Doing "Gendered Exit:"
Work, Care, and the Moral Practices of People with Disabilities

Abstract

This paper engages with the gendered moral practices of people with disabilities in employing the care ethic to claim themselves as useful social beings after their exit from the labor market. Previous research on disabled people's exclusion from paid work tends to place them in a fixed, undifferentiated category as the cared-for and implicitly affirms the work ethic as the sole legitimate source of dignity and citizenship. Drawing on in-depth interviews with 26 disabled Myasthenia Gravis patients and 7 of their close families, this paper finds that with an embodied understanding of the interdependence between people, these disabled people actively transcended the carer/cared-for dichotomy and employed the motif of reciprocity for their moral assertion through domestic work and voluntary activities. However, the availability of the cultural scripts of care is not distributed equally under the patriarchal system. While disabled men can at best be established as "peripheral carers," disabled women are placed at the crux where more opportunities as carers do not guarantee their greater ability to exchange this identity for moral recognition. This study demonstrates the differential and contingent nature of care as an alternative to the work ethic in granting equal social membership.

Introduction

Work plays a fundamental role in regulating individuals' identity, dignity, and citizenship in modern society (Grint 2005). However, multiple forms of disadvantages, including disabilities, can impair one's ability to participate in full-time employment, thus leading to an early exit from the labor market (Van Rijn et al. 2014). Due to their inability to actively participate as economic agents, disabled people are constantly marginalized and considered morally inferior in society (Abberley 2018; Garvin 2015). While most scholarly and policy discussions have focused on facilitating the disabled people's integration into the labor market (Hyde 1996; Barnes and Mercer 2005), others point out that disabled people are capable of exhibiting a "counter-hegemonic imagination" through which alternative ethics can be valued regardless of their productivity (Graby 2015). This study thus wants to explore how disabled people draw their sense of self-worth from other cultural scripts than the current work paradigm and claim themselves as valuable and moral social beings after their exit from the labor market.

Specifically, this study examines the availability of the care ethic to the jobless disable for moral assertion, which stresses the interdependent and reciprocal relationship between people, rather than the neoliberal ideals of autonomy and self-reliance (Gilligan 1993; Gibbs 2018). While

previous research has primarily placed them in a fixed, undifferentiated category as the cared-for (Morris 1993), recent studies suggest that disabled people actually engage in a variety of caring relationships through domestic work and voluntary activities (Taylor 2004). These care activities can therefore constitute a central site for the reestablishement of their subjectivity (Chattoo and Ahmad 2008). Meanwhile, we acknowledge that care is a "contested" concept that involves unneglectable power relations, stigmatizing practices and other vexing consequences (Morris 1993; Fine and Glendinning 2005; Mik-Meyer 2016). This study therefore aims at exploring both the possibilities and contingencies of the care ethic to disabled people, especially under the patriarchal system.

Interviews were conducted with twenty-six Myasthenia Gravis patients who were incapacitated to varying degrees due to the disease, and therefore unable to work full-time for at least half a year, along with seven interviews with their close families. Our findings demonstrate the agentive efforts of these patients to actively transcend the carer/cared-for dichotomy, but also point out that the disabled jobless people are not an undifferentiated category: gender and age can intersect with their disabled identity, creating both opportunities and constraints in taking up their caring activities in domestic labor and voluntary work for exchanges of moral recognition.

The rest of the article shall proceed as follows: we begin with a theoretical interrogation of the significance of exit from work and the alternative care ethic. After introducing our research methods, we go on to elaborate how female and male patients encounter differential availability of the care work. While we acknowledge through our analysis that women with disabilities are provided with ample chances of meeting a gendered sense of virtue especially through domestic labor, they do not necessarily have more freedom than men to exit the labor regime because of the essentializing and exclusionary nature of the carer role to them.

Work, ethics, and the sick role

This research is fundamentally concerned with the significance of "exit" from full-time employment in modern society. Regarded as a pivotal life transition, the idea of exit is embedded within social norms surrounding a certain age threshold, which are in turn sustained by institutional arrangements prescribing the temporal order of biographical events (Radl 2012). Early exit, therefore, is usually negatively perceived as a departure from the normative age paradigm, associated with undesirable work conditions (Solem and Mykletun 1997), work-family conflicts (Xue et al. 2020), health issues (Kouwenhoven-Pasmooij et al. 2016), etc. Particularly, disabilities can influence an individual's decision to exit employment early, through pathways such as disability pensions, unemployment, or early retirement (Van Rijn et al. 2014). While risk predictors of exit from work among people with disabilities have been examined extensively (Riphahn 1997; Milner et al. 2018), the significance associated with their transitions into post-working life has received much less scholarly attention (Radl 2012).

