not only in terms of the institutional arrangements that authorize removal but also in terms of their withdrawal, whether voluntary or coerced, from the totalizing work regime that dictates one's sense of worth in civil society (Voswinkel, 2012). Previous research has advocated attention to the "exit" of disabled persons in pursuit of a counter-hegemonic imagination that values alternative models of personhood beyond the productivity-oriented framework of the "sick role" (Graby, 2015). Disabled persons, as they persuasively have them, signify the potential of being a symbol for the claims of non-utilitarian values, a challenge against anyone who treats their job as an end itself (Hunt, 1966). A renewal of focus on the moral practices of disabled persons—the self-enactment of their own perceptions of virtuousness (Oakeshott, 1991)—rather than on the debilitating effects of their conditions impeaches the legitimacy of the discourse of work.

That said, what "work" amounts to needs *work*. Previous research that grapples with the moral practices of disabled persons following their exclusion from full-time employment triggers a re-negotiation of the definitional boundaries of "work" such that it encompasses not only paid jobs but also other pursuits that benefit society (Riach & Loretto, 2009; Taylor, 2004). A wide purview of "work" secures a sense of self that extends beyond the contours of the disabled/able-bodied bifurcation (Galvin, 2005; Garthwaite, 2015; Riach & Loretto, 2009). A diversity of "works" read in this interpretive tradition that encourages one to simply "remain active" will become evident among our participants. We argue, however, that these previous findings—however analytically expansive they might be—tend to conceptually colonize disabled persons as a unified and homogenous community. Where they forgo the constitutive complexities of disabled persons, they do not always account for the immanent (un-)availability of the cultural scripts of such "identitive work" (Thomas & Davies, 2005), which our participants see as instantiations of "care." Mimicking the public/private and paid/voluntary axes of understanding they have ideologically internalized, our participants also construct strict demarcations between "care" and "work."

3 | CARE, RECIPROCITY AND CONCERNS ON GENDER AND DISABILITY

We turn to the alternative ethics of care and ask how far it assists disabled persons in discharging an alternative moral strategy. In *In a different voice*, Gilligan (1993) famously argues for an ethics of care based on the moral concerns of human relationships. Following her, the ethics of care has been driven in synthetic directions that underscore the role of interconnectedness between human beings (Hamington, 2001). It has been said that the ways in which we confront pressing questions of our times would be systemically different if we cease to rely on principled moral theories of rights and obligations in favor of a vision that problematizes the moral incompleteness of an ethics that seeks to hold

up impartiality by maintaining a depersonalized, distancing attitude toward others (Robinson, 1997). While discussions of care have been incentivized by an array of differing concerns, disability studies have profited from the care ethics and proposed reciprocity as a pragmatic alternative to that of work. The rhetoric of disability offers a springboard for society to recognize the universal vulnerable condition and to respond to ever-constant human interdependence (Fineman & Grear, 2016). It is therefore through interrelated, differentiated and consistent forms of interdependence with each other that the significance of care ought to stand out as a new model of social order (Kittay, 1999).

However, mainstream references in disability literature to “care” often presuppose a dialectical relationship between the carer and the cared-for in disparate categories (Morris, 1993). Previous research cautions against dichotomizing the relationship between the two by affirming the permeability of positionalities. People can be a carer in one situation and cared-for in another (Williams, 2001). Furthermore, it is not only physical tasks of care, but also the emotional and spiritual aspects that animate it, that warrant recognition (Morris, 1993). The perspective that assumes disabled persons as passive recipients of care is simplistic, not least where their subjectivities as “competent social agent[s]” are subject to re-configurations that call into question the utility of the carer/cared-for distinction (Chattoo & Ahmad, 2008, p. 551). Where mobilized, their practices of care illuminate the conduits through which an ethics of reciprocity delivers “a potential safeguard against [the] threats” of neoliberal discourses that tend to unmake the personhood of the “dependent” disabled, helping them in the reassertion of their personal values and reconstructing them as fundamentally moral beings (Buch, 2014, p. 604). While previous research at this juncture does not abound, there has been the argument that the rewards of recognition and resilience for disabled persons emanate from the view that treats them as actants who bring a “gift of difference,” the promise of which advertises the significance of alternative altruistic values (Esdaile, 2009, p. 126).

