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# A DELICATE BALANCE

## Chronic Conditions and Workspace

This is a portion of a qualitative critical disability survey examining the timing and spacing realities in the lives women with physical disabilities. The women in this chapter identify as having a chronic condition or illness (Hansen), and each of the women chose their own pseudonym to disguise their identity. The social context of disability in public/private space is examined from their perspectives. Moving beyond individual incapacity in the workplace, this study explores wider social perceptions and attitudes. Through a series of in-depth interviews developed in conjunction with and involving women in Scotland and Canada, the interconnection of a community and workspaces is explored.

The amount of "work" required for many to "go to work" and "do the job" in "regular" inflexible workplaces is overwhelming. Constantly working against physical, social, and emotional barriers exacts a heavy personal toll, particularly when fatigue and impairment issues are a daily reality. Nonetheless, these women have devised complex and creative methods to work within and around the non-disabled parameters to make their own way on their own terms in the workplace.

### WORKSPACE AND IMPAIRMENT: SOCIAL JUXTAPOSITION

Assumptions about the nature of employment are often at odds with social perceptions of the incapacity that is commonly associated with disability and chronic illness. Parallels can be drawn with the presence of non-disabled women in the workplace: "the embodied woman appears as an inferior 'other'" (McDowell and Court 734).

Fear of job loss, or misperceptions of inability stemming from

negative social attitudes and stereotypes, lead many women to minimize or to conceal the reality of their condition in the workplace. Passing and resisting can be both physically and psychologically demanding:

> Social and physical environments are designed and built to exclude particular mind/body differences … histories of ableism, medical categorisation and surveillance can enlighten us, and how people collectively and individually resist embodied and social limitations that mind/body differences can bring.… (Butler and Parr 10)

Consequently, these individuals take great pains to "fit" into the non-disabled workplace with as little disruption as possible. McDowell and Court's study of women in banking noted that many of the women they interviewed: "[S]uggested that their workplace persona was unreal. They talked about 'building up a shell,' of 'adopting a different sense of myself'" (746).

Some women feel the need to justify the right to be present in the working environment. Kim's experience is typical:

> I'm in a chair, and they knew that from my application but they also knew, because where you state you have a disability, I always say that it's not progressive and that I'm fit and healthy enough, because really, I mean it means nothing, but yeah, it's good, it's hard work. (Kim, 48, Scotland)

Camryn sees advantages in an invisible condition (arthritis) as she is able to maintain some privacy. She is not on "display" to the same degree as those with visible markers of chronic illness, like wheelchairs. Her experience shows the level of energy required to maintain appearances:

> I'm lucky I guess in that way because I can pretty much hide it.… Some bosses I haven't told either … and I wouldn't because I don't think they would be accepting … after a while you forget who knows and who doesn't know! … So somebody asks … what happened, have I hurt my leg …

> or … if my feet are sore because of the shoes I'm wearing, and I can't remember if that person knows the real reason or not, so you tend to get into a bit of a mess.… (Camryn, 39, Canada)

Mitzi relates her experience:

> It wasn't something that anybody knew about [Mitzi has arthritis]. The only thing that bothered me was stairs.… Everybody knew I didn't like going up stairs. If there was a lift in the building, I'd use that; if I had to go upstairs, then I would, but other than that, no, I didn't go upstairs. That was really the only thing.… I was always able to work and able to do things myself … so it never really disabled me enough to stop me working. My knees used to be sore all the time, but I mean, no, it never bothered me. (Mitzi, 46, Scotland)

Others told of their conditions being discounted by their employers because the impairment was not readily identifiable and therefore "all in the head." Molly relates her experience prior to her diagnosis with multiple sclerosis (MS):

> I think everybody was very concerned, I got lots of help actually, and I saw lots of different neurologists and I had everyone telling me it was probably a psychological problem, and so we couldn't imagine quite why that would be. I even went to the extent of going to see a psychiatrist who told me that I seemed to be a very level-headed type of person. (Molly, 63, Canada)

The same thing happened to Chris:

> My director said, "There's nothing wrong with you, Chris [Chris has repetitive strain injury], it's all in your head," and I've had comments like that because people can't see anything wrong with me, and I think sometimes people with visible disabilities have a better chance at things than people with invisible ones [disabilities].… (Chris, 42, Canada)