Drawing from the discussions on work ethics, one of the powerful symbolic roles that "exit" plays revolves around the morality of the disabled — the "sick role" in Parson's (1951) words — within the current work paradigm. Pervasive discourses on the ethics of work situate work at the center of what fundamentally constitutes one's identity (Abberley 2018). An engagement with work mandates itself as a pre-eminent condition for one's full membership in a society and the recognition of an individual's citizenship (Barnes and Mercer 2005), an indication of the passage to adulthood (Frayne 2015), worthy and responsible family members, as well as disciplined and governable subjects for the extensive social and political modes of cooperation (Weeks 2011). Especially, paid work is valued over other work activities for its participation within the economic system, where one can establish himself as an independent being and contribute to the most valued areas of social life (Barnes and Mercer 2005). This contributes to the situation where mainstream political agendas have long shadowed the possibility of "leading active and varied lives outside of work" (Frayne 2015).

While it is generally acknowledged in most societies that the "sick role" is exempted from work obligations, critics have increasingly pointed out that people with disabilities are not free to exit the labor market in a morally upstanding manner. Rather, they constantly find themselves under the imperative to move off welfare and into the workforce (Frayne 2015). On the one hand, public policies often act as a proactive facilitator in this imperative with various training and education programs tailored especially for the disabled group, which is commonly criticized for an over-reliance on enhancing individual employability (Hyde 1996; Barnes and Mercer 2005). Even the inducement schemes for employers to hire the disabled tend to focus more on making individuals "attractive" to the labor market and less on broadening their choices (Barnes and Mercer 2005). On the other hand, academia is no less complicit in imposing work ethics upon the "sick role." The social model of disability, for example, can implicitly celebrate the integration of the disabled into the workforce as an indisputable good in its examination of the societal barriers that lead to their exclusion (Patrick 2012).

However, since employment can never be a way out for all people with impairments, "full integration of impaired people in social production can never constitute the future to which we as a movement aspire" (Abberley 2018). From this perspective, we are concerned with the "exit" of the "sick role" not only in the sense of their institutional arrangements, but also in the sense of their withdrawal, whether voluntary or involuntary, from the totalizing work regime that dictates one's sense of worth in the society (Voswinkel 2012). Scholars have called for the attention to the "exit" of the "sick role" in pursuit of a counter-hegemonic imagination that can value "alternative, impaired modes of being" regardless of its productivity (Graby 2015). Disabled people, as they argue, particularly possess the potential of being "a symbol for the pre-eminent claims of non-utilitarian values, a visible challenge to anyone who treats his job as a final end itself" (Hunt 1966). In this sense, the focus on the moral practices of the disabled people — the self-enactment of their

own perceptions virtuousness (Oakeshott 1991) — can have theoretical illuminations on the legitimacy of the hegemonic discourses of work as a whole.

Previous studies in this regard have examined multiple moral practices that people with disabilities engage in after they are excluded from full-time employment. One of the most prominent among them is a subjective negotiation of the conceptual boundaries of work so that work encompasses not only paid jobs, but also other creative or domestic activities that can benefit the society (Taylor 2004; Riach and Loretto 2009). Other identity work includes employing the motif of "being active," promoting a sense of self that extends beyond the disabled/able-bodied dichotomies, visually proving one's true condition, etc. (Riach and Loretto 2009; Galvin 2005; Garthwaite 2015). While insightful, these findings tend to, on the one hand, treat the disabled community as a unified, homogenous group without attending to the differences among this category, and on the other hand, produce fragmented accounts of the discursive self without taking into consideration of the cultural scripts available for their identity work (Thomas and Davies 2005). We therefore turn to the ethics of care to see if it could be an alternative moral practice for subject making of the sick role who have exited the labor market.

Care and reciprocity as an alternative ethic

In *In a different voice*, Gilligan (1993) has famously posited an ethic of care based on the moral concerns of human connections and relationships. Following her, numerous scholars have elaborated on and extended care ethics, emphasizing its acknowledgment of the interconnectedness and interdependence among human beings (Hamington 2001). While most of these discussions center around feminist concerns, disability studies have also developed from the care ethic and proposed reciprocity as an alternative to the neoliberal ideal that stresses autonomy and self-reliance (Gibbs 2018). The experience of disability provides the chance for society to recognize "universal vulnerable condition" and respond to constant human interdependence (Fineman and Grear 2016). It is therefore through interrelated, differentiated, and consistent forms of interdependence with each other that the significance of care should stand out as a new model of social justice (Kittay 2013).