At the same time, however, a diversion of socio-political appetite from the ethics of work to that of care is not a panacea that produces ethically sound outcomes. The caveat is that the availability of the “carer” role as a prolific repository for building up resilience against the work ethics is not always equally distributed. The evolving, interstitial and at times conflicting relationships individuals inhabit affect the roles made available to them (Mik-Meyer, 2016). While biographical and cultural particulars that relate to gender and age frequently structure the individual's opportunities to become a subject of “legitimate dependence” and to assume the care responsibilities it brings (Chattoo & Ahmad, 2008, p. 557), disabled persons may also encounter challenges in fulfilling their carer roles in sync with conventional forms of a meaningful life (Baraitser, 2017). Importantly, neither the market nor the state has provided sufficient reciprocal support for care activities, in terms of the institutionalization of decent pay or citizenship, leading to a continuous devaluation of care that disproportionately affects females (Regev-Messalem, 2022). Furthermore, the presumed but troubled nexus between care and the female's morality risks confining the ambit of the ethics to the private, familial locus of expression, reinforcing the discourse of traditional gender roles rather than exploring the potential of cosmopolitan values (Tronto, 1993). The pre-existing, intersectional structures of marginalization to which disabled persons might be victims also limit the autonomy with which they appreciate a reciprocal relationship (Buch, 2014).

Taking onboard the enigmatic nature of care, this paper explores its moral appropriation by disabled persons by addressing the two following questions. First, we investigate why disabled persons find care morally empowering and how, if at all, they enact it through transcending the carer/cared-for dichotomy. Second, we examine how their gendered positionality in conditions of patriarchy influences their differential access to and performance of care. These questions are raised through the cases of Myasthenia Gravis patients in China. By focusing on this chronic and variable health condition that might appear to be invisible, this paper contributes to the corpus of knowledge in disability studies that have often implicitly focused on visible physical impairments (Mollow, 2004). The intention is to encourage a sensitivity to the heterogeneity of the disability experience.

4 | CONTEXT, DATA AND METHODS

Myasthenia Gravis is a chronic autoimmune neuromuscular disease characterized by fatigue and the weakening of muscles that control the eyelids, facial expressions and eating, and it may also impair the patient's ability to walk and

stand (Gilhus & Verschuuren, 2015). We conducted for this paper in-depth interviews with 26 Myasthenia Gravis patients (including 7 males and 19 females) with moderate to high disease severity—that is, persons whose affected areas extend to their limb, axial or respiratory muscles—and in 7 of these cases, with their families (including 1 male and 6 females). We recruited our participants through Aili, a non-governmental organization for Myasthenia Gravis patients in China set up with the mission to enhance their quality of life and to promote public knowledge about the disease.

Our participants range from 29 to 71 years old. Eight of our participants reside in first-tier cities in China such as in Beijing, Guangzhou and Shenzhen, while the others in more rural areas. While 23 of our participants had not been in full-time employment for at least half a year prior to their interviews, the three others who were in full-time employment at the time of their interviews had all had previous experiences of joblessness of at least two successive years. Most of our participants have spent years moving between part-time paid jobs, domestic responsibilities, voluntary endeavors and a significant amount of time for treatment and recuperation, though a few others have spent almost the entirety of their adult lives primarily at home. Our participants were embedded in an eclectic range of evolving relationships and often played the simultaneous roles of a parent, a son, a daughter, a sibling and/or another significant member of the family, with varying degrees of emphasis attached to each of these roles before and after their diagnosis. Sixteen of them were married prior to the onset of their disease, while the remainder were single.

The study was approved by the Survey and Behavioral Research Ethics Committee of the Chinese University of Hong Kong (No. SBRE-21-0260). All interviews were conducted remotely via Tencent Meeting, a popular video conferencing platform in China. Consent to the purposes and the procedures of our research was individually obtained, and the participants were informed of their right to withdraw from it any time before or during the interviews. All participants were anonymized to ensure confidentiality. Each interview was recorded and transcribed *verbatim*. In-depth semi-structured interviews lasted between three to six hours for each participant. Each of the interviews began with a broad compendium of questions that helped our participants navigate the critical decisions they had made in their life-histories and the ways in which they had been fueled by their diagnosis. If illness creates a biographical disruption to the consistency of one's life-story (Bury, 1982), a narrative creating a re-construction bridges the gap between the self before illness and the self following its onset (Williams, 1984). We were particularly keen to devote attention to engaging with the different transitions our participants encountered in their “able” and “disabled” lives, the change to positionalities that accompanied them and the articulations and contestations of agency and self-worth that culminated.

