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Brain Injury Survivors: Impairment, identity and neoliberalism

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This paper reflects on my decades of activism and scholarly work with brain injury survivors, highlighting some of the challenges that survivors experience, and exploring the power dynamics associated with the 'survivor' identity. It explores the 'survivor' discourse/identity which has been widely adopted by people who have sustained a Traumatic Brain Injury (TBI) in the context of embodied cognitive changes, the dominant view of disability as a personal tragedy, and the wider political context of neoliberalism. The key argument is that the survivor identity adopted by many people with brain injuries simultaneously supports and challenges neoliberalism. The paper involves both autobiographical reflections and the results of my political involvement and research with other survivors.

I am an 'insider,' having experienced a brain injury and many other injuries as a result of being run over by a car. Being in rehabilitation with a group of other brain injury survivors gave me a sense of the collective experiences, identities, strengths, weaknesses, challenges, and barriers which people with a brain injury experience. My experience also gave me credibility when I spoke to other brain injury survivors – both in my own rehabilitation group and much later, around the world. I was a disability activist during my rehabilitation well before I returned to University to do a Ph.D centred on my experience of brain injury as well as other people who were in rehab with me. I found a home in Disability Studies because it recognizes disabled people as experts in their own lives (Curran and Runswick-Cole 2013, French and Swain 2011).

Insider research offered a number of advantages in terms of ethnography. It gave me credibility with the people being researched and created immediate trust; it made it easier to gain access to research participants; it gave people hope that I would "tell the truth" from the survivors' perspective; and it (arguably) enabled me to understand the population better. But an 'insider/outsider' status is not an absolute, fundamental, and static dichotomy. I prefer to see 'insiderness' as a continuum. (Some people are more of an insider than others). I also think that having dual roles as researcher and research participant can make people both an insider and an outsider. Other survivors I interviewed in my Ph.D. (who have chosen their own pseudonyms) said that they saw my insider status as a key reason why they wanted to support my research. They stated:

- "We don't have to explain ourselves to one another. We don't have to explain to, why we're like the way we are, because we know that's why we are the way we are" (Larry).
- "Non-brain injured people don't get it" (Reg).
- "You wouldn't get a foot in the door if you weren't a brainy" (Kirstyn).

I was central to organizing the first survivor-led organization in our city in Australia. The goals of the group, developed after extensive meetings over almost a year, were to:

- Understand the nature of our brain injuries and their effects;
- Share our stories;
- Organize by/for ourselves (away from existing paternalistic organizations such as the traditional, charity-based Brain Injury Association);
- Discuss our social, rehabilitation, financial, hospital and disability service provider experiences; and

- Help us understand the ways our identities changed because of our injuries.

There is a vital need to discuss the "impairment effects" of brain injuries (Thomas 1999). A key message from everyone in the brain injury group was that once you have a brain injury, many things change, including identity, personality, life skills, emotions, cognition (attention/concentration/memory/black and white thinking, etc.), energy/fatigue levels, physical changes; and people often develop 'challenging behaviour' (anger/aggression/impulse control difficulties). When someone's cognition is impaired, it can be difficult for them to actually recognize and be aware of the effects of the injury. People are often searching – for years – to understand the effects of their injury. Their memory problems, problems with insight, and problems with executive thinking mean that they cannot regularly connect many of their problems with their brain injury. It is sometimes difficult to work out whether something is an effect of the injury or is a residual effect of the pre-injury personality and behaviour traits.

Here are some examples of the reflections of people in my rehabilitation group about the effects of brain injury. Reg said, "There's so many different little pieces of your life it changes" and Larry said, "I wish I had died because I wouldn't have to go through all this shit." Uncontrollable anger, emotional outbursts and disinhibited communication were a common problem, as the following comment from Kirsten about an everyday problem illustrates: "I could have, not a problem, put a knife through her."

These problems are made worse when they are not provided with proper educational materials. People in our group therefore indicated that they wanted educational materials. They needed information about how to deal with anger, communication, memory, depression, anxiety, dealing with stress, and low self-esteem. Because these have often been goals of the survivors I

have worked with, I have provided such educational materials and run information/discussion sessions on these aspects of brain injury for them.