However, mainstream academic and policy debates on the caring relationship of the disabled are often framed around a dichotomous notion that places the carer and the patient in separate, fixed categories (Morris 1993). Recent studies have argued against this dichotomy, pointing out that people can practically be carers or cared-for across a variety of different scenarios without being attached to one single position (Williams 2001). Furthermore, it is not only physical tasks of care that need to be recognized, but also the emotional and spiritual part of caring in a reciprocal relationship (Morris 1993). Following this perspective, people with disabilities should not simply be seen as passive recipients of care. Their blurring roles as carers/cared-for actually constitute a key site for negotiating their subjectivity as a "competent social agent" (Chattoo and Ahmad 2008). When brought forth, their caring practices can illuminate how an ethic of

reciprocity can function as "a potential safeguard against these threats" of neoliberal discourses that tend to unmake the personhood of the dependent, thus helping them reassert their personal value and reconstructing them as moral beings (Buch 2014). Research does not particularly abound in this regard, but studies have indicated that when the disabled are viewed as bringing a "gift of difference" to the society with the promise of enhancing alternative altruistic values, it can carry additional recognition for the disabled and help them build up resilience against the odds (Esdaile 2009).

Meanwhile, a redirection from the ethic of work to that of care and reciprocity does not always produce ethically sound outcomes. For one thing, the availability of the "carer" role as a potential repository for building up resilience against the work ethic is not equally distributed across the population. Bodies are always differentially placed and understood, encountering vulnerabilities as well as opportunities over the time of their lives (Gibbs 2018). The changing, intersectional, and sometimes conflicting relationships individuals inhabit can affect certain roles available to them (Mik-Meyer 2016). For the disabled people, their roles as carers under certain circumstances may not be acknowledged as "occurring in sync with recognized forms of a meaningful life and politics" (Gibbs 2018). Especially for the already marginalized group, their deteriorating position within the larger institution can lead to their shrinking freedom of defining the reciprocal relationship as they want (Buch 2014). For another, reciprocity does not guarantee equity. Complicated power relations always find their way into reciprocity relations, making it neither symmetric nor voluntary (Komter 1996). Other scholars have also pointed out that reciprocal relationships sometimes require one party to achieve and maintain some particular embodiment, which is sometimes assigned based on the stereotype attached to a disadvantaged social group (Tyler and Taylor 1998). It can also in certain cases be characterized by "compulsory altruism" or "prescriptive altruism," which is especially common for female members in kin relations (Tyler and Taylor 1998; Komter 1996).

This research thus goes on to raise the following questions: How and to what extent can the disabled people, when excluded from full-time employment, draw their sense of self-worth through their engagement in domestic labor and voluntary work? How is the availability of the cultural scripts of care as a potential mechanism for 'exit' differentially distributed across the disabled community? How do individuals' positionality in the patriarchal system influences their ability of mobilizing the care ethic for exchanges of moral recognition?

Context, Data and Methods

To explore the questions above, we conducted a qualitative study of disabled Myasthenia Gravis patients in China. Myasthenia Gravis is a long-term neuromuscular disease that is characterized by fatigue and muscle weakness in varying degrees, including those related to the eyes, face, and those linked to the ability to walk or stand. This study is part of a larger project that examines the overall patient journey of these Myasthenia Gravis patients as well as their life surrounding work, family

and social support. While Myasthenia Gravis can vary widely in severity, and some patients can lead normal or near normal lives through proper treatment and active physical training, this study purposefully selected patients with moderate to high disease severity, that is, those of whom the affected areas include limb, axial, or even respiratory muscles, to study the influence of their highly debilitating conditions on their lives. Therefore, many of the study participants' experiences can provide a window into the wider disabled community.

The data used for analysis are based on in-depth interviews with 26 Myasthenia Gravis patients, including 7 men and 19 women, along with 7 of their close families. The participants were recruited through Aili, a non-governmental organization for Myasthenia Gravis patients in China aimed primarily at enhancing their quality of life and promoting the public's knowledge about this disease. The age of the recruited participants ranged from 29 to 71 years old. Eight of the participants were from first-line cities in China such as Beijing, Guangzhou, Shenzhen, etc., while the others were from less developed cities and rural areas. The participants had diverse occupational backgrounds. Twenty-three of the participants had not been engaged in full-time paid jobs for at least half a year at the moment of their interviews, and for the other three patients who were holding a full-time job, they both had experienced at least two years of joblessness because of their restricted physical capabilities. Most of the participants, after their diagnosis of Myasthenia Gravis, had spent years juggling between part-time paid jobs – as clerks, online customer service staff, market researchers, online editors, etc. – domestic work, voluntary work, and large amounts of time for treatment, rest, and rehabilitation. There were also a few of the participants who had never engaged in any form of employment, but spent the entire of their adult life primarily at home.