Data analysis was conducted in two stages. At the first stage, we manually coded the first 10 interviews by looking for emergent themes in our transcripts. Repeated references among them to “paid work,” “care activities,” “burden” and “worth/recognition” became obvious. Diversity within each of these themes was analyzed by way of gender and age. At the second stage, we coded our transcripts with NVivo (Release 1.6.2) to identify sub-themes by way of a comparative, inter-categorical approach (Bauer & Scheim, 2019) that focuses on the positionality of a disabled person at the intersection of age and gender. We held regular project meetings to discuss these themes, the relevant theoretical literature as well as the conceptual framework we had developed to organize our findings.

5 | FINDINGS

5.1 | Out of work without being a burden: The fluidity of “carer” and “cared-for” categories

An “exit” from full-time employment was difficult for many of our participants. The familiar narrative is one that laments the feeling of becoming a burden to others, sensitive to a sense of humiliation that compromises the dignity and pride that come with the ideal-typical self-reliant agent. One of our participants, a breadwinner in his family before he left his job, described his first two months following his diagnosis as follows:

I used to work at a construction site and I could easily carry a 100-kg load, but during the time when my symptoms were most severe I could not even walk for 3 minutes. I spent my days in bed, feeling so guilty

looking at my father preparing meals for me. I reminded myself that my parents would have expected me to provide for them...but now the situation is reversed, I just cannot see any meaning in life.

The ideological temptation of the work ethics was so overbearing that many of our participants desired to return to work once they felt that their symptoms had been alleviated, only to find it almost impossible to do so. Tan, a 42-year-old female who holds a bachelor's degree from a prestigious university, has been repeatedly turned away on every occasion she applied for a new job. As she explained, employers shy away from situations where there are risks of labor disputes. "As long as I am in that company, they have to cover the fees for my medical and social insurance. They hate to hire someone who can easily go to ICU. They're not legally allowed to fire me if that happens." In other cases where our participants have been able to secure employment, the majority of them found themselves physically incapable of performing the tasks they had been assigned. The quandary for our participants was often not whether they would resign from their jobs but rather when they would do so, with the more fortunate among them able to resort to flexible, part-time jobs as alternative fields of productivity.

While the construction of agency for disabled persons by challenging "the embedded concept of illness as unidirectional and deteriorating" (Riach & Loretto, 2009, p. 109) is well-documented, we argue here that it is the acceptance rather than the denial of the permanence of disability that privileges the possibility for our participants to explore an alternative ethics that reorients their meaning in life. The possession of a disability certificate is a useful case in point. All of our participants think with the benefit of hindsight of their decision to apply for a disability certificate as socially productive, and refer to being awarded one as a turning point that prompted them to re-evaluate the priorities of their lives. Instead of becoming trapped in the stereotypical role of a disabled person whose life is marred by restriction (Kanter, 1977), making peace with the notion that they have to be somewhat "cared for" in turn inspired alternative possibilities of personhood. Tan explained why she resorted to applying for a disability certificate:

It's a change in mentality. I used to think of myself as a patient, so I focused primarily on curing the disease. Now I accept my identity as a disabled person, and I don't think it will change in the near future. So I begin to think about how to live better with the disease.

For many of our participants, however, the distinction in their roles between being "cared-for" on the one hand and a "carer" on the other is far from neat. What our participants find even more socially productive than their disability certificates is their calibration of themselves as making useful contributions. It is the *abled* possibilities from the recognition of disability that count. The domestic duties they now perform overlap with those they had undertaken before the onset of their illness, although they often speak of the former more emotionally than they do the latter. As our participants suggested, the act of caring delegitimizes their condition of dependency. Lu, a 37-year-old female, expressed contentment with her current condition because both her husband and herself were grateful for her presence at home:

I clean the house, cook meals, and take care of everything about my daughter, including her regular studies and art classes on the weekends. I know I'm irreplaceable at home because my daughter is doing great at school even though she did not take any pre-school courses. My husband also thanks me for my parenting.

