Public space and impairment: an introspective case study of disabling and enabling experiences

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The present article takes a phenomenological approach to the study of disability in the social setting of public space. It is an autobiographical account. The introspective methodology expands the already contested field of illness narratives in qualitative research. Three major themes are addressed: accessibility of public space; routines for managing with functional limitations; and inner dialogues of being on display for self and others. Moral and emotional reflections over acquired impairment and over ‘successful’ managing of impairment are discussed within conceptual frameworks of embodied consciousness, fluidity of movement, and staring. In this case study of body–space relations, enabling moments are primarily experienced and sought in terms of the ‘absent’ body. Disabling moments are to be found in physical and emotional barriers to navigating space and in self-surveillance. Ongoing oscillation between enabling and disabling states of mind is experienced.

Keywords: illness narrative; self; body; public space; accessibility; strangers; disability; impairment; chronic pain

Introduction

The present article discusses public space and the reflexive construction of disability through embodied consciousness, practices, and feelings. It is a first-person account – a case study of the author, by the author. By presenting a personal illness narrative, it contributes to an understanding of disabling and enabling experiences, giving witness to a reflexive inner dialogue accompanying an acquired impairment. The geographical and relational dimensions of public space elicit a variety of practices and emotional responses. Venturing out into public space has opposing consequences, both disabling and enabling.

The article begins with a presentation of the self-reflexive methodology employed here. Introductory definitions of key concepts and impairment background pertinent to the discussion follow. Subsequent sections of the article deal with a case study of generalized reflections over public space and disability, pragmatic understandings of accessibility, and practices constructing routines as a crutch to reduce the physical and emotional demands of journeys and participation in public space. Emphasis is placed on the relational aspects of being in public space with strangers, with being on display to others, on self-surveillance and on implications for moral integrity.

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Varying and fleeting modes of embodied consciousness are dimensions in the lived experience of disability.

The self-reflexive method

The present article is a first-person account of practices and reflections of the author as a disabled sociologist and disability researcher using public spaces and places. The methodology of this autobiographical ‘case study’ is one of introspection grounded in a conceptual framework of embodied consciousness and contextualized socially in public space. The text is personal without being private. The narrative of practices and reflections is edited for structure, clarity, and coherence without reducing complexity and ambiguity. Seasoned reflexivity requires honesty and a willingness to express politically incorrect or unflattering positions that one may have. Reflexive writing is an ‘identity site’ (Holstein and Gubrium 1995) in much the same manner as an intensive qualitative interview, a performance of self-presentation but without the directions or interference of an interviewer. The genre has a confessional nature, creating more room for ‘the dark side’ of inner feelings than traditional interview techniques. The self-reflexive method is a slow process, finished only when the edited text rings true to the inner ear. The critical distance of the researcher to his or her subject is replaced by the author’s critical distance to the text. No sooner than thoughts are expressed in writing do they begin ‘a life of their own’ subject to the author’s scrutiny and interpretation.

As a single case, no claim can be made of representing others. Still, much of the general is manifest in the individual. Many persons, disabled, chronically ill and able-bodied alike, may be able to identify themselves with parts of the story. The place and analytic approach to narrative methods in the study of illness and impairment is highly contested, as shown by Thomas (2010) and the responses to her presentation of the debate (Atkinson, Bochner and Frank 2010). In this heated terrain, first-person accounts are seemingly always fronted by someone else, a researcher, who either helps the narrator’s voice take form or deconstructs it to another level or manner of discourse. This autobiographical article does without the middleman. The author presents her own impairment narrative.

Autobiographical accounts by impaired academics are not uncommon in the disability literature, but they typically are published in anthologies and monographs, not research journal articles. This is unfortunate in my view because it restricts our ability to contribute to disability discourses. It is a paradox that while often dismissed as not being ‘research’, first-person accounts are frequently cited as evidence and used as data in research by other parties, entering professional discourse by the back door. An Institute for Scientific Information (ISI) Web of Science-cited reference search showed that Robert Murphy’s (1987) autobiographical account The Body Silent, for instance, had 267 citations in professional works as of August 2011.