In-depth semi-structured interviews lasted between three to six hours for each interviewee. With each participant, the researcher began with broad questions that helped them walk through their important decisions made regarding medication, work, and family considerations after their diagnosis. Our focus on the patients' life courses was especially helpful for building up an intersectional perspective, with which researchers could simultaneously examine the various intersecting structural and cultural constraints faced by individuals as well as their active agency (Clegg 2016). It also helped to view the participants' change of positionalities across time as they grew older. We paid attention to transitions in their life course such as job hunting/resignation, marriage, childbirth, etc. For each transition, we asked about what effects, in their hindsight, these experiences had on their sense of self-worth. We also asked the patients to describe their daily life in detail and whether they had different career plans for the future. Last, we asked the participants whether they felt recognized from their close relationships as well as from the outside world. For ethical considerations, consent on the purposes and procedures of the research were obtained individually, and the patients were informed of their right to withdraw at any moment before or during the interviews. All participants were anonymized to ensure confidentiality. Each interview was recorded and transcribed verbatim.

Data analysis was conducted in two stages iteratively. In the first stage, we manually coded the first ten interviews by looking for emerging themes in each text, comparing different texts to look for repetitions, similarities or contrasts, and identifying possible mechanisms linking the repetitive themes. As the first stage of analysis was completed, "burden," "caring for others," "worth/recognition" and "future work-related plans" turned out to be recurring themes across the narratives of different interviewees. Major differences surrounding these themes were also identified along axes of gender and generation. In the second stage, we coded all of the interview transcripts with NVivo (Release 1.6.2) to identify subthemes under these major themes and analyze them using a comparative, intercategorical approach (Bauer and Scheim 2019) that focuses specifically on the positionality of a disabled individual at the intersection of age and gender. We held project meetings regularly to discuss the emerging themes, relevant theoretical literature, and our conceptual framework to present our results. The findings of our study are shown below.

Findings

Out of work without being a burden: the fluidity as the cared-for/carer

An "exit" from full-time employment was not easy for any of the patients. The experience as someone out of work and dependent on the care of others made invisible, at least for a time being, all the other roles they had previously taken, thus dictating both their self-recognition as the "sick role" as well as others' perception of them as such. It is however worth noting that the imposition of a long-term "sick role" onto their identity was not a smooth, taken-for-granted process, but involved an active struggle against the "loss of self" that could haunt those encountering biographically disruptive event (Charmaz 2010). The experience often brought about a humiliating feeling of becoming a burden on others, which directly collided with their dignity and pride as a self-reliant subject. One of the patients, the primary income contributor in his family before he quit his job, described his first two months following diagnosis as such:

> I used to work at a construction site and I could easily carry 100 kg of concrete, but during the time when my symptoms were most severe I could not even walk for 3 minutes. I spent my entire day in bed, feeling so guilty looking at my father preparing meals for me. Everytime 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 imperative of the work ethics was so overbearing that many of the participants had attempted to return to work when their symptoms were briefly relieved, only to find it almost impossible to do so. 42-year old Tsai, who held a bachelor's degree from a prestigious university, had been consistently turned down every time she applied for a new job. As she explained, employers would never put themselves in a situation where there were 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, even when the patients were able to secure a job, most of them simply found themselves physically incapable of performing the assigned tasks. Resignation was therefore

only a matter of time, with the more fortunate among them able to turn to flexible, part-time jobs as an alternative source of income to partially cover their medical expenditures.

Studies have highlighted the disabled people's agency in reconstructing their identity by challenging "the embedded concept of illness as unidirectional and deteriorating" (Riach and Loretto 2009). Contrary to this previous knowledge, our study discovers that it is the acceptance of the permanence of disability that more often than not opens up the possibility of exploring new ethics for remapping one's meaning in life. This is most evident when it comes to the issue of holding a disability certificate. None of the patients, when looking back, showed any signs of evasiveness or denial talking about their decision to apply for a disability certificate, but referred to it as a turning point that prompted them to "refocus my life on how to live with the disabilities rather than on how to cure myself." Instead of becoming entrapped within the stereotypical role as a disabled person (Kanter 1977), settling down with the fact that one has to be the "cared-for" for the rest of their lives in turn allowed their disabled status to fade into the backstage and facilitated the rolling-in of other potential roles and relationship.