Babette refers to "tricks of the trade" to "pass" as a sighted person in the more "public" spaces of her job setting when she held the position of university lecturer. (She has limited vision resulting from a stroke.) She did this in order to be seen as competent and professional by stu- dents and colleagues:

> I taught three courses a year and I always got really good ratings, but I used to go into the classroom before I would actually teach in it and get the lay of the land, so that I'd know where the steps were and if there were stairs that went up into the classroom, or how the ledge was for the board, and I used to write on the board, and I used to memorize my overheads and point to them as though I could see it. Then I'd stand back—you know the tricks of the trade—you'd stand back, and somebody would say what's the fourth word and I'd say, "Oh, I haven't got my glasses on, what word are you talking about?" … so no one ever knew I was vision impaired. (Babette, 47, Canada)

Women expressed real fear that their employers would discover their conditions. Barbie felt that employer knowledge would compound an already difficult working environment:

> I didn't tell them.… That was when I worked in the De- partment and it was really very hard going because … I had to put up with a lot of jokes because I was the only girl. (Barbie, 38, Scotland)

Olive did not want to change her work activity for as long as possible (visiting clients) and adopted a label to help explain her condition in a manner that she felt would be more palatable to her supervisors:

> I still continued the job I was doing, but not telling anybody that I had MS.… I was frightened, I think, because the group of people I used to go round [Olive was a community nurse] and see it was in the evening.… I did a round where there were quite a few people with MS, really bad MS, and I felt that if I told … the people I was working for, the health board, that they might stop me from going to these people, so I didn't

> tell them. I didn't want a lighter load, so I didn't tell them. I did get support from my GP, who used to write out "post-viral debility" instead of saying she's got MS, so that was quite useful. (Olive, 52, Scotland)

Alfie shares the experience of different levels of disclosure arising because some impairments are considered more socially acceptable than others. She believes her bodily scars resulting from burns are more acceptable than the less visible chronic depression. She speaks about the possible detriment to her career should her depression be discovered. Alfie relates the conditional nature of the level of acceptance of im- pairment in her workplace and the reality of the "public" and "private" nature of her condition:

> … a couple of people at work know I'm on medication, that I see a shrink once a week, so it's possible that they knew and if they do then they're okay about it.… With the appearance thing, I'm fairly upfront with people once I get to know them a little bit and can assume that they want to know what's different or wrong with me, and so I'm fairly forthcoming about that. I guess the fear is that if people actually knew—if my boss or senior people in the department who may in the future be looking at hiring me or promoting me—were aware of my psychiatric disability, that could … would … impede my chances of climbing the ladder, even though I really don't want to climb all that much higher than where I am now. I want to at least maintain the flexibility, and if they knew, if it was known that I have problems of chronic depression.… (Alfie, 34, Canada)

## SUPERWOMAN: PROVING WORTH

Many of the women felt that they had to prove their worth as employees by performing at an exceptional level in order to justify their presence to supervisors and other workers. They felt that they were always "on approval," and because of that had to work to a much higher standard than the "average" non-disabled worker to be perceived as competent as Mary Lou relates:

> I feel at times I'm having to always sort of make up for that and put in maybe a 150 percent, but I'm getting better in that regard. I do my job as best I can and don't have the same sense that I'm always having to really prove that I can in fact do with my training what I'm trained to do. (Mary Lou, 45, Canada)

Part-time work is a necessity for some workers in this study in order to manage levels of fatigue or discomfort associated with certain types of impairment. Chris expressed sentiments common to many women working part-time:

> I think that even though I work part-time, I still feel as if I should be doing the work of a full-time employee and I still fit five days' worth of work into four days. I often take work home with me to compensate for the fact that I'm not in the other day, but then I do all that toward time off.… But I feel like I do have to work that bit harder because I'm only here part time. (Chris, 42, Canada)

Camryn speaks of feeling compelled to perform while dealing with energy restrictions:

> Some days I don't find … I have the energy levels I used to, so I do feel I'm underperforming, but that's not really anything that's said to me, that's just me. I do feel pressure, the bosses … I can't even put it into words. (Camryn, 39, Canada)

However, a supportive workplace environment can substantively enable chronically ill employees to work to the fullest, as Mary Lou explains:

> The years prior coming to my current job site was at a rehabilitation hospital and actually they were very accommodating there. I really had the opposite experience—things were in place for me immediately. Certainly one example comes to mind—that I had trouble holding the phone to dictate reports into a central word-processing centre—so within a few days of mentioning that to my supervisor, I had