Being isolated was also common. For instance, John had no family. He was the victim of a hit-and-run accident. He was left for dead on the side of the road and had been in a nursing home for 8 years when I first heard about his situation. In all that time, he had never been provided with information about brain injury, as the following conversation demonstrates:

Mark – Has anyone ever given you information about brain injury?

John – No.

Mark – Would it have helped to have it?

John – It might help now.

Rather than seeing these problems as individual misfortunes, survivors found them to be collective barriers – demonstrating a challenge to the individualist focus neoliberalism. The collective problems identified for collective advocacy included:

- Social Isolation
- Low expectations
- Abuse
- Negative public attitudes about disability & brain injury
- Employment barriers
- Transport barriers
- Inadequate medical care & rehabilitation
- Disabling services
- Inappropriate & inadequate accommodation options

- Lack of technical aids & equipment

Comments from survivors about these problems included:

- "I used to have heaps of friends before, like when I was going to school, and after school. And before my accident I used to have heaps of them. But after it, no one came to see me at all." (Madonna)
- (About being in the locked ward and with people who are in very grave conditions) "It's depressing and I just thought just let me out, I'll do it myself. How am I supposed to progress in rehabilitation, when I've got to look at this?" (Kirsten)
- (About the rehabilitation centres) "They promise you everything and get your hopes up but they don't do anything." (Reg)
- "Once the employers found out that I had an injury and that I had special needs, they didn't want to know you." (Larry)

Cliff's powerful comments deserve to be quoted at length. He said, "If they're going to go to all the expense of saving your life and you know, cost to the community of hundreds of thousands of dollars to save our lives, and then they let you just scavenge and you know, leave you by yourself so you're virtually helpless and you have to do everything yourself. So that's the things that I've got a problem with. You know if they didn't save my life and I was dead and stuff, that'd be fine, I wouldn't be here to worry about it. But I am here, and they should be helping me; give me back my independence and everything else. It really makes me angry actually. Yeah, it really does." A few years after he made these comments, Cliff killed himself. His life story is too complex to be discussed at length here, but it is important to state that brain injury survivors face unique impairment-related issues which exacerbate conflict, relationship,

and communication problems. Even when they are provided with appropriate supports and advocacy, and are deeply committed to a strong, resilient, survivor identity, such impairment effects can leave significant emotional scars, frailty, and even suicidality.

Overall, people wanted to make sense of their new identities and new social roles.

- Most emphasized the ways their previous goals and relationships had been shattered;
- Many felt betrayed by other people who'd promised to love them or be their friends;
- Most constantly struggled with self-esteem, awareness issues, and problems not achieving goals (due to a mixture of both individual and social factors);
- All struggled with being a different person from their pre-injury identity;
- Some were inappropriately placed in nursing homes.

As a result of hearing about all these injustices, I took it on as a personal mission to visit young disabled people in nursing homes and to advocate to get them into supported accommodation in the community. The youngest person I met in an aged care nursing home was 13. This is totally inappropriate housing accommodation. Additionally, I worked with other survivors to challenge such oppressive policies and practices. I personally helped get many survivors out of nursing homes and encouraged other survivors to visit these places and offer support to the survivors inside this inappropriate accommodation. Although many survivors were reluctant to get involved in such visits themselves, four did occasionally accompany me, and others agreed that this topic should be included in our general advocacy.

Survivor identities and support for neoliberalism

In some ways, the "survivor" discourse appeals to many groups because of its links to widely held neoliberal beliefs about the capacity of individuals to shape their own fortune, regardless of the circumstances in which they find themselves. For people with a TBI who adopt such a perspective, the 'survivor' identity is almost always uncritically used as an "illness narrative" (Kleinman 1988), particularly in informal meetings with other people who have sustained brain injuries. It is commonly repeated as people make sense of their experience - usually from an individual, autobiographical, informal and phenomenological perspective (Sherry 2006). In doing so, the telling of stories about TBI is consistent with many other "illness narratives" which are socially required, difficult, imposing, and yet resisted in multiple ways and multiple contexts (Manderson 2014).