It would appear as though our participants comply docilely with the traditional gendered values that surround care activities for the purposes of self-identification (Stone, 2007). We find it normatively myopic, however, to account for these practices by recourse to the reductive idea that disabled persons are confined to "feminized work" under the gendered paradigm of labor division, or that the exit of the disabled person from the labor market turns out to reinforce the hierarchical ideologies of work defined by both masculinity and ableism (Phillips & Taylor, 1980). Even with respect to our female participants who have been predominantly occupied with domestic care responsibilities, many ushered portrayals of themselves as ambitious, eager to excel and uncomfortable with being dependent on others. Those who developed Myasthenia Gravis after they had become adults shared shattered visions of their lives

as secondary school teachers, airport ground crew members and truck drivers, just to name but a few. Their exit from the labor market was, however, made legible by themselves not as an exercise of compromise. It was the apposite presentation of an opportunity to re-adjust the objectives of their lives. As one participant described:

I felt that someone needed me. This was what refilled hope in my life... I felt that keeping a close relationship with your families and friends would also stabilize my condition. A job might help you grow from the outside, whereas this experience helped me grow from within.

However, the care activities carried through by our participants were neither confined to the domestic space nor the prerogative of the female. Zhao, now 67 years old, developed Myasthenia Gravis a few years before his retirement. He described the transition he had undergone from an able to a “disabled” person as unwittingly “a relief from the pursuit of achievement and promotion”:

I should have retired earlier. Looking back, I find it the greatest virtue to do what I can to help others. I joined the volunteer training program a few years ago Yesterday I showed a stranger the way to a local street. It was not easy to find so I took him there myself. It took some additional effort, but it was worth it.

Participation in care activities acquainted our participants with the apparatus for self-assertion. Meanwhile, they remain involuntarily privy to the vulnerabilities of corporeal experience. They are attentive to the minuscule particularities that enliven their responsibilities of care, and they actively rehearse in their narratives the notion of reciprocity they consider indispensable to the “material and moral dimensions of ...[their]... responsibilities” (Finch & Mason, 1993, p. 167). These sentiments were captured by the words of Sun, a female participant who had been participating in a “voluntary caregiver” program in an NGO:

I’ve been in that desperate situation so I know what it is. I just want to pass on the kindness I have received to others in need.

As one participant put it, “everybody experiences pain, although maybe in different forms or degrees.” We are reminded here that disability amounts, no more no less, to a permutation that emerges from the “interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation on an equal basis with others” (Preamble, Convention on the Rights of Persons with Disabilities 2007). “Disabling” comes not from disabilities themselves but from the biases and prejudices that interpret them. For our participants, they turned on its head their experience of “disability” and the conventional parlance of resultant dependence by invoking the universal vulnerable condition (Fineman & Grear, 2016): the destabilizing recognition of vulnerability as “a temporally and differentially manifested, but nonetheless consistent potentiality of human experience” (Gibbs, 2018, p. 28). They transcend the reified dichotomy between the “carer” and the “cared-for” by moving between and across these identities, and the ethics of care and reciprocity they mobilize become critical outlets of self-assertion in circumstances where their exit from the labor market effectively eliminates it.

5.2 | The differential availability of the care ethics

Despite their apparent universality, however, conditions of vulnerability are ameliorated by social, economic and cultural resources that are differentially distributed (Fineman & Grear, 2016). The availability of the care ethics as a potential cultural script for the justification of their exit from paid employment—and for the lubrication of their transition into post-work life—is constrained by the expectations attached to their relational roles and responsibilities, particularly in conditions of patriarchy. The ethics of care that empirically results becomes a gendered outcome, amenable to differential modes of appropriation across an individual’s life course (Chattoo & Ahmad, 2008).