> a hands-free Dictaphone system on my desk, which I used with a foot pedal, and I could simply just sit and dictate my reports and it was terrific. Also, just in terms of shelving and things that were adapted in my own office, they were done very quickly, sometimes even before me pointing them out. I just had a really exceptional supervisor who just seemed to be willing to have everything in place to enable me to do my job. (Mary Lou, 45, Canada)

## BUILDING COMFORT LEVELS

Many women spent their energy trying to create and to maintain their physical space in the workplace. These women work hard at trying to accommodate their conditions in addition to meeting the requirements of their position. Indeed, these requirements must be addressed before dealing with employment duties.

Performance and ability remain bound up in physicality (McDowell). Lack of creativity and the inflexibility of some employers restrict workplace opportunities for many women. Barbie's experience is typical:

> I mean they said things to me like, "Well, you can't get training anyway because you won't be able to stand and you can't use your arm." (Barbie, 38, Scotland)

Workplace accommodations are frequently done grudgingly and women often feel that their need for adaptation disrupts the "natural" functioning or flow and order of the workspace as Mary Lou explains:

> I'm just feeling that I have to continually advocate to make sure the accommodations are in place.… It really has taken a toll because your energy is being channelled in that area instead of … being able to … do my work. (Mary Lou, 45, Canada)

Chris discusses the experience of seeking necessary accommodations:

> It's very stressful, especially as disabled employees are, well, obviously if you're disabled enough, that helps to start off with, but you're not as strong, you're weaker, not necessarily weaker,

> but you don't have the energies often to fight with, and I think they use that, knowing that you're more apt to back down, and a lot of disabled people I know that feel uncomfortable asking for special things or something different, not necessarily special, but something they need. (Chris, 42, Canada)

Requests for employment accommodation are often avoided by the women for fear of questions relating to work competency, as Camryn relates:

> I just don't even go there and I should, right? So that would make it easier, and most of that might just be me too, right? But I'm not willing to step out of that one and say, "I need this, I want this." It would make life easier, I think, being able to order ergonomic equipment … like I would want something better for my arm to rest on. Right now I have something, but it's not that great, but asking for something better or different [makes] you feel kind of like you're asking [for] something unreasonable. (Camryn, 39, Canada)

High levels of stress and anxiety resulting from struggling for accommodation is a common issue. For individuals with compromised energy levels, this is taxing, as Mary Lou conveys:

> I certainly have sensed from early on that it probably isn't a level playing field in terms of some of the accommodations I've needed. I often have to really persist, certainly in terms of getting a wheelchair-accessible washroom. It took about eight years for that to be completed. In terms of my office set-up too, it's just a constant struggle.… (Mary Lou, 45, Canada)

The "workings" of the workplace entail more than the job. The social-cultural intricacies are often quite complex. There are micro-social relationships, some of which bear directly on advancement or salary increases. Accessing these elements can be difficult for chronically ill employees because of fear on the part of non-disabled

people. It is usually left to the employee to address the situation, as Alfie explains:

> I've developed more of a sense of humour about it, and I try and kid around a bit, or if they're opening a conversation and I'm comfortable with the person or the people there, I'll use the opportunity to explain and they're usually quite surprised. Well, not surprised because they all usually wonder what the scars are about … (Alfie, 34, Canada)

Employees can be supported and accommodated within the workspace when the information they share is met with creativity and empathy. In many instances this holistic approach to the workplace has been instrumental in building self-esteem and a positive self-image, as Barbie's experience illustrates:

> The agency … offered me the job.… It completely changed my life in a fantastic way, and I just felt so valued and useful and I felt like I was creative for the first time in my life, and I felt I was innovative for the first time in my life and I felt I had good ideas. It was just a fantastic job for me and I was working from home and I had incredible flexibility and if I had to travel, which I had to do quite a bit of travelling, they were happy to pay me travel expenses because they knew I couldn't drive far … so it was just a great job. It was really sort of putting me back together again. I was kind of like a remodelled person! (Barbie, 38, Scotland)

Employers can be ill at ease with a worker with a newly diagnosed chronic illness returning to the job, as Barbie illustrates in an experience with her previous employer:

> [T]hey just said, "You know, this isn't working," and if I went back to work, I wouldn't be allowed to stay on as an assistant manager and they wouldn't let me keep that grade because I was trying to maybe reduce my hours and go back part-time, but they said, well, I couldn't do the job … and that was it. (Barbie, 38, Scotland)