Taking up the role as a "carer" is one of the most visible and accessible ways for these disabled people to reaffirm themselves as capable of making useful contributions. For many of the participants, there was no clear-cut line between themselves as a "cared-for" or as a "carer" – the daily activities they were engaged in easily overlapped with their domestic duties they had undertaken before the onset of their illness, although they had not been credited with such salience as they were now. As the patients suggested, the act of caring was itself a manifestation of personal value capable of nullifying, or at least destigmatizing, their condition of dependency. 37-year-old Li, for example, expressed her satisfaction with the current status because both her husband and herself were grateful for her presence at home:

> I clean the house, cook meals, and take care of everything surrounding my daughter, including her regular study and her art classes on 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 seem that the patients were subsuming themselves under a long-standing female imaginary surrounding care work by falling back on traditional gendered values for self-identification (Stone 2007). However, we find it insufficient to account for these practices simply by arguing that the "sick role" can only be relegated to the "feminized work" under the traditional, gendered paradigm of the division of labor, or that the exit of the sick role from the labor market only ends up reinforcing the hierarchical ideologies of work marked by both masculinity and ableism (Phillips and Taylor 1980). Instead, we want to point out that the way these disabled people managed and prioritized their lives around work, care, leisure and other activities constituted a consistent struggle that strove to balance pragmatic choices, ethical obligations and ideological imperatives. Even for the female patients who were mainly engaged in domestic caring activities, they were strong and independent characters before they became incapicitated and excluded from the labor market. Many described themselves as "ambitious," "eager to excel," and

"uncomfortable with being dependent on others." Especially for those who developed Myasthenia Gravis after they turned adults, none of them had imagined themselves as a "traditional housewife" before they became disabled, but all had their careers planned out, albeit not necessarily in a long-term manner, as secondary school teachers, airport ground crew members, masseurs, truck drivers, etc. Nonetheless, their exit from the labor market was not altogether seen by themselves as a "compromise," but more as a chance to "rethink what is really important to me."

Furthermore, the caring practices that these disabled people took up were in no way restricted within the domestic sphere, nor exclusive to the female patients only. An observation of the aggregate forms of work done by the disabled community can provide opportunities for a more ambitious recognition that establishes the ethic of care as a commitment to the larger society. 67-year-old Zhang, for example, developed Myasthenia Gravis just a few years before retiring. Looking back, he described the transition he had gone through as "a relief from the pursuit of achievement and promotion" and said,

> 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.

Engaging in caring activities provided a strong foundation for self-assertion through demonstrating their ability to "give out" in the most direct, embodied, and tangible manner while they were experiencing, in possibly one of the deepest ways, the vulnerability of the human body. This is manifested not only in their frequent mentioning of the seemingly mundane yet extremely corporal details of their efforts, but also in the recurring notion of reciprocity throughout the participants' narratives, where they situated care within "precious cycles of material and moral inheritance" (Edwards, Finch, and Mason 1994). This was nicely captured by the words of Shi, a female patient 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 mentioned to us, "everybody experiences pain, although maybe in different forms or degrees," the experience of disability and the resulting dependence led to their embodied perception of the "universal vulnerable condition" (Fineman 2010): the recognition of vulnerability as "a temporally and differentially manifested, but nonetheless consistent potentiality of human experience" (Gibbs 2018). These patients exhibited tremendous agentive efforts in transcending the often reified dichotomy of the carer and the cared for, and employing the motif of care and reciprocity for self-assertion and self-validation when conventional affirmation of personal value is no longer available due to their forced exit from the labor market.

The differential availability of the care ethic
While recognizing that vulnerability is a universal experience, different groups have differentially distributed social, economic and cultural assets that can provide them with the resources to build

up their resilience against the vulnerable condition (Fineman and Grear 2016). In our case, the disabled people's capacity of responding to the crisis of personal value caused by the forced exit from the labor market is also potentially strengthened or impaired, depending on the institutions and cultural norms within which individuals are embedded. Especially, the availability of the care ethic as a potential cultural script for justifying their exit from paid employment is constrained by their expected roles and responsibilities under the patriarchal system. Such availability is not only a gendered construction, but can also be enacted differently during different phases of an individual's life course (Chattoo and Ahmad 2008). This makes the alternative ethic of care at the same time inclusive and exclusive, flexible and rigid.