It is admittedly problematic to analyze one’s own account critically but all analysis is riddled with potholes of misunderstanding and inevitable partiality. Here the author/researcher succeeds in experiencing the ‘native’s point of view’, a shared horizon and empathetic interpretation of the subject characterizing hermeneutics of restoration (Josselson 2004). The social positioning and the voice of the researcher/author are almost identical to that of the subject of the account. The discordance rests in academic terminology and language structure. I, the case under study, think in
terms of embodied consciousness because of personal experiences and professional training, but would be unlikely to use such terms in non academic discourse.

**Conceptualization of key concepts**

**Disabling and enabling experiences**

Key concepts of this discussion are ‘enabling’ and ‘disabling’ experiences and reflections. ‘Enabling’ experiences are twofold – one active and one reflexive. In the active modus, I ‘just do it’. My body is a vehicle for performing a task – walking down a street, hiking on a trail. My body is ‘absent’ as attention is directed outwards toward the world and my participation in the world. Embodied consciousness sinks into the background (Crossley 2006; Williams 1996; Leder 1990). The mind-set of the absent body is a personal goal for some waking moments every day. In the reflexive modus, ‘parts’ or aspects of my body are present, the positive parts. In the reflexive modus, I reflect upon the capabilities I possess and capabilities which I may develop in the future. The satisfaction of mastering participation in activities accumulates and combines with visions of future possibilities, strengthening my confidence and resolve for further participation. This reflexive modus of constructing enabling moments is likewise a personal goal.

‘Disabling experiences’ are also twofold and refer to situations whereby I experience and/or reflect upon reduced and inadequate capability, difference, abnormality, estrangement, and restricted options. More or less objective environmental barriers to being in public space and participating in various activities are at issue. The main focus of the present article, however, is on subjective experience of disabling moments. In disabling experiences embodied consciousness is front of stage in a negative sense. Leder (1990) called it ‘dys-appearance’ to stress how consciousness of something being wrong with the body brings the ‘absent body’ to the fore. Chronic pain, for instance, draws attention away from the world and participation in it, forcibly drawing attention to one’s body or bits thereof that hurt. As Leder (1990) notes, however, even chronic pain is marked with an episodic nature, changing in character and intensity according to one’s activity and position.

**Staring**

Another key concept of this analysis is staring. The visual field occupies a privileged position in modern society (Hughes 1999). It is commonly assumed that seeing is knowing. We who have sight use it non-stop and presume that others are doing the same. Public space is occupied by others, known and unknown, physically present or potentially present and we are ‘on display’ to others and self. Garland-Thomson (2009) has written about staring encounters with an emphasis on the impulse and social restrictions of staring at persons of visual novelty in order to make sense of them. Garland-Thomson terms the person being stared at as the ‘staree’ and the person staring as the ‘starer’. An important point here is that we all interchangeably take these positions and experience these encounters.

In a reflexive modus, a person is both the starer and the staree, locking horns in an internal dialogue. This draws on the classical position of Mead (1934), whereby the self is a product of a dialogue between the self as subject and self as object. The
self as object becomes known through imagining the responses of others to us. In
self-surveillance the objectification of the gaze is internalized.

Impairment particulars

Approximately 15 years ago at the age of 49, I sustained a spinal cord injury. My
impairments are not always readily visible to others and vary with good days and
bad. Principle limitations relevant to the discussion are reduced stamina, chronic
pain and clumsiness. Walking is strenuous and slow. My ‘new’ body remains foreign
to me in the sense I am cognisant of it being ‘wrong’ and ‘abnormally’ outside wilful
control. A Cartesian dualism characterizes my sense of self, a strong split between
mind and body. In a sense I live as, and with, two persons, a pre- and post-injury self.
I have been socialized and established in adult life as an able-bodied person. I have
personal memory of ‘embodied normality’ to accompany me in my post-injury life.

