

Researching the Social Construction of Blindness

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Abstract: Research on blind people has been dominated by literature written from the perspectives of medicine, rehabilitation and psychology, focusing on disease and its effects, psychological aspects of blindness (grief and loss), adaptation and coping strategies, and employment. Blindness is positioned absolutely on the individual, as if it occurs in a social vacuum. This approach assumes that blindness is solely a medical event, and not a social process. One exception to this pattern is Scott's (1969) groundbreaking social constructionist approach to blindness and society. Scott's phrase "blind men (sic) are born, not made" emphasized the role of blindness workers in the socialization of blind people. Scott's work on the social construction of blindness has been built upon in the last decade by interdisciplinary blindness literature, strongly influenced by disability studies (e.g., Michalko, 1999, 2001, 2003; Kleege, 1999; Kudlick, 2002; French, 2001, 1999; 1993). This paper will analyze the contributions of this new literature, and highlight gaps which still exist within the literature on the experience of blindness both as an impairment and as a set of disabling social processes. In this context, I will briefly discuss my plan to do insider research with legally blind people. This paper asserts that doing social constructionist research on both impairment and disablement will help fill gaps in both the blindness and disability studies literature. My own research on blindness seems to be the first study in the United States which utilizes the British-born emancipatory social model of disability. By infusing this model into American blindness research I hope to contribute to the expanding international discourse on disability studies.

Key Words: insider research, blindness, social construction

Introduction

Research on blind people has been dominated by literature written from the perspectives of medicine, rehabilitation and psychology. The focus of these studies has tended to be disease and its effects, psychological aspects of blindness (loss, grief, and, eventual "acceptance"), adaptation and coping strategies, and employment of blind people.

Blindness is positioned absolutely on the individual with little societal context taken into consideration, as if blindness occurs in a social vacuum. This approach tends to assume that blindness is solely a physiological event, and not a social process.

One exception to this pattern was Scott's (1969) pioneering social constructionist approach to blindness and society. Scott's phrase "blind men [sic] are born, not made" emphasized the role of blindness workers in the socialization of blind people. Scott's work has been built upon in the last decade by interdisciplinary blindness literature, strongly influenced by blind disability studies scholars, (e.g., Michalko, 1999, 1998; Kleege, 1999; Kudlick, 2001; French, 2001, 1999; 1993). This paper examines the contributions of some of these new works in re-theorizing blindness both as impairment and as a set of disabling social processes.

Current Trends in Blindness Literature

One need only type in “blindness” on any Internet search engine to understand the nature of available blindness information – disease, rehabilitation and counseling services, product catalogues, blindness “etiquette,” blindness prevention, and medical research. A sparse sprinkling exists of information about organizations *of* the blind, which are most often initiated and controlled by blind people themselves, and are consumer and rights oriented. The more prevalent (and more well-funded) associations *for* the blind have deep historical roots in the medical model and are usually administered by sighted people. Often charity-based, these organizations promote blindness prevention media campaigns, information about specific eye diseases and related services and product information, reports of medical research aimed at prevention and cure. Generally, neither type of blindness organization engages in social or even medical research.

Although some charity-based organizations sometimes raise money to help fund prevention and/or cure research (and to fund their own jobs), the actual protocols regarding decision-making and research work are left to medical and educational establishments. Medical institutions devote their energies to prevention, diagnosis, treatment, and cure while educational institutions attend to matters of adaptation, accommodation, and rehabilitative training.

Even as I laud the value of the medical, rehabilitation, and educational establishments’ work in helping to improve the lives of blind people, I also understand that medical model research focuses on the function of the eyes, on the body, and largely fails to inquire about social processes or even about the personal experience of blindness. Disability Studies is changing all that by re-theorizing blindness within socio-cultural contexts.

However, current disability studies literature is often based in the humanities, and actual participant research projects are rare. Historical literary analysis, memoir, autobiography and auto-ethnography appear to be the preferred genres of study thus far.

Kudlick and Weygand (2001) translated writings of a young blind girl in post-Revolutionary France. The first half of the book contains Adele Husson’s writings while the translators devote the second section to commentary. What is remarkable and valuable about this small volume of one person’s blindness experience is how things remain the same with regard to dominant societal attitudes toward blindness and blind people. Husson writes:

When they [blind people] appear in public the stares of the multitude are fixed upon them, and agonizing words strike their ears: ‘what a shame!’ ‘How unfortunate!’ ‘Death would be preferable to such a cruel privation!’ There are even some people who seek out the blind to tell them these things so that they don’t miss any of the sad exclamation (Husson in Kudlick and Weygand, 2001, p. 25).