This was reflected in the contrasting framing of the uptake of the care work between female and male participants in our interviews. Women with disabilities tend to view care as an "alternative," a "substitute," or something that constitutes an entirely separate realm from work but possesses equal, if not greater, significance. The centrality of the notion of reciprocity overlaps with a gendered sense of self-worth as a good mother, wife, or daughter who is capable of reciprocating the affection and love she receives from her close relationships. To be a caregiver is a thing of its own right, and to a certain extent, the modernized evolution of family paradigms in China in turn makes the cultural role of "caregiver" more available to these female patients, especially the single and childless ones. Previous research has pointed out that the Chinese society, as many other countries, is going through "a reconfiguration of the relations of gendered generational interdependence typical of patriarchal family structures" (Santos 2017). This transformation has given rise to new practices of "surrogate parenting," which rely on multiple-mothering formations to perform the "feminine" work of everyday care when the actual parents both focus on the "masculine" work of participating in full-time employment (Santos 2017). This reconfiguration process is especially notable in China where public welfare structures remain limited in most of the rural areas. While the "multiple-mothering formations" normally consist of intergenerational support from grandparents (Cong and Silverstein 2012), our study extends this finding by pointing out that disabled female family members can also play an active role in the multiple-caregiver network in the emerging patriarchal arrangements.

49-year-old Ju, for example, had been living with her aunt since she was struck down by the disease. Completely dependent on her aunt's care 20 years ago, Ju's situation had significantly improved over the years, and she was proud to be able to perform household chores again and took care of her aunt's son. Ju had also made some progress in her career as her symptoms relieved, holding part-time jobs such as online editor. She was looking forward to becoming a certified social worker in the future, but when asked if her aunt would need intensive care at some point as she grew older, Ju 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?

Ju had become the *de facto* "daughter" to her aunt. Her role as the new caregiver in the family was rooted in and further reinforced her perception of care and work as occupying two

distinct, exclusive spheres where taking up the former can justify foregoing the latter. The same was true for disabled women in NGOs. They took great pride in their involvement in these caregiving activities. When asked about the difference between voluntary work and their previous jobs, one patient said, "If it's work, it's pretty much only about earning some money. But being a volunteer gives me a feeling of solidarity and warmness." Previous research has pointed out the naturalization of gender inequality in the workplace where women's achievements in their careers and care relationships are perceived to be trade-offs (Niemistö et al. 2021). While our observations are in line with this finding, we want to further point out that such dominant naturalizing discourses can also be utilized by the disadvantaged group, i.e. women with disabilities in our case, to leverage cultural resources for their claim of recognition and dignity.

Males with disabilities, in contrast, face stricter conditions in their enactment of the carer role. Under some circumstances, their care work can even reproduce and reinforce the gendered structure in the division of labor, thus further narrowing the availability of the care discourses for them. Zhang had been a renowned editor, a career he had been proud of, in state media for almost 30 years. He developed Myasthenia Gravis just a few years before retiring, but managed to stick in his position, though constantly taking sick leaves, till the age of official retirement. He felt satisfied joining voluntary caregiving activities occasionally and shouldering household work as a gesture to support his wife in "learning whatever she wants." However, he also admitted that it was because he was "less concerned with money issues now," which was something unthinkable for him when he was younger. In fact, Zhang was the only male participant throughout our interviews who brought up the topic of caring activities by himself. The invoking of the care discourses only served to reaffirm the masculine "breadwinner" ideal, a privilege reserved only for a tiny few.

For those male patients who had not fulfilled their patriarchal roles, their contributions at home or in voluntary organizations could at best establish themselves as "peripheral carers," a term adapted from the "peripheral worker" role that women have long been, and constantly still are, relegated to in the labor market (Aglietta 2000). Their takeup of the caring activities could hardly be regarded, both by their families and by themselves, as a sufficient "tradeoff" for their paid job. In fact, the naturalizing of the "ideal worker" notion – the picture of a man in full-time employment with a wife at home managing familial care – has been so ingrained that the caring activities men are involved in can only be viewed "as a secondary adjunct to their primary roles" (Berger and Piore 1980: 50). Therefore, for those men who do not have their traditional roles to lean on, they can suffer consistent feelings of "failing." This sense of "failing" can be most evidently embodied in the male patients' dedication to meet the "ideal worker" standard by struggling to bring in the largest share of household income through their patchwork of part-time jobs or outsourcing orders. Wu, a former manager at a counseling company, for example, spent most of his day tutoring his daughter on her coursework and doing other household chores after he quit the lucrative position because of his progressing illness. However, what he was most proud of was being able to remain the major income source in his family by contracting freelance orders

through his former connections at work. Others were not as fortunate. 29-year-old Guo, a part-time grassroots internet celebrity with 120 thousand followers on a video streaming website, still constantly felt "humiliated" because his job was not visible enough in his rural hometown, especially to his relatives and friends who still largely regarded him as the "cripple." He barely talked about his care work, though he was the *de facto* caregiver to his old mother. For Guo, the greatest blow he had undergone was the experience of successfully landing a job as a factory worker, but ending up being fired four days later because of 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.