I suspect that my perception of being in the world has become warped by
disability. That I am older and for that reason alone in a different position than pre-
injury, does not figure into my perception. Time stands still as acquired impairment
displaces aging. Estrangement from others is readily attributed by me to disability. I
forget or chose not to think about other sources or causes of estrangement introvert personality, shyness, being an immigrant, misunderstanding of cultural codes, etc. Disability has become the over-reaching paradigm, the master status in my
reflections.

Impairments which are not readily visible or which are variable offer special
challenges to their bearers owing to the ambiguity of social recognition and the
uncertainty or doubt raised in the minds of others. With invisible and/or variable
impairments there is no easy answer to the question of what is ‘wrong’, no pre-
established mental categories. Suspicions or doubts may be raised as to the impaired
person’s moral standing. Persons with invisible impairments and/or variable levels of
functional capacity face dilemmas of concealment and disclosure of their impair-
ments, an added, perhaps self-constructed need to explain and defend themselves
(Lingsom 2008; Lingsom and Ingebretsen 2009; Romsland 2009; Elstad, Grue, and
Eriksen 2005; Rosenfeld and Faircloth 2004).

Global reflections on public space

Public space is understood here as physical space open to the public; i.e., space one
does not require a personal invitation to enter, space where individuals have little or
no control over which other persons they might meet. Public space is thus
fundamentally a relational concept in addition to being a physical one. It is a stage
for spontaneous meetings with others, in principle if not in fact. It represents almost
endless opportunities for participation in activities. What makes public space special
is that the pulse of mainstream society is felt there. Exclusion from, or margin-
alization in, public space is hurtful.

I experience the physical world outside my door (and car) as public space – a
simple dichotomy between mine and not mine. Participation in the narrow sense of
being physically in public space is only part of the experience. Physical public space is
a social construction known to me through my body, my memories, and my ideas of
spaces, places, self and others – perceptions affected by social discourse and cultural
reading of both space and disability. I experience public space as a mental category
with temporal boundaries wide enough to include anticipation, preparation, and an aftermath of reflection and recovery.

My first thoughts about public space are of public space writ large, a global rather than a local room, the unknown and unreachable rather than the known and accessible. Public space in general, the concept of it, represents to me the outside world beyond my mobility capabilities. It is a world mediated to me largely through newspapers, radio and television. It is a highly troubled world. It is a world where trains do not come on time and people have to wait out in the cold, where buses are fully packed with barely standing room in rush hours, where planes are cancelled, and traffic jams and car accidents are common place. It is a world with an unknown number of steps between A and B. The ongoing media discourse of transportation delays and breakdowns tell people like me to stay at home.

Mainstream society seems to be constantly on the move. Moving in and through public spaces, going places and doing things, seems to be the very essence of vitality and social status in modern Western society. I participate little in this great flux of modernity. Reflecting on public space writ large thus increases my awareness of difference from able-bodied peers and my pre-injury self. Awareness of reduced capability is heightened by the ‘social imperative of participation’; I grieve over lost opportunities. My underlying emotions are ones of sadness and resignation. Thinking about public space writ large also brings forth generalized anxiety and vulnerability. These reflections feel, and thus are, disabling. I have recurrent nightmares of being unable to navigate public spaces, of moving too slowly and not finding my way.

When I visualize others using public spaces, I tend to create an idealized picture of persons enjoying themselves. When I imagine myself in public places I can feel fatigue and pain chipping away enjoyment, raising the important question of whether participation would be ‘worth it or not’ in a cognitive and emotional cost–benefit analysis. The reality of active participation in the social is often far less attractive than the ideal. Fatigue, pain and anxiety generally hold me semi-withdrawn in my ‘comfort zone’.