The care ethics as it relates to the uptake of care activities was borne out in contrastive ways between our female and male participants. Females with disabilities tend to view care as a substitute. It informs an entirely separate realm of social existence from that of work, though it is just as significant. The notion of reciprocity that dovetails with a gendered sense of self-worth produces a good mother, wife, or daughter capable of reciprocating the products of affect she receives from her intimate relationships. To be a carer is to assume a character in their own right, and the matrimonial landscape in China configures the cultural role of the “carer” in ways that make it more available to our female participants than to their male counterparts, particularly to those who are single and childless.

Previous research has been quick to identify Chinese cultural processes as part of “a reconfiguration of the relations of gendered generational interdependence typical of patriarchal family structures” (Santos, 2017, p. 106). These transformations, prevalent particularly in rural areas of China where they have gained much social traction in large part because public welfare structures remain limited, have given rise to unprecedented practices of “surrogate parenting” that rely on multiple-mothering formations to perform the “feminine” work of quotidian care. All the while, biological parents confine themselves to efforts of “masculine” work by participating in full-time employment (Cong & Silverstein, 2012, p. 125). Despite the support frequently garnered from grandparents in these “multiple-mothering formations” (Santos, 2017, p. 95), we also suggest that disabled female family members meaningfully contribute to the multiple-caregiver network in a patriarchal environment.

Jin, a 49-year-old female, has, for example, been residing with her aunt since she was first embattled by the disease some 20 years ago. She used to be entirely dependent on the care of her aunt, but her situation has undergone significant improvement. She was proud to have been once again able to fill the “care slot” (see Leinaweaver, 2010) by performing household chores and by looking after her aunt's son. Jin has also made progress in her career as her symptoms subsided. She has taken up part-time employment as an online editor, and looks forward to becoming a certified social worker in the future. When confronted with the possibility of her aunt's demand for more intensive care, however, Jin is resolute about her priorities. Jin said:

I will definitely give up my job. We need to pay back the debts we owe to others. They have devoted so much to me. Why can't I also give up something when the time comes?

The emphasis in the relationship between Jin and her family has shifted over time. While she was previously a *de facto* daughter to her aunt, she is now better seen as the new carer in the family. Despite so, however, care and work are spheres of activity that remain thematically similar but conceptually distinct. So is true also of the life-worlds of our female participants working in NGO's. When asked about the difference if any between voluntary work and their previous jobs, a participant remarked, “If it's work, it's pretty much only about earning some money. But being a volunteer gives me a feeling of solidarity and warmth.” Previous research points to the forces in the workplace that occlude questions of gender inequality in formulations that antagonize as trade-off's the female's achievements in their careers on the one hand and the make-up of their relationships of care on the other (Niemistö et al., 2021). While our observations supplement critiques of this nature, we also see that these naturalizing discourses might present vehicles of appropriation for disadvantaged identities.

Males with disabilities, by contrast, encounter different barriers in their performance of care. It should be noted at the outset that the relatively small number of participants who identify as male here, while not unusual, limits the extent to which we might generalize the ethics of care as gendered. But what ties the narratives of our male participants together is the ways in which their care activities unequivocally relate to the gendered structure under which division of labor takes place. The effect is that they become further removed from the availability of the care ethics. Zhao has been a renowned editor in state-governed media for over 30 years. He had fallen prey to Myasthenia Gravis a few years before he was due to retire, though he managed to remain in employment by going on repetitious sick leaves. He feels a sense of satisfaction from his occasional participation in voluntary care activities, and his contribution to household chores evinces a practical gesture to support his wife in “learning whatever she wants.” However, he admits that these evaluations reflect the order of his prevailing priorities in which he is “less concerned with money issues now,” perhaps because

he had already established himself in relation to other family members as a respectable elder prior to the deterioration of his physical abilities. In fact, Zhao was the only male participant who made reference of their own volition to the domain of care activities, even if it served only to reproduce the masculine “breadwinner” prototype that was now the privilege for a select few.