Within the medical model of disability, disability is often seen as a personal tragedy (Oliver 1990). The 'unfortunate victims' are usually presented as needing pity, charity and sympathy, while doctors are seen as neutral and professional 'experts'. The medical model has a profound effect on social policies, including policies and practices related to disability. Health professionals are gatekeepers in the sense that they identify the 'pathological' symptoms of disabled people, who may then become eligible for various forms of financial, educational and social welfare assistance. The medical model also has a profound effect on interactions between nondisabled and disabled people. Constituting disabled people as the tragic 'other' makes it easier to justify exclusion from ordinary community activities.

The personal tragedy model of disability overlaps deeply with neoliberalism. Neoliberalism, in the words of Gray and Lawrence (Gray and Lawrence 2001) consistently involves "translating structural problems into issues for which there only appear to be individualistic solutions" (p.

383). Neoliberalism is a key element of health policies (Sue 2001); collective political mobilization that challenges medical authority is not. Disability rights campaigns which emphasize the principles of representation, recognition and redistribution therefore involve significant challenges to neoliberalism (Soldatic and Chapman 2010). The flaws of neoliberalism are obvious when one considers disability politics in terms of collective needs, collective identities, and collective struggles (Dodd 2013).

The term “survivor” (usually framed in an individual sense) is not unique to people who have experienced a brain injury – far from it, in fact. Perhaps the dominant use of the survivor identity/discourse among those dealing with serious health issues is the case of people who have experienced cancer (Smith et al. 2016, Cheung and Delfabbro 2016). Many battered women also chose to describe themselves as survivors of domestic violence (Gondolf and Fisher 1988, Dunn 2005, Clough et al. 2014, Arroyo et al. 2017), as do some people who have experienced various forms of trauma such as rape, intimate violence, sexual abuse and incest (Lee 2017, Greenfield 2014, Hoff 1990, Gagnier and Collin-Vézina 2016, Karakurt and Silver 2014).

Being a “survivor” is, at least at first glance, a perspective on identity which empowers. It is the opposite, in many ways, to the traditional oppressive images which have been attributed to women, disabled people, and children – images of helplessness and dependency. Also, survivors are not tragic figures - they are remarkable and resilient, rather than weak and vulnerable. “Survivors” may have experienced terrible things, but they are not defeated by them. Individually, they ‘overcome’ the experience – in the same way as disabled people more generally are encouraged through an individualistic approach to ‘overcome’ their experience of disability (Rousso 2013).

The danger with being a “survivor,” however, is that it does not fully capture the negative impairment effects of brain injury, nor does it capture the fluidity and nuance associated with the deployment of the term. For instance, brain injury is commonly associated with depression – partly in response to organic changes in the brain, and often in response to the trauma of the incident which has precipitated the injury (Rao et al. 2010, Jain et al. 2015). I have visited people who have acquired their injuries as a result of drunk driving – some of whom have killed others in the process – and the long-term negative guilt and shame of their ‘survival’ is undeniable. So instead of simply emphasizing the empowered ‘survivor’ identity, it seems more fruitful to incorporate the negatives and the ambiguities of the experience.

Psychological responses to an experience of disability are notoriously complex – both as a result of the power of “psycho-emotional disablism” in fostering an incredibly negative view of life as a disabled person (Reeve 2002, 2004, 2008), and also because of the (literal and cognitive) pain associated with certain forms of embodiments and traumatic experiences (Price 2015). In such circumstances, the survivor discourse/identity seems far too optimistic, and doesn’t allow for the role of grief – a criticism that has also been applied to the overly optimistic survivor discourse which dominates neoliberal, corporate-driven breast cancer campaigns such as the Race for the Cure (King 2006). One does not need to endorse the dominant association of disability with loss to recognize the universal aspects of loss which affect all of us. Denying this emotional experience runs the risk of contributing to self-alienation (Watermeyer 2009).