Alternatively, Joanne's employers showed what can happen when teamwork and creative thinking come together to facilitate accommodation of a newly diagnosed condition:

> They've been fantastic … really good. They've tried to keep me on, much longer than they need to. I don't just mean legally, they kept me on even more than they had to within the local authority. They've been very, very supportive, given me equipment at home, computers, comfortable chairs, you know, worked with me to decide what little bits and pieces I could work with them, even though I was still off work. (Joanne, 48, Scotland)

## TIMING AND SPACING

Time use is a pivotal factor for individuals with restricted levels of mobility, agility, dexterity, and energy. Maintaining time, speed, and personal energy levels is a constant, delicate balancing exercise for chronically ill women. This level of time management is largely unknown to the non-disabled. As Chouinard explains:

> For women with disabilities, negotiating spaces of everyday life, such as the home and workplace, is often difficult, contradictory and oppressive. This is because experiencing spaces through a disabled body not only involves significant physical and mental challenges, dealing with significant limits to one's ability to act, but also encountering and responding to complex, often social rules and cultural codes which mark the disabled body. (142)

Chronically ill women are using and battling with space and environments in order to present themselves as competent workers, as Kim and Dolly relate:

> [I] have it organized so that most of my teaching is in the morning.… I've more energy in the morning. I've said to them, "Look, if I can do my teaching in the morning, then I can go home and crawl into bed in the afternoon.… There's been lots of times when I work at home. (Kim, 48, Scotland)

> I have to empty my bladder every couple of hours, and I also have to make sure that I'm not sitting or standing for long periods of time … I tire easily. (Dolly, 34, Canada)

Time-space demands are an integral part of the job for any employee. There are those that apply specifically to chronically ill women managing their own time and space to allow them to be seen as competent employees before, as it were, any of the specific requirements of the job are taken into consideration. For example, Olive speaks of extreme fatigue experienced at the end of a workday and how it impacts heavily on her domestic life:

> Sometimes it's quite hard because I have to go in maybe at lunchtime, and then I'm not getting home until after 8 p.m., which is very tiring. It is very long, but I usually have somebody waiting in here so that when I come back, they can sort of help me get to bed and maybe make me something to eat if I'm not past it by that time, so that's quite a hard day. (Olive, 52, Scotland)

Maureen has ME, or Chronic Fatigue Syndrome. Her positive experience shows how, with a bit of creative thinking and flexibility, employers and employees are able to develop approaches to timing and spacing:

> One of the ways that we managed to accommodate my needs to work in this environment was to have a seven-day week and flexible hours with the ability to work from home as needed and not scheduled.… I was given taxi chits to go to courses, whereas most employees would have to travel by local transport system, so again in a confidential and privileged manner, I was allowed to spare energy by the gov- ernment paying for my transportation costs [and avoid fatigue by taking taxis instead of public transportation]. (Maureen, 49, Canada)

## DOMESTIC TIME/WORKSPACE

Traditionally, the "public" environment of the workplace is viewed as separate from the "private" environment of the home, reflecting

socially ascribed beliefs. Convention dictates "private" domestic activity does not impact on the "public" domain of the workplace. But as Davies (2001) explains, the time/space demands lack demarcation for women:

> Space and time are thereby not individual resources as such; rather they must be understood in a relational manner. Put in simple terms, where women find themselves and when they find themselves and when they find themselves where they are, are importantly determined by the needs of others. (137)

The "home" environment has a profound impact on individual ability to access workspace. Personal care and domestic activities are generally treated as both "personal" and "private," yet, for chronically ill women, they connect.

Fawcett (2000) showed that respondents with impairments often spent significantly more time and energy on household and personal care responsibilities than they did on employment-related duties. Fawcett (1996) drew strong links between support in the household and the person's availability for employment. Organization and timing at home can often play a pivotal role in workplace success. "Activities cannot be neatly scheduled; the unexpected repeatedly rears its head and demands flexibility and a process relation to time" (Davies 143).