The other male participants who were unable to retain some form of employment could only at best establish themselves as “peripheral carers,” an expression analogous to that of the “peripheral worker” assigned to the female worker in the labor market (see Aglietta, 2000). This is because their responsibility for care activities could hardly be regarded, by their families or by themselves, as a sufficient trade-off for paid employment. In fact, the notion of the “ideal worker” that evokes the image of a man in full-time employment with his wife managing familial care in the household has been so deep-seated that the care relationships in which men are involved can only be assessed “as ...[an]... adjunct to their primary roles” (Berger & Piore, 1980, p. 50). Wen, a former manager at a counseling company, for example, spends most of his day tutoring his daughter and completing other household chores following his departure from a lucrative position. However, he is proud that he remains the overriding source of income for his family by contracting freelance orders made possible by his pre-existing connections from his previous job. For those who do not have traditional roles on which to fall back, complaints about obdurate feelings of failure are not uncommon. Gu, a 29-year-old part-time grassroots Internet celebrity with a large following on a video streaming website, feels humiliated because of the lack of visibility of his job in his rural environment, particularly to his relatives and friends who ridicule him as a “cripple.” He rarely discusses his care activities, though only he performs the caregiving his old mother receives. For Gu, the greatest episode of disappointment comes from landing a job as a factory worker but being let go of 4 days into his role owing to his physical limitations. As he said:

I'm not seen as working ever since that ... My childhood friends are either working at local shops or going out of town as migrant workers. They don't know what I am doing and they think I'm useless ... they don't know I'm a popular Kuaishou (the streaming platform) star.

Similarly, 40-year-old Liu, who resigned from his high-salary job in Shanghai and returned home to care for his mother and daughter following the onset of Myasthenia Gravis, also described:

Even today, I can feel the discriminatory attitudes towards me because I am not seen as taking “actual responsibility” for my family... Upon first meeting me, people would assume that I am a macho man (大男人), judging by my appearance, and obviously being at home should not be an appropriate thing for me to do.

There has been the acute observation from Alber and Drotbohm (2015) that alongside the valorization of “care work” in a range of professional and domestic activities is the extension of the concept of “work” into spheres that are not usually labeled as such. They cite Hochschild's (2012) classic term of emotional labor, which treats emotions as an indelible element of professional behavior. Where the ethics of care might accommodate the nomenclature of “care work,” however, we delineate here that the dimensional restrictions of each of “care” and “work” encountered by our participants and the ideologically-peculiar contexts in which they have been implemented undermine its totality. Work, for them, is remunerated and takes place outside the household. “Care work” or “care labor” is oxymoronic where both “care” and “work” remain arenas of exchange our participants refuse to weave together. In the lives of our participants who are both disabled and male, this resistance takes place by “drawing in ready-made, and very specific meanings” of the two concepts that are prejudiced by the patriarchal framework of the division of labor (Ransome, 2007, p. 378).

5.3 | More availability, more recognition?

The benevolent perspective that treats care as the primary source of self-validation for those at the intersection of multiple disadvantages also runs the risk of conflating the availability of cultural identities with the ability to own and perform them (Adkins & Lury, 1999). We argue here that care can be exclusionary, transitory and essentializing. Tan, for example, spent 6 years babysitting her two newborn nephews after she developed Myasthenia Gravis and found herself unable to land a regular, full-time job. However, as the two children reached school age, they were sent increasingly infrequently to Tan's since they were now considered the responsibility of their own biological parents. Although Tan continued to shoulder household duties in the extended family, her involvement was not considered as "a legitimate business" since her parents were not dependent on her critical care. Tan therefore found herself inadvertently deprived of the "carer" role and saddened by the feeling of uselessness that prompted her urge to return to work.

"Why are you still sticking around us all day?" I can feel that my parents are constantly judging me like this shortly after I am relieved from the duty of babysitting my nephews. I am a pain in their hearts ... I got a part-time job as an online editor a few months later.

The recognition of care responsibilities in Tan's case was credited not to her but to the nominal "carer" in the household who was elected by temporally-specific means, which she opportunistically assumed at the irreplicable moment in which her inability to perform a paid job coincided with the family's need for care. In other words, Tan did not "own" her role as a carer in the sense that she could make use of her care responsibilities as a resource for recognition whenever she desired. This finding extends previous research that examines the inalienability of females' sexualized identities from their selves in the gendered relations of production (Adkins & Lury, 1999). Many sexualized identitive practices are so intrinsic to female workers that they are not as well-equipped as their male counterparts to claim them as their own property, outsource them to the labor market and receive compensation for so doing. In a similar vein, we argue that being both female and disabled for some of our participants intensifies the intrinsicity of their care performances (Varul, 2010). Even if the intersecting positionalities between being disabled and female might render the cultural scripts of care more accessible to them, they are not necessarily charged with qualities that are temporally infinite.