One of the unfortunate consequences of viewing everyone who has lived with a TBI as a ‘survivor’ is that this approach may ignore the fluidity and contextuality of the deployment of ‘survivor’ narratives, thereby failing to capture the complexities, nuances and subtleties of lived experience and identity. It is essential to recognize that people adopt the ‘survivor’ identity in

some circumstances, but not in others, and that they often feel ambiguous about it. Indeed, the in-between moments of hesitation, where people are unsure of what to do and which identities to adopt (or refuse), reveal a great deal about difference, power, identification, and exclusion. Such experiences highlight the difficulties associated with narratives of resilience as well as survival.

The fluid and contextual nature of identity politics is associated in part with the balance it seeks to find between having unique circumstances of inequality redressed and the wider need for the same rights as other people (Sedgwick 2007). This balancing act is negotiated in different ways at different times by survivors, and moments of hesitation/indecision are common. For instance, many of the people with a TBI who I have spoken to speak of the difficulties around whether to ask for accommodations at work. They want to be treated with the same respect and rights as others, but the need for accommodations that address unique cognitive/emotional/physical issue raises the spectre of discrimination and potential loss of employment. The risky nature of disclosure is something survivors share with other disabled people (Brune and Wilson 2013). Most survivors decide not to disclose, because of the fear of discrimination, but they then worry that the lack of accommodations harms their performance, also raising the possibility of termination of employment. It is not simply that people with a TBI adopt a survivor discourse/identity in every situation; they do not disclose it in some situations, or they partially disclose it to a small number of trusted people.

Having stressed the ways in which the survivor identity is linked to neoliberalism, and also discussed the complexities and nuances associated with the fluidity with which it is deployed, it still needs to be said that it has also been deployed in progressive ways that challenge neoliberal individualism. The key to recognizing the transgressive nature of the survivor identity is to recognize that while the individual effects of impairment are absolutely

central to the experience of disabled people (Sherry 2016), it is also necessary to understand the collective struggles against disabling barriers, which involve a direct challenge to neoliberal individualism.

Challenging neoliberalism through collective advocacy and struggle

The survivor identity also challenges neoliberal individualism when it is framed in terms of a *collective* struggle for rights, recognition, resources and power. Indeed, one of the collective struggles of brain injury survivors has been to shift focus to a wide range of social factors that have influenced their experiences. Themes of social exclusion, inadequate resources, and a struggle for basic human rights are central to these experiences. Far from being passive and dependent victims of brain injury who need sympathy and charity, or the unique person facing individual problems which underlies neoliberalism, brain injury survivors, collectively, been remarkably active in trying to create better lives for ourselves. Against a background of social exclusion and poverty, survivors fight for very basic human rights – like the right to live in the community and the right to work.

In this collective approach, living with a TBI is not just a matter of ‘surviving’ something that could have killed the person. It is a matter of ‘surviving’ a world that constantly denies rights, opportunities, inclusion, respect, and relationships. TBI survivors and their families consistently challenge – even militantly challenge on some occasions - barriers caused by welfare bureaucracies, disability agencies, rehabilitation providers, employment agencies, and more (Sherry 2006). Like many disabled people who face social exclusion and a lack of social capital (Dimakos et al. 2016), TBI survivors experience political, economic, cultural and social

marginalization. These structural forces were consistently challenged by the survivor groups in which I have been involved.

To demonstrate such collective struggles, I will now provide a brief description of some of the actions the which the group I was involved with in Australia took. First, we worked tirelessly to raise community awareness about our concerns. For instance, we had a 'Survivor Day' tree planting ceremony aimed at raising public awareness on brain injury issues and were interviewed by local media. Second, some members of our group also took part in a National Day of Action against the inappropriate placement of young brain injury survivors in nursing homes. Third, one of the members of our group, "J," addressed local school children and gave a talk about his experiences and Rick made regular visits to the survivors still in hospital. Also, in order to improve the rehabilitation practices at the Hospital, Rick wrote a letter to the Hospital and also wrote a letter to the State Brain Injury Association newsletter. He also gave a number of talks on brain injury. These included talks to his local Rotary club, to second year psychology students at Griffith University, and to students at Queensland University of Technology. Rick also was interviewed by his local newspaper, who wrote a two-page story on his recovery. Fourth, Rick set up an additional meeting time (outside our political meetings) for survivors to meet and emotionally support each other once a month. At this meeting, people would have lunch together and talk about what is going on in their lives and what issues are important to them. Fifth, some of our members have lobbied politicians for a better deal for brain injury survivors. For instance, Cliff wrote to the Minister responsible for Disability Services and J met with a Federal Politician to lobby for a better deal for people with a disability.