Kudlick (2001) further utilizes historical documents to frame blindness within the cultural context of Victorianism. She traces the roots of an ideological split within the blindness community, which exists to this day. Movements are often measured by new interest in their histories; therefore, Kudlick’s commitment to recording the cultural aspects of disability history is important, especially when understood as a marker of the growing strength of the disability civil rights movement and respect for disability studies as a legitimate, serious discipline. In her memoir, *Sight Unseen* (1999), Georgina Kleege describes her experience of growing up with progressive vision loss. Kleege uses examples from her own life to place blindness within a cultural context. The book is divided into three main sections: Blindness and Culture, Blind

Phenomenology, and Blind Reading: Voice, Texture, Identity. Even though these topic headings convey the idea that the book is oriented within the social model, Kleege's exaggerated emphasis on impairment rather than disability often contradicts such an approach. For instance, she writes, "Writing this book made me blind" (p. 1), "This book made me understand for the first time how little I actually see" (p. 2), and, she characterizes the book as "my attempt to specify my own visual experience" (p. 103)... "A coming out narrative." Clearly, the main theme of her memoir is identity formation.

Rather than embracing blindness as an alternate ontology, Kleege writes that blindness is "not so bad" (p. 32) and "this really isn't as terrible as you were always led to believe" (p. 34). Throughout the book, Kleege mentions "normal," sans italics or quotation marks to contest the concept. Apparently she accepts the notion of normality, e.g., "normal daily activities" (p. 167), which is highly problematic from a social model perspective. By using such simplistic descriptions of the blindness experience, Kleege unconsciously endorses a non-disabled, medicalized discourse that positions blindness as a loss and an exclusively negative experience. Many other personal narratives from blind people suggest that the experience is far more complex and has more nuances than such simplistic descriptions suggest.

The humanities play an important part in the interdisciplinary nature of disability studies, and Kleege's memoir is, in that regard, a good contribution. Even though French (December, 2002) found *Sight Unseen* "unsurprising," she states that it "provides good material for anyone interested in the meaning of visual impairment and the growing field of disability studies" (p. 859).

Even so, as one would expect of the genre of memoir, the heart of Kleege's work remains largely with the individual's adaptation to blindness rather than turning the gaze back onto society's treatment of blind people. One danger of disability memoirs is that readers may understand them to be "inspirational" stories about personal triumph over tragedy, or other medical model stereotypes about disability as an individual problem.

Another shortcoming of memoir is that it relies solely on personal outlook, which grants the author gratis permission to espouse theoretically based opinion without being required to apply the rigors of social scientific citation, which builds upon prior academic knowledge and provides substantiation to the authors' positions. Consequently, even when an author committed to the social model of disability writes memoir, theoretical re-framing of disability and impairment may fail to be noticed or understood.

In contrast to literary analyses and memoir writing, White (2003) uses queer theory, disability studies, and blindness literature to analyze the social construction of heterosexuality in blindness sex education for young blind people, and concludes that it socially creates blindness as a heterosexual experience. White delves into dominant beliefs about sexuality being a visual process, and how this construct frames young people as sexually underdeveloped. He writes, "blind people are in a sense queer, in that heterosexuality, at least in its institutionalized forms, presumes a sighted subject" (p. 134).

Sally French (2001, 1999, 1996, 1993) uses prior social models of disability literature to buttress her analysis of how society works to manage the blindness experience. She writes, "Conflicting discourses arise when sighted people define what is 'acceptable' and 'normal' behavior for a visually disabled person and use these definitions to contest that person's identity" (1999, p. 21). In her study of visually impaired physiotherapists, French (2001) uses a grounded theory approach to address both issues of impairment and disablement. Through the use of questionnaires and semi-structured interviews, she examines, for example, how society has

perceived physiotherapy as a legitimate profession for visually impaired persons, and then uses participant interview transcripts to elucidate how visually impaired physiotherapists perceive their engagement in the profession as points of advocacy. Her participants discuss how they meet and manage barriers that arise in their everyday work lives. French's growing body of work incorporates both her personal experience and social model analysis; thus, her work helps shape the future of disability studies literature, in general, and blindness research in particular.