Accompanied by able-bodied others my range is larger and anxiety substantially less. Companions become my buffer and protection against the unexpected. I become their responsibility. When with companions I feel a need to consider how my movements may reflect back on or be interpreted by them. To what degree am I an embarrassment for my companions? How much of a responsibility and liability for them do I represent? Trying to be considerate and avoid holding others back (owing to slow movement, need for rests, and need for retreat) I am often hesitant about joining able-bodied others in journeys out into public spaces.

**Accessibility**

Physical accessibility of public places is a fundamental dimension underlying disabling or enabling experiences. Physical accessibility determines who is excluded and who is potentially allowed entry. Requirements vary widely by type and degree of impairment. Accessibility is more than universal design. I will argue that the concept of physical accessibility needs to be situated in a context of participation. I judge the accessibility of public space and place in terms of the combined physical and emotional demands involved in a specific journey and participation in a specific activity at a specific site.
Journeys begin from my home. Some journeys are short and uncomplicated, others long and difficult. They are typically round-trips; energy must be saved for the return home. Journeys also typically have not only a destination but also intent of participating in some activity. The physical accessibility of a place for me is not so much related to the place itself (a specific building for example), its entry way and layout, although building size, a lack of benches for resting, and the amount of walking required may represent a problem; it is more a question of location relative to my home and planned type of activity at the location. I want to visit a place and plan to participate in some sort of activity at that place. I need to anticipate what the activity will require of me and what ‘avenues of retreat’ are available. If I do too much, I know I will suffer fatigue and discomfort and require time afterwards to recover. How much I can manage is not a static affair. Planning for utilizing but not overtaxing my capacities is like shooting at a moving target.

The component of accessibility that can be most easily manipulated is the physical exertion and anxiety of the journey. Public transportation is too demanding for most of my journeys from home. I am fortunate that I can drive and have a car. I generally drive my car directly to my destination. Perhaps the most important accessibility factor for me is easily accessible parking. I have learned over time to select my activities from options with easy parking; the municipality has granted me a license for handicap parking, which is a scarce commodity in the city centre. The number and location of handicap parking spaces is a political decision.

The winter climate where I live often presents serious obstacles for journeys. Ice and snow are facts of nature but their presence on sidewalks and roads is a political act. When sidewalks and pedestrian roads are icy or blocked with snow I am anxious of falling and tense, further reducing my balance. Should I find a parking spot on a poorly cleared street I have difficulty getting out of my car. Winter obstacles could be lessened by better snow removal and sanding of sidewalks. There is, therefore, a clear seasonal variation in accessibility with winter conditions and political response to winter conditions being disabling. The temperate summers, on the other hand, are enabling. I function poorly in hot weather and would have greater difficulties in warmer climates.

The role of personal routines

Personal routines allow us to develop ways of proceeding through our lives as efficiently as possible. As per the definition, a routine requires a minimum of thought. The mind–body works on automatic gear. Not having to think about what one is doing – the hows, whens, and whys – is enabling because embodied consciousness fades into the background. Routines offer a degree of protection against anxiety; they put us at ease. One can be reasonably confident of managing the task ahead, at least to the extent that nothing unexpected happens to interrupt the smooth functioning of the routine. Routines may also be developed for managing the unexpected or unlikely, a Plan B. Routines do not appear out of the blue. They are developed over time through repetition.

I will argue that routines are particularly important for people with impairments – at least they are for me. Routines are a means of compensating for reduced functional capacity and expanding accessibility of public space, a ‘crutch’ that I use. I have personal routines connected to journeys, getting from home to the planned destination and back. I often take a test drive to a new destination prior to
participation to lessen anxiety over finding my way. I allow generous time margins and prefer to arrive early to lessen anxiety of the journey.

My participation in activities also follows a routine. I have accumulated knowledge of particular activities and places and the other social actors I expect to encounter. My ventures out into public space are usually short and well planned. I venture forth when I think I have the capacity necessary for some specific goal or set of goals. The consequence of living within the parameters of my impairments is that I usually restrict myself to public space I know. I do not often venture far from home and have come to know and appreciate my local community more than I did pre-injury, when my radius of action and appetite for novelty were greater.

