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Culture and Disability in Sexuality Studies: A Methodological and Content Review of Literature

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Abstract Disabilities impact individuals across all demographic groups, resulting in multiculturalism within the *culture of disability*. Several years ago researchers within the area of disabilities studies noted a tendency to overlook the cultural heterogeneity within their samples of individuals with disabilities and called for greater awareness. It is unclear to what degree research psychologists as well as other disciplines have heeded the call to adopt a cultural lens when studying populations with disabilities. A methodological and content review of sexuality and disability studies was conducted to evaluate how researchers are conceptualizing and presenting cultural data. Recent articles in four leading disability journals from 2002 to 2006 were reviewed, yielding 54 studies and over 11,000 participants. The content analysis found tremendous inconsistency in the collection style and reporting of cultural information (e.g. gender, race, ethnicity, socio-economic status, sexual orientation). Results indicate ethnic minorities may continue to be under-recruited and understudied in the disability and sexuality literature.

Keywords Culture · Disability · Ethnicity · Sexuality · Methodology

Introduction

An estimated 20% of U.S. residents have a disabling condition, making up the largest minority group in the United States [1]. The term *disability culture* has been used to describe the shared meaning and experiences faced by individuals with disabilities [2]. Yet, disability impacts people across all demographic groups, creating multiculturalism within the *culture of disability*. Some have criticized existing empirical research for ignoring the diversity inherent in populations with disabilities and for assuming that disability status eclipses other type of culture variation [3]. By 2000, Neville found that there was a notable increase in the number of disabilities studies that integrated issues of cultural diversity into theoretical and empirical research, but qualified this progress, noting that some researchers

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continue to neglect to report the racial and/or ethnic characteristics of their sample and when cultural information is presented, it is not always integrated into the study in a meaningful way [4]. Recently, Menz and Thomas reiterated the call for examining heterogeneity in disability research studies, echoing that despite improvement, most studies adequately do not attend to this issue [5].

The under-appreciation of cultural factors in research is an issue that scholars have been striving to remedy. Culture has been defined as "the system of shared beliefs, values, customs, behaviors, and artifacts that the members of society use to cope with their world and with one another, and that are transmitted from generation to generation through learning" [6]. Established professional guidelines suggest that patients should be helped to understand, maintain, and resolve their socio-cultural identity for themselves [7]. Current guidelines from the American Psychological Association (APA) encourage psychologists and extend the invitation to other professionals to engage in practices that advance the equitable treatment of all cultural groups [8]. In fact, with respect to race and ethnicity, by these guidelines researchers are required not only to accurately report these data for their subjects but also to consider the relevant contextual factors of ethnicity [9]. Despite these recommendations, it is unclear to what degree research psychologists (as well as professionals in other disciplines) have heeded the call for adopting a cultural lens when conducting research among populations with disabilities.

Giving a voice to all individuals, particularly those that have been marginalized or ignored by society, is a central value within the field of disability studies [10]. Research is a critical forum for addressing the needs of all individuals with disabilities. If our research methodology does not appreciate the impact of cultural and contextual variation, a critical opportunity to understand the needs of individuals with disabilities is missed. To this end, the present study will examine the recruitment, data collection, and operationalization of cultural variables.

Trends in Disability Research

Nearly two decades ago, the *Disability Culture Movement* began, leading to a heated discussion on the concept of a separate *disability culture* [11]. Scholars debated whether a unified cultural group existed, given the tremendous within group variation [12]. In question was the idea of whether there are sufficient shared experiences among people with disabilities, in spite of the variations in spoken language, country of origin, age, type of disability, and gender among others [13]. The debate culminated in the delineation of four factors common to disability culture, namely: fortification against oppression, unification, commitment, and recruitment [2]. This represented progress for those striving to unify and strengthen the collective voice of individuals with disabilities. Nonetheless, researchers must balance union with the acknowledgement that people with disabilities are not monolithic.

There is evidence to suggest that cultural differences, including gender, race, and socioeconomic status, etc. all affect one's experience as an individual with a disability [14]. For example, the presence of "double discrimination" has been documented for people with disabilities who also belong to an ethnic minority group [15]. One study examined the employment experiences of Asian-Americans and found that nearly half reported that they were affected by racial discrimination [15]. Similarly, Vernon in a study of women with disabilities, shared accounts of the sexism the women experienced in the both family and community settings [16].

Cultural factors can also impact the way people conceptualize their disability. In a recent study, Devlieger et al. sought to examine whether disability culture existed outside of *mainstream white society* [13]. To do so, they conducted a 5-year study of young African-American men with violently acquired spinal cord injuries.

The results of their study identified unique cultural factors impacting the young African-American gunshot victims with spinal cord injuries. These young men faced poverty, discrimination, and exposure to gang violence, all of which contributed to social alienation prior to their disabling injury. These pre-existing factors affected their identity development and overall adjustment to their disability.