While the discourses of care can be seemingly encompassing, the cases above show instead that definitional flexibility of "care" and "work" can actually have the effect of "narrowing the discourse," particularly for disabled men, by "drawing in ready-made, and very specific meanings" of the two concepts taken from the patriarchal framework of the division of labor (Ransome 2007). The exit from one category does not automatically guarantee entry into the other. Therefore, the double exclusion of the work and care ethics left Guo – as well as other male patients who were supposed to be playing the "breadwinner" role in their families – no other space for meaning making.

More availability, more recognition?

As demonstrated in the last section, for female patients who have exited the labor market, the flexibility of the reconfigured patriarchal paradigm enables an easier mobilization of the care discourse by resorting to the traditional gendered sense of self-worth. In some sense, the availability of the "carer" role can be "empowering" as it could serve as a source of self-validation in the face of life-changing adversities for a subject at the intersection of multiple disadvantages. However, as I will argue in this section, this way of thinking runs the risk of equalizing the availability of cultural identities with the ability to own and perform them (Adkins and Lury 1999). The ethic of care can also be exclusionary, transitory and essentializing, subject not only to patriarchal norms but also to temporal restrictions, exactly because of the non-detachable nature of the "carer" role to women.

Tsai, for example, spent six years babysitting her two new-born nephews after she developed Myasthenia Gravis and found herself unable to land a regular, full-time job. She perfectly fit into the role as a "mother" in a traditional sense, with the children's biological parents being dual-earner couples. She described this experience as "refilling hope into my life." However, as the two kids reached school age, they were less and less sent to Tsai's place and increasingly, by contrast, seen as the responsibility of their own parents. Although Tsai continued to shoulder household duties in the family, this was not regarded as "a legitimate business" since her parents were not old enough to be fully dependent on her. All of a sudden, Tsai found herself deprived of the "carer" role and, again, haunted by the feeling of uselessness and the 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.

In Tsai's case, the recognition of her care work was credited not to the individual herself, but to the expected "caregiver" in the family which was temporarily naturalized as part of her identity. In other words, Tsai did not "own" her role as a carer in the sense that she could make use of her care work as a resource for recognition anytime or anywhere she intended. This finding extends previous studies examining the inalienability of women's sexualized identities from their selves in the gendered relations of production (Adkins and Lury 1999). Particularly, many sexualized identity practices are so intrinsic to women workers that they are not as well placed as their male counterparts to claim those as their own property, contract them out for labor market resources and get fairly rewarded. In a similar vein, we argue here that for these female patients, their double identity as the disabled further adds to the intrinsicality of their caring performances, as acts of reciprocity are fundamentally expected from the "sick role" for an exchange of deservingness (Varul 2010). Therefore, even though the intersecting positionality of disability and female identity might make the cultural scripts of care more accessible to them, this accessibility does not naturally translate to qualities that can be detached and mobilized from an abstract human being for their own uses. As a result, their achievement of this cultural self is not necessarily rewarded in the moral arena. As these disabled females do not take full control of the symbolic value of their care work, their resort to care as an alternative ethic can only be contingent, dependent upon constantly changing patriarchal relations for the emergence or maintenance of the "caregiver" role.

Even worse, the expectation that the disabled women "should feel indebted and reciprocate the care" can be so normalized that those who want to subvert the normalization may find themselves unable to attain recognition in other ethical spheres that primarily endorse adventures, self-discovery or personal development. In other words, they are denied the authorship of their own identity and the ability to claim their own moral anchoring of the self as acknowledged ways of living (Adkins and Lury 1999). 36-year-old Sun, for example, had two ambitious dreams: to become a writer and to "go to Beijing one day and learn traditional medicine from a real master." However, in the eyes of her parents, this was not what she was supposed to be pursuing after being 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.

Women with disabilities are thus placed at a crux – while their positionality in the patriarchal system entails larger availability of the cultural scripts of care after their exit from the labor market, that availability does not necessarily translate into their better prospects of claiming the care work as their own property and freely exchange that in the moral arena for recognition. In

this sense, care is "contested" in another meaning: while it seemingly provides legitimate ways for the constitution of subjectivity out of the moral commands of the labor regime, the essentializing nature of care can make it further exclusionary for both men and women (though in different ways), thus capable of creating new modes of oppression.