There is a complex "science" of timings, spacings, and organization enabling these women to manage in non-disabled space and gain the "approval" of colleagues and society. It is as if these private activities are remote. Often these "taken for granted" and "private" activities have a profound individual and social impact, so obvious but "invisible." Little conscious awareness from these women of the time, effort, or importance involved does not suggest insignificance. Lilly and Vicki explain:

> It's a science. I've been working on this for the past four years, just because I have difficulty getting up early, so in order to catch my 7:30 a.m. bus, I need to be very organized and structured the night before, [and] do all the prep the night before, otherwise I would not have enough time in the morning. (Lilly, 34, Canada)

> It's planned to the minute. Well, I get up as late as possible. I hate getting up, and I just shower or wash, get dressed. If I'm really organized, I'll have planned what I'm going to wear the night before. I'll have it all out, even down to jewellery. (Vicki, 29, Scotland)

Frequently a difficult balance is sustained between fixed amounts of time and limited energy levels (Fawcett 1996). It may take longer to complete personal care or domestic tasks. These women begin their mornings at a very early hour in order for their medication to take effect, thereby enabling them to function effectively on the job, as Barbie illustrates:

> I'm managing really by … [going] to bed really early. I have to rest as much as I can. I have to get up really early to get myself dressed and ready in time, and to be able to drive in the morning is quite difficult, as it's really painful driving in the morning, so I have to get up really early and get medicated really early and I do that. I wake up about 6:30 a.m. and take all the medication and I eat at 6:30 a.m., and then I get up at 7:00 a.m. (Barbie, 38, Scotland)

The time and effort required for personal care, such as bathing or housework and meals, is often overlooked, but it is the real "work" that begins the working day for many women. Kim's experience is common:

> I'm up about 6:30 a.m. and 6:45 a.m., shower, breakfast, unlock the door because I hate sitting in traffic, and my first class is at 9:15 a.m. I like that quiet hour. If I'm in at 8 a.m., I can have a coffee … organize myself for the day a bit … up and out after a healthy breakfast, just my usual shower, and then I'm out the door.… (Kim, 48, Scotland)

Links between employment and domestic assistance must be understood: Employment should not preclude the need for domestic help, which may assist work performance. Domestic assistance would be cost-effective, thus enabling more women to enter paid work. Audrey and Babette discuss this need:

> We tend not to get home help because you're working.… Well, … they seem to think that because you're working, if you're able to work, you're able to do housework. (Audrey, 55, Scotland)

> I would really benefit from a couple of hours of home support where someone could chop vegetables for me, or whatever, and I could make a chili, but I don't have that.… You have to be incapable of standing for a certain amount of time, and I am sometimes, but other times I'm perfectly capable of doing it, so it's the variability of my symptoms that prevents me from accessing anything, and it's also—and I say this with some caution, but it's true—I don't like to say it, but it's true. It's also because my physicians don't want to see me as needing home support so that when I broach it with them, it's … "Oh, you're young and you're okay." (Babette, 47, Canada)

Wider community space in relation to work is an important factor in a chronically ill woman's ability to function in and access workspace. Many do not drive or have their own means of transport and therefore utilize other mechanisms. Proximity takes on greater significance when speed, fatigue, and distance are complicating factors. Hence, centrally located housing, shopping, and medical services enable these women to schedule numerous activities.

Working-life experiences are markedly different. Babette has more control over her workspace (she is a psychologist). Her experience in this respect is very different from many of the women I interviewed.

> Recently I've closed an office that was out of my building because I was travelling by [disability transport] and it was taking me roughly an hour and a half to get to work in the morning, so I now have a practice where my office is one apartment away from my own home, so getting to the office is no longer an issue, it's just basically walking to an office. (Babette, 47, Canada)

Yet, despite a different educational experience, Wendy has been able to adapt her work in the home around a changing impairment:

> I did bed and breakfast, just two rooms, when I found out I couldn't work. I wanted to do something, and bed and breakfast is fine when you have a young family. What I did when I was running the B&B is, I'd rest in between each activity, like after making beds I'd rest for an hour; after cleaning I'd rest for another hour. I really had to measure what I did. I never hurried. It's hard because I was always a fast person. Now I do everything in sections. (Wendy, 56, Scotland)

## CONCLUSION

The effort required to work (paid or unpaid) begins long before chronically ill women enter the working environment. Revolutionary changes are needed in order to achieve substantive results. In order to facilitate this process, the depth, texture, and complexity of chronic illness in a relational context must be fully understood. If real progress is to be made, a grounded sensitivity to the timings and spacings of everyday life for women with chronic illness is needed. Imagine if the majority world thought beyond established boundaries and recognized the potential of these women on their terms.

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