Rod Michalko, a postmodern sociologist, uses social constructivist theory to deconstruct medical, psychological, and societal ideas and practices around blindness. Chapter Four in *Mystery of the Eye and the Shadow of Blindness* (1998) is devoted to a critical examination of blindness rehabilitation. Noting that once ophthalmologists have prognosticated their patient as destined for permanent blindness, they refer the patient out for rehabilitation, Michalko writes, "Ophthalmology is recommending *agency* as an *actor* presented as qualified to speak about, and act upon, permanent blindness. This suggests that blindness requires agency and needs to be acted upon in order for it to be lived with. Rehabilitation, too, conceives of the seeing life as the only good life" (pp. 66- 67).

In his second book, *The Two-in-One: Walking with Smokie: Walking with Blindness* (1998) Michalko employs auto-ethnography as a methodological framework to describe and analyze his experience of vision loss and acquisition of a dog guide. He uses postcolonial concepts of "home" and "exile" to describe his personal experience of living in a world built by and for sighted people, how his dog, Smokie, lives in exile in a world built by and for humans, and how their relationship brings "home" into both of their lives. Michalko also deconstructs how the dog guide school creates expectations of blind students' behavior and the school's physical environment based on sighted notions about the blindness experience. According to Sherry (2003), Michalko's most important contribution to blindness and disability studies literature is his postmodernist deconstruction of the blindness/sightedness binary, which extracts blindness from its perceived "lack," and places it, instead, on its own merit as an alternate way of knowing the world. Michalko writes: "Blindness, when compared with sight, becomes a thing of shadows... Anything seen as a mere shadow of its former self is understood as less than or not as good as the original... Sight *is* status and is a status *former* to blindness. Sight is not a mere shadow of its former self since it has no former self. Thus sight is not regarded as needful of restoration" (Michalko, 1998, pp. 67-68)

Michalko's work will have far-reaching impact on both blindness research, and, hopefully, on how societal institutions perceive, teach about, and treat blind people.

Conclusion

This small representation of four genres within the disability studies literature on blindness, i.e., literary analysis, memoir, queer studies, and social constructionism, has brought to surface three general shortcomings. First, the writings are mostly housed in the humanities, although there is a bit of limited research in the social sciences. Aside from Sally French's recent study of visually impaired physiotherapists, there appears to be a lack of applied research about the blindness experience. Even though Michalko used ethnographic methods to theorize and analyze blindness, he has, to date, not yet expanded his research beyond his personal experience.

Secondly, none of the work employs a materialist analysis, which is a fundamental and significant factor in the social model of disability. Blind people experience economic oppression

and social isolation in even larger percentages than many other disabled people, i.e., unemployment and underemployment rates, and lack of access to basic print information. Potential employers, community development and urban planners, mainstream technocrats, rehabilitation agencies, and retailers alike balk at the financial cost of environmental barrier removal and universal design, leaving blind people stranded in or altogether shut out of the workplace, hence, out of a consumer economy. What is more, government agencies, nonprofit charities and for-profit businesses employ tens of thousands of sighted workers engaged in maintaining institutionalized oppression of blind people. Failure to examine these factors as influences in blind people's lives is failure to mine a deep and rich source of research data. Moreover, the literature generally focuses *either* on impairment or disability, but not both. Distinctions between impairment and disability are muddled because authors often use these terms interchangeably. This causes theoretical confusion and linguistic chaos because it becomes difficult for readers to grasp theoretical concepts when the terms of the language used to align oneself with a particular ideology speaks for all sides of the arguments.

Finally, none of the studies claim to be using an emancipatory research design. This paradigm involves change at every step in the research process, including "the relationship between disability researchers and those they research; the ways in which the products or findings of research are written up, disseminated, and utilized" (Ward & Flynn, p. 31). This can be especially meaningful for blind people who have often been shut out of disability research altogether because many researchers fail to make the research itself or the results in accessible formats.

It is in this context that I am undertaking a project which combines emancipatory and insider research, and develops an analysis based on theories of social constructivism, embodiment, and materialism. I intend not to shy away from discussing the impact of participant impairments because blindness does, indeed, affect how people conduct their daily living. However, in addition to asking participants to reflect on their individual lived experience, I will ask them questions about the power dynamics involved in interpreting that experience, such as "Where did you get the idea that you should adapt in order to appear *normal*?"

Doing social constructionist research on both impairment and disablement will help fill gaps in the blindness and disability studies literature. My own research on blindness seems to be the first study in the United States that utilizes the British-born emancipatory social model of disability. By infusing this model into American blindness research I hope to contribute to the expanding international discourse on disability studies, in general, and blindness, in particular.

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