Submissions Abstract Book - All Papers (All Submissions)

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The lived experience of being ill and/or disabled in academia

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Research Domain: Academic practice ,work, careers and cultures (AP)

Abstract: The lived experience of being ill and/or disabled in academia

This presentation reports on a research project into the lived experience of chronic illness and disability in academia. Data collection was in three phases via a questionnaire through survey monkey with 300 participants, one-to-one skype interviews with 25 participants and a creative workshop. Data was collated and coded in Nvivo and data analysis was an iterative process of constructing themes in a "transparent, reflexive and critical" manner. The three dominant themes presented here are: feeling marginalized due to perceived deficits, being silenced, and what academic organizations can do to improve their experiences as people with disabilities. The overarching experience is one of being marginalized within a group of marginalized individuals who are not able to voice their experiences openly for fear of stigmatisation and repercussions. An overall attitudinal shift is required. I will conclude the presentation with some creative outcomes from the workshop.

Paper:

Introduction

In recent years interest in ableism in academia has increased drastically within the English-speaking countries across the world. However, personnel within academia who are disclosing their health conditions and specific needs are low in comparison to students or the general public disclosing their needs (Brown and Leigh, 2018). Discourses within disability and ableism studies fuelled by media interest highlight discriminatory practices and societal attitudes that foster a culture of non-disclosure. Disclosure is a very private event and requires a form of personal commitment on the part of the individual (Brown and Leigh, 2018). Disclosing one's needs is a decision of weighing benefits and costs and identifying whether the risks may not be too great. Within today's neoliberal academia the continued waves of marketization and commercialization result in more precarious contractual conditions for employees (Blix et al., 1994; Tytherleigh et al., 2005; Watts and Robertson, 2011). As a consequence, competition on the employment market becomes fiercer and individuals fear being discriminated against if they disclose their conditions, as this feels like "admitting to having specific needs".

Research approach

In the autumn of 2017, a few colleagues and I decided to organize a conference on the topic of ableism in academia and make it fully accessible (Brown et al., 2018). The main concern of all those involved in and associated with the conference related to the experience of disability itself. Following on from the success of the conference, I embarked on further qualitative research in order to explore in more depth and greater detail what it feels like to be disabled or chronically ill in academia. This more structured approach to data collection was in three stages: 1) surveymonkey questionnaire with 300 participants, 2) one-to-one skype interviews with 25 participants and 3) a creative workshop.

Data analysis was an iterative process of searching for and identifying themes by following *hotspots* from within the data (MacLure, 2011). The analysis therefore loosely followed a thematic approach. The researcher's role was a *trickster* and *jack-of-all-trades* (Denzin, 2016), an active data manager who constructs themes from the data in a "transparent, reflexive and critical" way (Brown, 2019, p.11). Questionnaire data and interview transcripts were collated and coded within Nvivo. Data was used to generate overarching themes around ableism and disability within academia. The resulting themes were dominant in the data: feeling marginalized due to their perceived deficits, being silenced, and what academic organizations can do to improve their experiences as people with disabilities.

Findings

Marginalisation

Participants felt strongly about otherness and being othered and consistently commented on how specific ways of working or living were not accepted and acceptable in academia. For them, their lived experiences of being disabled or ill represented a "different physical reality". Disability may result in consequences that will affect productivity and attendance. For example, negotiating everyday pressures, alongside managing a condition and soundscapes of bright rooms in busy buildings lead to increased levels of tiredness and fatigue that those without sensory processing disorders will not experience. Otherness and othering in this context are not necessarily intentional, but are a reality of life when managing bodies and emotions. Marginalization in academia is even more complex, once the individual experiences of those with disabilities are concerned. These individuals are marginalized for their differences, but they also feel marginalized amongst an entire group of disabled academics. Delegates' understanding of what is *normal* is so internalized that some participants not only measured themselves against the societally acceptable, standardized norms but also against internalized criteria of disability. When participants exchanged their experiences of being *different* and *othered* in the workshops and discussions, some individuals almost apologized for their *issues* not being "as serious as yours". Despite the environment and atmosphere having been one of acceptance and mutual understanding, some individuals felt invisible and hypervisible at the same time. They felt marginalized within a group of marginalized individuals.

Being silenced

Where the lived experience of disability related to academia, individuals specifically referred to the prevalent culture of overwork and productivity. Participants consistently highlighted the time and effort required for self-advocacy in order to gain access to reasonable adjustment; time and effort that other academics can spend on preparing grant proposals and publications. The burden of proof to provide necessary evidence for support lies with the individual, but at no point is there a consideration of how attending to doctors' appointments and completing relevant forms disrupts the everyday academic routine. The capacity of individuals to conform in order to meet the required demands of working in academia is narrowly framed and constrains the disabled ability to function appropriately and effectively. This conference was a different experience for some as it allowed them to discuss "uncomfortable truths that academia would prefer weren't talked about". This statement encapsulates the experience of being silenced when it comes to exploring the issues and concerns of those with disabilities. However, academics with a disability also feel silenced in relation to their scholarly work. Academics who have openly disclosed a condition are expected to become disability activists and advocates and as such are recognized for these activities rather than their research foci. As a consequence, the kinds of scholarly debates they are privy to are of specific natures and kinds, and they feel silenced as contributors to scholarly knowledge in their own right.

Recommendations for improvements

The conference itself was considered as modelling best practices and enabled individuals to engage in academic work in an unprecedented way. The overall sentiment was, however, that institutional and indeed sector-wide changes are needed to improve the experiences of academics with disabilities. Such changes would only be possible with more awareness in relation to the lived experience of chronic illness and disability in academia. This is because many instances of ableism, discrimination and marginalization occur unintentionally but due to lack of awareness and understanding of individuals and institutions. To this end, more research and activism is required. Therein lie issues, because academics with a vested interest in improving the situation for the disabled may not necessarily have the energy or means to pursue activism. At the same time, education on its own is not sufficient, and policies are required to enforce cultural and attitudinal changes in the long-term. Ultimately, individuals talked about moving away from what is expected as *normal* and *standard* to an environment where different forms of working and living are embraced to such an extent that "no adjustments are required".

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