It is important to emphasize that our group was limited to survivors and family members and had a political focus, unlike the Brain Injury Association which was dominated by the "personal tragedy model of disability" (Oliver 1996) and had a charity-based focus. Members of our group attended meetings about the formation of Disability Services Queensland (DSQ), the new statewide disability department, and lobbied the new Department to acknowledge and address the collective political concerns of brain injury survivors. After DSQ was formed, our group held another (unsuccessful) meeting with its representatives to lobby for funding so that the group could conduct peer advocacy. When we were unsuccessful in obtaining funding for ourselves, members of our group lobbied other disability organizations to take up some of the issues affecting brain injury survivors. For instance, we held meetings with Queensland Advocacy Incorporated, a systems advocacy organisation, in order to encourage them to address the issues associated with brain injury survivors inappropriately placed in nursing homes. Cliff and I also held a meeting with members of a parent advocacy organisation, Queensland Parents of People with A Disability, in order to share our stories, ask for their support, and hear their suggestions for lobbying.

Our group also emailed disability advocacy organisations throughout Australia and asked for messages of support for our activities. We received one answer in response, from a self-advocacy organisation for brain injury survivors in Melbourne called Bear in Mind. This message of support led to the establishment of an informal alliance with that group on many issues. We have shared information about our campaigns and about our personal struggles. Additionally, our group also was the first disability group to take advantage of the "Disability Grape Vine" in order to advertise our functions. The Disability Grape Vine is an internet newspaper addressing disabilities issues and concerns. All articles are written by people with

disabilities. We advertised our Survivor Day function through the Disability Grape Vine in order to raise our profile within the disability movement.

These activities organised by the members of our group reflect our determination not to be tragic victims, but instead to have a range of opportunities and relationships and a quality life. This is, unmistakably, a collective struggle. J reflected this belief when he said that "We are the modern pioneers that are trying to strive for a better quality of life". J said that he is involved in the group because "I am a fighter and this is the thing that we are trying to fight for. We need more resources so we can carry on with our lives". Rick also believes that the opportunity to control the group ourselves is a major element in our philosophy: "We are taking charge of it ourselves and not having to look over our shoulder all the time, not having to ask someone every time we want to do something... I think we're going to go places soon."

My experience of collective mobilization of TBI survivors in the US

These collective struggles of brain injury survivors are not isolated to Australia. I moved to the US in 2002 and immediately got involved with local, state and national survivor groups. Many of the same themes have been raised by these groups. Because of my experience and motivation, I became an informal leader again within the survivor movement, organizing meetings, giving talks and organizing talks by others on various topics, providing education sessions, doing media work, helping to find resources, and so on. When I moved to Toledo USA in 2004, I needed to re-establish connections with the local brain injury community. Fortunately, my appointment at The University of Toledo got some press and I was immediately invited to be on the Board of the Ohio Brain Injury Association and the Epilepsy Center.

I gave approximately 50 talks at local disability organizations in my first year, so I had re-established myself quickly. I gave talks to (and required my students to attend meetings at) most of the major organizations representing disabled people in the city, including the Ability Center, Sight Center, Deaf Club, Epilepsy Center, Brain Injury Association, Self-Help for Hard of Hearing, National Multiple Sclerosis Society, People First, the National Association of the Mentally Ill, a user-led psychiatric survivor group, two local autism groups, two service dog groups, and many others. Representatives of these organizations also came and spoke at my classes. I'd also met with people from (and given talks at) the County Board of Developmental Disabilities, the Bureau of Vocational Rehabilitation, the local First Responders Groups (ambulance/fire/police), some hospitals, and the Governor's Council on Disability. I was also on the Mayor's Commission on Disability.