Routines in general represent the accumulation of experience of successful navigation in and through public space. One belongs in one’s routines. Routines protect the self from feeling out of place. Use of public space has, however, at its core an element of spontaneity. The unexpected may happen, as in meeting new people, changing plans, facing delays, being forced to visit new places, etc. This spontaneity is both stimulating and threatening. Routines can be disabling when holding them restricts personal development and social participation. There is thus an underlying tension or mismatch between the openness and spontaneity of public space and the fixed regime of routines. Spontaneity is lost when relying only on routine to function in the outside world. Spontaneity is an important resource in our lives, opening new opportunities for learning. The ability to face spontaneity needs to be nurtured. I am conscious of the need to resist disabling dependence on established routines. I know that I need to work at establishing new routines and expanding my comfort zone.

‘First visits’ are a physiological and pragmatic barrier that I struggle to overcome.

On display
Social patterns of public space usage are common knowledge. Different social groups tend to gather in different geographical settings at different times. The population frequenting late-night city streets is a far cry from the mid-day population in the same streets. We thus exercise some choice as to which others we will see and be seen by in public spaces when we choose to visit a particular physical and temporal setting.

Shopping centres score highly on physical accessibility and attract many of the non-working adult population with reduced functional capacities in late morning and early afternoon weekdays. Shopping centres are not only stores; they are accessible indoor streets and meeting places, particularly in the winter months. I am one of the persons attracted by easy accessibility. Working only part-time I can shop early in the day when I am well rested and when stores are not crowded. Looking around at the other ‘mid-day people’ at shopping centres, I find many others who do not fit the ideals of the body-perfect. Lots of people seem to have difficulty walking, but perhaps I have developed an eye for spotting them. Mid-day people I see on ‘warm water days’ at my local public swimming pool are another concentration of individuals with physical limitations. In the showers and dressing rooms, a variety of bodies are on display – none approaching body-perfect ideals. My independent ventures out into public space usually take place mid-day and the others I meet are mainly other mid-day people.

To the degree that my awareness of, and focus on, embodied difference is a function of the others I am seeing and who are seeing me in public places, I ‘should’ feel less disabled together with the mid-day people of shopping centres and public
swimming pools. In resembling the others, I should not need to feel like matter out of place or be forced to think about my body. I wish it were so simple. Unfortunately, being surrounded with others who seem to have problems of their own does not, in general, lessen my awareness of embodied difference and physical limitations. It does not help me to achieve the goal state of the ‘absent body’.

When I am sitting, for example, in a restaurant or in a cinema, I generally feel comfortable and believe that I look comfortably ‘normal’. I look my gender, age, race and class (white, middle-class female, 63 years of age), and not much more. A little less stylish than I would have liked, but acceptable. Others are unlikely to see my impairments. I may, however, see myself as matter out of place because, as earlier mentioned, I may be experiencing fatigue and discomfort and feeling participation not worth the cost.

When I move it is obvious to all who can see that I have some sort of problem. Others may not understand why I move as I do, but they can see that something is ‘wrong’. When I move about I may lurch and bump into tables or walls. Walking in a straight line is not something I take for granted. I may look like I am drunk or drugged in some manner (a moral flaw) or that I am so careless of my person and of other people’s space that I move clumsily (another moral flaw). I sometimes fear others look at me and read me in one of these ways. Some may assume that my slow, uneven gait and poor balance mean that I am temporarily experiencing a bad back or leg, a passing problem on the mend. Some people may read me ‘correctly’ as disabled.

I have little clue as to what strangers think when they see me in different settings. It is difficult to ask others, and if one does, one can expect politically correct answers. I have asked my physiotherapist how I look when I move about. He says straightforwardly that I look like I am drunk and wonders if I receive many negative reactions from strangers. I know when I am sober and when I am not. I do not think that my overall appearance (facial expression, eye contact, etc.) suggest intoxication. The picture I make as I move may, however, be ambiguous to others. This represents an obstacle for me to being ‘at ease’ in public space.