Worse still, the expectation that the disabled female should feel indebted to and reciprocate offerings of care might have been so ideologically entrenched that those who attempt to circumvent their care relationships might find themselves falling short of attaining recognition in other ethical spheres that endorse possibilities of self-discovery. Su, for example, dreams of becoming a writer and of "going to Beijing one day and learning traditional medicine from a real master." To her parents, however, Su's dreams were simply inappropriate pursuits after having been dependent upon the family for so many years. As she said:

I know I need to find my own position in the world and make my contributions. That said, my parents are still frustrated with me, and sometimes even annoyed at me, because I can neither take care of them nor do I want to have children. My parents don't understand me but I forgive them.

6 | DISCUSSION AND CONCLUSION

While abled-bodied adults of working age claim access to social membership by their performance of labor (Anderson, 2004), disabled persons are often devoid of these moral possibilities filtered by the domineering ethics of work. Taking as a point of departure the philosophy that "a just society must assure to all citizens effective access to the social bases of equal standing as citizens" (Anderson, 2004, p. 251), a people-centered commitment draws attention

to the moral practices of disabled persons following their exit from full-time employment that determine how they manage, prioritize and locate meaning in their care activities that permeate both private and public spaces. By way of the narratives of self-worth from both our male and female participants that encapsulate the alternative ethics of care, this paper reveals how the inter-mediation between age, gender and ableism shapes its differential availability.

In theoretical terms, a re-shifting of the borders of the prevailing conversation on the concept of exit from paid labor for disabled persons might prove to be fertile. Previous research often considers those decoupled from paid labor as “abnormal” social entities characteristic of “spoiled” identities that exaggerate the stigma against unemployed individuals (Garthwaite, 2015, p. 8). The consequential reinforcement of the primacy of the work ethics leads to the problematic foreclosure of the possibility for “a homogenized, abject non-working identity...[to become]...the initial benchmark from which individuals draw their sense of identity” (Riach & Loretto, 2009, p. 114). We therefore treat “exit” in a way that surrenders mainstream bases of self-recognition (Voswinkel, 2012). We provoke reflection on how policy-driven thinking might benefit from “care” as a prism to complement the lived expectations and realities of disabled persons, beyond the kneejerk and often non-chalant dishing out of disability pensions or employment training programs (Anderson, 2004).

In parsing out the notion of exit under the alternative rubric of care, however, we take *care* to allude to the agency of our participants in defining the imaginative parameters they have reason to value, in tandem with the very structural conditions that both encourage and limit these agentic possibilities. While the possibilities of the care ethics are renewed in crafting a kind of citizenship that is antithetical to the neo-liberal principles of self-sufficiency, the idea that care might be differential and contingent is not new. Individuals and communities have been designated as suitable recipients of care (Muehlebach, 2012; Stevenson, 2014), and practices of care have the propensity to both sustain and interrupt human relationships (Rasell, 2020). In conditions where the pernicious tension evolves between financial and relational aspects of care, substitution for care is not always unorthodox (Biehl, 2012).

We proffer here, however, care as an ethical object available for conditional appropriation that transcends rather than oscillates between the “carer” and “cared-for” categories of analysis. While embracing it as an alternative of significant promise, we reiterate the critical observation that care has sometimes been susceptible to over-determination and that it must be approached by considering it for what it is (Aulino, 2019). We would do well to take heed that “belonging to multiple disadvantaged and excluded groups does not always translate into multiple forms of disadvantage” (Meliou & Mallett, 2022, p. 113). If a politics of care is anti-political since it defends the *status quo* rather than generates a radical political critique (Ticktin, 2011), however, we should never be estopped from imagining better possibilities. Where this paper exposes the circumstances in which care informs new avenues of exclusion, however, the ethics of care we disseminate is fastidiously qualified rather than unwaveringly celebrated.

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CONFLICT OF INTEREST STATEMENT

There is no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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