Despite this eclectic entrée to disability politics in Toledo, I soon became more focused on my own group centred around my primary impairment, brain injury. I was deeply involved and eventually helped to run a support group for brain injury survivors for approximately 10 years. For many years, brain injury survivors had been neglected by the local Center for Independent Living, the Ability Center of Toledo, so they organized separately from it. They looked for free meeting spaces and were offered a free meeting room once a month at a local hospital. The hope was that the hospital would refer people with newly-acquired injuries to the group, but medical people (unfortunately) seemed to be solely committed to a traditional approach involving professional control and such connections did not eventuate. Nevertheless, the brain injury group I have been involved in has provided feedback to local hospitals to change their practices by emphasizing the unmet needs of survivors in these institutions. Personally, I solicited such feedback from survivors and their families which I have included when I have

been invited to teach rounds in Neurology and Psychiatry. There is enormous power in being able to say, "This is what patients in your ward are saying about you, and information they got/didn't get, connections they didn't know about, and we want to work together so that the whole response to brain injury can improve." In this way, we have changed the pedagogy of medical education to make it more into a (albeit staggered) dialogue. This has definitely challenged some of the established power dynamics. Having quotes from survivors is the most powerful form of testimony that is available. For instance, one survivor in Toledo, Jason, explained similar impairment effects to those discussed by others I had worked with in Australia: Brain injury was completely unknown to me until after I had a TBI. Memory loss and stubbornness from myself have been among the biggest challenges. Support from family and others with TBIs has been greatly helpful. The one thing that helped me the most was addressing one problem at a time and allowing enough time to pass so I can adjust to it. Recovery takes time. Have someone with you to fill out forms, fill in information at appointments. In this conversation, another Toledo survivor who was happy to be quoted but did not wish to be named at all said: "For me, it's hard to describe. Things that you could do before, balance, memory, etc. I can't do as well, but there are ways to get around it if you get the help that is needed. I don't try to do everything myself. I accept the things that I am not good at and create things to counteract them." His advice for families and friends was "Accept it and support your loved ones and get them the treatment they deserve".

Interestingly, discussions of impairment effects by survivors are not always framed through an individualist lens. For instance, people in the group emphasized the collective experience of survivors in terms of impairment effects in order to challenge the practices of first responders. TBI survivors in the group have experienced have conflict with first responders due

to their challenging behaviour. As indicated earlier in the discussion of impairment effects, uncontrollable anger and aggression often accompany brain injury (particularly frontal lobe injuries). In some medical and first responder discourses, brain injury survivors have been framed as sociopaths (Blair and Cipolotti 2000, Damasio, Tranel and Damasio 1990, Roskies 2003, Saver and Damasio 1991). There are established (and problematic) first responder protocols for responding to people with such anger, disinhibition and aggression. For instance, ambulance workers are allowed to leave the scene if they are not safe and police are allowed to use force with violent people.

I have represented the group in meetings with first responders. Some first responders have told me that they refer to some local people with brain injuries as "frequent flyers" or "repeat offenders". However, working with survivors and their families, I have been able to talk with first responders about dealing with such challenging behaviour in different ways. I have listened to survivors and their families discuss the effective ways to deal with such behaviour, through redirection and diversion strategies, and have shared these lessons with first responders. For instance, I gave a keynote talk at the regional First Responders Conference to promote such changes. De-escalation techniques that first responders range from direct instruction to separation, explanation, scripting, positive reinterpretation, being calm but assertive and even doing nothing in some situations.

I have also worked with adolescents and families who are dealing with brain injury. The age at which someone acquires a brain injury has a great effect on their long-term prognosis. In general, the younger the person is, the better the outcome can be expected... but we always have to wait to see what the long term outcomes are... no one knows, and every brain is unique and recovery is unpredictable. One father reflected on his daughter's experience and gave the

following advice. "Love the TBI survivor unconditionally. Accept them as they are. Just expecting them to come back to their old self – they don't need that pressure. Don't accept a hopeless prognosis... there's hope. Spend a lot of time with the survivor – especially while in the hospital – to ensure great care." When I asked him what one thing helped most, he responded "Trusting God and leaning on faith. Support group." This reliance on religious faith is actually a common experience in American responses to brain injury (Stewart 2014), far more than the Australian experience.