**Staring**

I am not aware of being stared at by curious children or adults. I realize rationally that strangers in public places are not very interested in looking at me. Their attention is likely to be directed elsewhere, to what they are doing, and how they are being perceived by others. However, I often feel hyper-visible, as if I often were on stage in public spaces. I often feel like others are looking at me, looking without looking. As Garland-Thomson (2009) discusses, there are strong social conventions against open staring at others.

I am hyper-visible to myself. I find myself frequently looking at myself from the outside, objectivizing myself, checking and disapproving of my uneven gait in store windows and mirrors, and mentally visualizing each step of my awkward, strenuous movement. The violence of the gaze, the objectification of being seen by non-disabled others said to constitute the social nature of impairments (Hughes 1999) has been internalized. I, the starer, have a mind-set which closely corresponds with the mind-set of the able-bodied, middle-class, white female I was pre-injury. I, the staree, struggling to move about in a broken body, frequently feel the disapproval of this gaze. Perhaps my middle-class position, expecting to be at ease and focusing on style
above functionality, causes me to attach special significance to physical awkwardness. Perhaps it is the discomfort involved that fuels visualization. There is little novelty involved in this staring encounter unless the repeated reminder of difference can be counted as separate, novel events.

A major theme in feminist literature has been the effects of gender and class on self-surveillance of the body. Middle-class women are notorious for monitoring their bodies and the bodies of their families. Ill health, impairments, and variable levels of functional capacity compound the inward focus on the body. Techniques of body maintenance have almost become a full-time job. My post-injury life has been filled with rehabilitation, doctors, physiotherapists and a daily regime of physical training of my own design. It is thus hardly strange that I watch myself closely, that I am looking at and judging my movements in relation to changing performance and appearance. My ‘new body’ is constantly being judged by my pre-injury embodied consciousness of what a body ‘should’ be and do.

I am often embarrassed by my awkwardness as deviance from the ideal of graceful flow of able-bodied movement. As Rosenfeld and Faircloth (2004) contend, ‘embodied fluidity’ (the timely and fluid movement through time and space) is central to sense of self, a social and a moral matter. Failure to achieve embodied fluidity, moving at a slower pace and over shorter distances, interrupts the normal flow of social interaction.

Being embarrassed by my awkwardness many years post-injury implies that I have not fully accepted my comparatively moderate disabilities, that I have not adjusted successfully (failure being another moral flaw). People are increasingly made to feel responsible for how well they manage their illness and impairments – medically, socially, and emotionally (Frank 1997). Many feel a need to keep up a ‘happy face’ in order to be agreeable company for self and others. No one wants to listen to chronic health complaints and dwell on the vulnerability of the body. ‘Managing well’ seems to make everyone feel good. Attention is shifted from troubled bodies to social skills, perseverance and resilience. Disability discourses preach pride, not shame. Feeling embarrassed implies that I initially had, and continue to have, negative perceptions of disabled people attaching stigma to self and others (Goffman 1963). My moral integrity seems to be at stake as I appear to be a carrier of discriminatory attitudes (prejudice being a big moral flaw). I am ashamed of my embarrassment, especially when I think of others who are more severely disabled than I am. It seems to me that there are many ‘shoulds’ and ‘should nots’ attached to feelings disabled people are supposed to have, socially and politically correct emotional prescriptions to the lived experience of disability.