Discussion and conclusions

This work is fundamentally grounded on the belief that "a just society must assure to all citizens effective access to the social bases of equal standing as citizens" (Anderson 2004). While abled-bodied adults of working age usually have access to full membership in society by fulfilling some role in the division of labor (Anderson 2004), people with disabilities are effectively deprived of most of these moral possibilities, especially under the pervasive culture of "work ethic." This article thus sets out to explore their moral practices after their exit from full-time employment, focusing on how they manage, prioritize, and make meaning of their caring activities both in private and in public spheres. In examining both female and male patients' narratives on their sense of self-worth, this study shows how age, gender and ableism intersect to shape not only the differential availability of the cultural scripts of care to each individual under the patriarchal system, but also their ability to actually make use of their care work for moral exchanges of recognition and empowerment.

As the foregoing analysis demonstrates, people who were physically incapacitated, with an embodied understanding of the vulnerability of the human body, exhibited agentive efforts to make tangible contributions and establish themselves as useful social beings through engaging in domestic caring relationships an public voluntary activities. However, the opportunities to take up the cultural scripts of care were distributed unequally across the population — disabled men could at best be acknowledged as "peripheral carers," with their caring practices only serving to reinforce the hierarchical, gendered division of labor; in contrast, different generations of disabled women were provided with more chances of meeting a gendered sense of virtue, partly thanks to the "modernized" reconfiguration and reimposition of patriarchal roles. While this could be a source of self-assertion, this study also points out that females with disabilities are placed at the crux where the availability of the cultural identities as carers does not guarantee their ability to exchange this identity for moral recognition, because their double identity could further normalize and essentialize the expectation that they are obliged to reciprocate the care they have received. Furthermore, the care discourses could even deprive disabled women of the opportunities for pursuing other ethics that primarily endorse self-development and self-actualization.

Theoretically, this study seeks to contribute to the current debates on the notion of exit from paid labor, especially those concerning issues on disability. Previous studies have primarily considered those not engaged in paid labor as "abnormal," often drawing on Goffman's notion of "spoiled identities" to examine the stigma attached to unemployed individuals (Garthwaite 2015). This not only naturalizes and reinforces the work ethic discourse, but also implies that "a

homogenized, abject non-working identity is the initial benchmark from which individuals draw their sense of identity" (Riach and Loretto 2009), thus denying their own authorship of their identity. This study, instead, draws on a more proactive dimension of "exit" to account for their practices of self-assertion that give up on the mainstream basis of recognition (Voswinkel 2012). In exploring this notion of exit, this study attends to both the agency of disabled people in defining the kind of evaluation that is appropriate to them, as well as the structural conditions that affect the possibilities and barriers they face. Our findings on the shift of values are consistent with other studies that are conducted not around the disabled or sick, but other groups excluded from the labor market, such as housewives (Stone 2007). By bringing forward the moral practices of their exit, this study also calls for the necessity of policy reforms that can grant institutional recognition and status to unemployed individuals, rather than only relying on the use of disability pensions or employment training programs (Anderson 2004).

This study also contributes to the dialogues on the possibilities offered by the care ethic in creating a kind of citizenship that stands in opposition to neoliberal values of autonomy and self-reliance. While celebrating the care ethic as a promising alternative, this study share similar insights with past research that care is an inherently "contested" concept (Shakespeare 2000). However, our study goes beyond past research that have largely approached this issue by addressing the power relations surrounding care and the resulting dependency or stigma (Morris 1993; Fine and Glendinning 2005; Mik-Meyer 2016). By looking into the differential and contingent access to the care discourse within the disabled jobless people themselves, we point out that the capability of mobilizing care work for recognition is conditioned, first, on the availability of the specific cultural script to individuals that the existing social system deems legitimate, and second, on the detachability of such cultural roles for moral exchanges as they see fit. Especially, our discussion on the latter points to circumstances under which care can be essentializing and exclusionary, leading to new forms of oppression.

Finally, we want to mention that our findings from the analysis of both female and male disabled people are in line with other scholars' opinion that "belonging to multiple disadvantaged and excluded groups does not always translate into multiple forms of disadvantage" (Meliou and Mallett 2022). Being a female disabled person, in our case, may have easier access to other cultural scripts in terms of maintaining one's self-perceived virtue than being a male one. However, we also demonstrate through our study that an intersectional approach requires not only the attention to what an individual's positionality might entail regarding the availability of resources, but also how capable these individuals actually are in terms of mobilizing the resources for recognition. An examination of the latter may reveal the differential capabilities across the population that cannot be reduced to the unequal distribution of resources, but involve a deeper structural configuration of the access to freedom and power.

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