But just as much as survivors and their families in Toledo have discussed individual responses to the experiences of children and adolescents, they have also identified structural changes which need to occur, particularly in the education system. Advocacy around education has revolved around the following issues:

- Finding accommodations and understanding effects around issues such as memory, attention, problem solving, information processing and cognition, psychosocial behaviour and the ability to deal with changing or overstimulating environments.
- Getting an appropriate Individual Education Plan;
- Finding a strong, informed advocate who understands brain injury;
- Developing positive relationships with schools; and
- Addressing challenging behavior in helpful ways when it occurs in schools;
- Developing knowledge about appropriate disability policies, practices and laws.

Dealing with general identity changes in adolescence, and developing a vision for a better life, are also issues which survivors and families experience. It is also necessary to note that these general issues may include dealing with the multiple identities of survivors, such as race, class, gender, and sexuality.

Survivor identities and multiple identities

One danger of the survivor discourse is that it can make the influence of social inequalities which strongly influence the outcomes they experience. Social location and in particular race, class, and gender are tied to both the incidence of TBI, the type of TBI sustained, and the outcomes for survivors (Sherry 2006). The universalist ‘survivor’ discourse/identity has the potential to downplay the different ways in which people ‘survive,’ including the differences in their physical and cognitive outcomes, their medical, rehabilitation and housing situations, and their degree of social isolation or social capital post-injury. Such differences are often related to the person’s experience of privilege, itself associated with wider power structures in society. Denying these realities means that the need for wider social change is ignored – and yet the incidence of impairment and disability is thoroughly associated with social inequality, a social justice concern which demands broader change in social, economic and political power (Sherry 2016).

Forms of social inequality such as race and class are strongly correlated to the incidence, and final outcomes of brain injury. McQuiston et al. (2016) reviewed the outcomes of 187,354 patients over a ten-year period, concluding “Race/ethnicity and insurance status significantly affect TBI patient outcomes, even after controlling for demographic and injury characteristics” (261). While McQuiston et al. highlighted the experience of African Americans in particular, similar racial and insurance status disparities have been noted elsewhere for Hispanic populations (Budnick, Tyroch and Milan 2017). Unfortunately, like so many other “colorblind” narratives, the survivor discourse eviscerates racial difference and avoids the topic of racism – itself a form of “racism without racists” (Bonilla-Silva 2017). Similarly, the links between

insurance and social class are almost always avoided in the survivor discourse. Lower socioeconomic status greatly increases the risk of experiencing brain injury and the impairment effects experienced by survivors (Kisser, Waldstein, Evans et al. 2017, Rabinowitz, Li, McCauley et al. 2015).

Many brain injuries are caused by domestic violence and other gendered forms of violence (Corrigan, Wolfe, Mysiw et al. 2003). One of the prominent forms of progressive activism in Toledo is around sex trafficking, because Toledo is a common destination, transit and source area for trafficking throughout the US (Williamson and Baker 2012, Wilson and Dalton 2007). Indeed, it has been identified as the number one city in the US for trafficking per capita (Meyer 2010). Local trafficking groups have begun screening for head injuries after my public and private critiques of them, an important expansion of social activism around brain injury. But a "survivor" identity alone runs the risk of ignoring the need for multifaceted activism on this important social issue.

Conclusion

Brain injury survivors both support and disrupt hegemonic ideologies around disability, brain injury, and neoliberalism. Some have adopted the personal tragedy model of disability, emphasized individual responsibility for recovery and adopted a neoliberal, individualist perspective regarding those who 'overcome' disability. On the other hand, the collective struggle of brain injury survivors challenges such individualism and confronts established power structures (both within disability organizations and in the wider community). Such progressive activism challenges medical dominance, first responder practices, disablist educational practices, and the unjust institutionalization of brain injury survivors in nursing homes. The survivor

perspective may, however, underestimate social differences among survivors, such as those around race, class and gender. Focusing on brain injury (or more broadly, disability) through single-issue politics effectively excludes the concerns of people who experience inequality on multiple levels and ignores the need for wider social change. A survivor identity which ignores the need to challenge for changes in gender relations, racial inequality and class inequality can paradoxically support the individualist neoliberal power structures that a collective survivor identity must challenge.

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