Enabling moments
As everyone else, I stare at others on occasion. I find myself sometimes starring at young able-bodied persons, concentrating on their strength and graceful movement. I think I am starting to embarrass a young body builder at the training studio where I exercise each week. Straining to do my small exercises, I stare at him as he lifts heavy weights. He is a source of inspiration to me. Some measure of strength is transmitted, perhaps stolen, from him and absorbed into my sense of self. Accompanied by friends, my perception of being on display in public spaces often lessens. My friends function as a shield helping to deflect or at least delay introspection.
I obtain on occasion what has been termed the absent body (Leder 1990) or the blind spot of the body (Crossley 2006). The absent body is what I seek. It releases me from the discomfort of my body and stops visualization. It is enabling. My body disappears when following a routine that has become almost effortless. My body disappears when I am so involved with what is happening in the world, in my being in the world, that I lose thought of the ‘me’ my body represents. These are moments of being in flow (Csikszentmihalyi 1990) when so engaged in and energized by what I am doing that the passage of time goes unrecognized, no barriers impede, and life is good. I am drawn to the contexts where I function best and am naturally thankful for these. Some of these ‘flow-contexts’ are new to me, opportunities which opened post-injury. I am conscious of the luxury of being able to wander the nearby forests in the weekday sunshine. I communicate deeply with nature and find my glass there definitely half full, not half empty. Without my impairments and disability pension I would be ‘stuck’ full-time in my office. I would not have had time or the necessary motivation to take up new entertaining forms for physical training and new hobbies. Enabling moments also come in a reflexive modus when thoughts turn to what I can manage and what the future might bring. These moments occur rarely while physically present in public space but may occur in anticipation of journeys into public space or in their aftermath.

Oscillation

Enabling and disabling experiences are not stable, long-lasting or predictable, even within my comfort zone of routine ventures into public space. They may subtly fade into the other or turn quickly from the one to the other. Oscillation is grounded primarily in my perception of events, my state of mind. There appears to be no direct relation between enabling and disabling states of mind – the one does not set off, bring on, or cause the other. To complicate matters further, it seems possible to have two thoughts at once and experience moments as both enabling and disabling.

I can and do walk substantially further and with less effort on woodland trails than on city streets. My mobility capacities/disabilities vary greatly by context. I find the variation in my capabilities/disabilities by context to be disquieting and often ponder the differences. The variation is suggestive of a subjective dimension to my impairments that I do not understand or welcome. The variation creates self-doubt. How impaired am I? Self-doubt raises moral questions. Am I trying hard enough? How much discomfort should I be able to overlook?

A problem with consciously seeking the absent body is that attention is tuned to monitoring the body to see if it is or is becoming absent, thus undermining the likelihood of embodied consciousness sinking into the background. A second problem is that the situations in which the body becomes absent are episodic, unpredictable in duration and seemingly dependent on an endless number of factors to do with my physical form at the time, my frame of mind, degree of concentration, nature of social interaction and sensory stimulation, and what participation demands. Again a topic of internal dialogue, I attempt to reduce my inclination for explanations and control, accepting that my body may ‘disappear’ when I least expect it to. I also attempt to focus on capabilities and opportunities rather than disabilities and restricted options so that enabling moments may be constructed reflexively through foregrounding a positive sense of embodied consciousnesses.
It is difficult for me to find structures or regularities in the effects strangers have on the way I experience the moment. As previously mentioned, I have an ambivalent perspective on being with mid-day people like myself. I acknowledge our ‘sameness’ but find no comfort in it. Encounters with persons who are severely disabled, particularly by neurological injury, are in one sense enabling. These encounters temporarily alter my primary reference group from able-bodied peers and pre-injury self to persons more severely impaired than I am. My impairments ‘shrink’ and I become thankful for all I can manage. However, I also physically feel the injuries of others and this ‘empathetic bridge’ can turn these encounters into disabling moments. The lively company of fast-moving, interesting people of all ages and functional capacities can be enabling – at least until fatigue sets in. Enabling moments built on contrast with persons more severely impaired than myself or by association with more active persons, are not long-lasting. Often times when I look at and listen to lively company strong feelings of the disabling difference emerge.

Summary and discussion

The present article draws on the author’s experiences and reflections as a disabled adult in an attempt to contribute to the phenomenology of disability. There are many means of generating knowledge; introspection is one of them. Qualitative research champions closeness to the field, empathy with the subject, and positioning of the researcher throughout the research process. Autobiographical case studies, such as this article, score high on these dimensions but are admittedly lacking in critical distance to their subject. In introspective analysis, critical distance to the study object is replaced with the author’s critical distance to his or her text.

The sociology of impairment and chronic illness is to a large degree embedded in illness narratives. There is no dearth of first-person accounts but they appear in research journals primarily in the form of citations, seemingly needing a third party to give them voice. This glass ceiling has provided a methodological aim for the present article; i.e., to expand the repertoire of illness narrative research and the forum of journal discourse to include conceptually grounded, introspective narratives. Frank (1997) claims there is an ethical responsibility of the wounded storyteller for bearing witness when experiencing serious illness, a responsibility for expanding society’s repository of stories. As an impaired, disability researcher, the professional responsibility for contributing to the disability discourse motivates self-reflexive analysis.

The substantive aim of the present article is to increase understanding of the phenomenology of disability in the social setting of public space. Feelings, practices, and embodied consciousness pertaining to accessibility and use of public space are discussed. Emphasis is also placed on the reflexive construction of disability, the ongoing, inner dialogue creating enabling and disabling moments. The article highlights the agency of disabled persons in managing reduced functional capacities, choices made and strategies followed in construction of routines. As social beings, disabled persons may be carriers of mainstream discriminatory attitudes that act as secondary impairments and contribute to objectifying, critical views of self. Class and gender intersect with impairment in sustaining self-surveillance of the body and feelings of being on display in social settings.

The construction of routines in daily life is a key strategy for compensating for reduced functional capacities – a self-help technique. The present article has
discussed the construction of routines connected to travel and use of public space against a media discourse of the dangers and unreliability of transportation. Routines are seen to be enabling, but only to a point where they become constricting in relation to spontaneity. ‘First visits’ to new settings and activities must be taken without the protective crutch of a routine.

Physical accessibility of public spaces determines who is and who is not excluded from the social. Accessibility is more than universal design of the built environment. It is argued here that accessibility should be conceived in a wider context of participation and travel. Accessibility starts with the journey required from home and back. Emphasis here has been on availability of handicap or easy parking and on the quality of winter snow and ice removal on streets and sidewalks. Accessibility is also determined by the physical and emotional demands of participation in activity at a specific socio-temporal setting. Public space writ large is endless and its pace unnerving. Local contexts are more easily integrated into one’s comfort zone.

Public space is, by definition, open to others and all present compose a visual field with varying degree of interaction. All are ‘on display’. Feelings of being on display for others and the uncertainty this generates are discussed. The hyper-visibility of self in the social setting of public space, the objectivizing, monitoring, internalized gaze contributes to the social construction of disability.

Among able-bodied persons embodied consciousness is assumed to be in the background, the body taken for given or ‘absent’. An ‘absent body’ or an approximation of a same may be a goal state when living with the dys-ease of impairment, particularly when experiencing chronic pain. Enabling moments, where one’s focus is outward to the world and participation in it, help achieve this goal. In disabling moments, embodied consciousness is at the foreground in a negative sense and cognitive focus is on reduced capabilities and limited options. There is oscillation between enabling and disabling states of perception.

Case studies raise rather than answer questions. Age, gender, and class effects on reflexive practices of self-monitoring warrant study. What is the social and moral significance of deviance from ideals of graceful, timely, controlled movement? How does association with different categories of strangers affect self-perception? What is the role of physically present or imaginary others as props on a stage in construction of enabling or disabling moments? A conclusion that may be drawn from this illness narrative is that emotions and reflections should receive attention in disability research.

It is not difficult to appreciate the limitations of case studies. They are but one story among countless others and allow for no generalizations. Impairment particulars – the type, severity and history – vary widely, as do the environmental conditions and resources of disabled persons. An autobiographical account may be viewed with scepticism as the author lacks a critical distance to his or her subject. Introspective methods afford, however, a unique perspective on inner dialogues and an opportunity for the development of concepts of reflection experience.

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References