Greater attention and assessment of cultural issues will be valuable in increasing our understanding of the myriad challenges faced by people with disabilities. With this goal in mind, certain minimal research methods are necessary for conducting research that examines the impact of cultural variation, such as the inclusion of diverse samples and the standardized collection of detailed cultural data. However, it is unknown whether these methods are regularly used. One technique that has been used to gauge progress in incorporating cultural considerations is a methodological analysis of the literature. Within counseling psychology, Delgado-Romero et al. examined a subset of the literature from 1990 to 1999 and found African-American, Native American and Hispanic populations to be underrepresented in research samples [17]. Ali et al. conducted a critical review of the childhood disability literature and found similar disparities [18]. To our knowledge, no comparable content analysis has been done in the disability and sexuality literature.

Studies on physical disability, by definition, are inclusive of a cultural minority group (i.e. individuals with disabilities), but to what extent are other cultural factors regularly examined in this literature? The manner in which research is conducted can reinforce power imbalances or serve as an important catalyst for change. With this in mind, a content review provides useful data and serves as a benchmark for progress made in incorporating culture into the research methodology of disability studies.

Present Study

The present study investigated the approach of studying the issue of cultural variation among recently published disability and sexuality articles. The topic of sexuality was selected because of the universality of the topic, as well as, the potential bias to selectively attend to the topic of sexuality [19]. Because the articles reviewed for the present study did not distinguish between race and ethnicity in their data collection, these concepts were considered together in our analysis of cultural constructs. However, it is important to note that they are not interchangeable concepts (and this is a rationale for collecting data to study these variables independently). Wilkinson defines the social constructed variable of *race* as "a category of persons who are related by a common heredity or ancestry and/or who are perceived and responded to in terms of external features or traits" [20]. The reliance upon external appearance for determining race can lead to a somewhat arbitrary distinction. *Ethnicity,* on the other hand, generally refers to "a shared culture and lifestyle" [20]. In other words, individuals of differing *race* may have the same *ethnicity* and vice versa. This example highlights the complexity of studying cultural factors.

Based upon our analysis of the literature we hope to address the following questions: (1) With respect to ethnicity/race and gender, how does ethnic/racial minority and gender representation in the sexuality and disability literature compare with U.S. national averages and how do researchers collect and utilize these demographic data in their studies? (2)

What settings are individuals being sampled from? and (3) how does reporting of cultural variable differ in foreign studies as compared to U.S. based studies?

Method

Procedure

The present study reviewed a 5-year sample of sexuality and disability studies from four journals in rehabilitation, disability, and sexuality. Specifically, articles from *Rehabilitation Psychology*, *Disability and Rehabilitation*, *SCI Psychosocial Process*, and *Sexuality and Disability* were analyzed. These journals were selected due to their status as leading, peer-reviewed journals within the field of disability. In order to provide a current assessment of research trends, journals published in the time period of January 2002–December 2006 were considered. Articles were included based upon presence of the words *disability* and *sexuality* in the title and/or key words. Editorials, book reviews, commentaries and other articles without research subjects were excluded.

To ensure reliability in data collections, the data were audited to check for accuracy in the collection. Any errors or discrepancies were handled by group consensus of the coders. This method of checking the coded data is comparable to methods used in similar research studies [17].

Results

The inclusion criteria for this study yielded a total of 54 studies involving more than 11,000 participants. A majority was published in *Sexuality and Disability* (77.7%), followed by *Disability and Rehabilitation* (13.0%), and *SCI Psychosocial Process* (9.3%). In *Rehabilitation Psychology*, no research studies published from the years 2002–2006 met full inclusion criteria (although a number of research articles on sexuality and disability outside of the 2002–2006 time criterion were published in this journal).

Overall, 57% of studies indicated a focus upon a specific cultural group in their title (e.g. Women, Elderly, African-American). Gender was the most common cultural area of emphasis, representing 71.0% of the studies that stated a focus upon a cultural group. More studies were quantitative in nature (61.1%) than qualitative (37.0%), and a small fraction were mixed in design (1.9%). Among studies that reported cultural data on their participants, 49% of studies utilized this information in their analyses. Countries represented in the studies were: Australia, Belgium, Canada, China, Denmark, Greece, India, Iran, Israel, Mexico, the Netherlands, Poland, Rwanda, South Africa, South Korea, Sweden, Thailand, Uganda, the United Kingdom, United States of America, and Zambia.

Age

The majority of studies (83.3%) reported participant age data. Of these studies participants ranged from age 10–91 with a mean age of 37.57. Nearly all of the studies included adults in their sample (95.2%). Nearly one-third (27%) included children (under 18) in their sample and 39.5% included individuals over the age of 65.

Sex and Gender

With respect to gender, 83.3% of studies reported this information. Two studies of 54 (3.7%), reported assessing for and/or including transgender participants. In studies that provided gender information, 54% of participants were female (6,429) and 46% were male (5,470).

Ethnicity/Race

For ethnicity and race, 37.7% of all studies reported ethnic and/or racial status. Likelihood of reporting varied significantly by location of study. Studies conducted within the U.S. were significantly more likely to describe these characteristics in their sample, χ^2 (1, 53) = 24.120, $p < .000$. U.S. studies reported ethnic and/or racial data 83.3% of the time. Of those conducted with U.S. samples and reporting these data, the vast majority of participants were European-American/Caucasian/White (88.7%), followed African American (6.1%). The category, *other* represented 3.6% of the participants and Hispanic/Latino was .83%. Other categorizations including Asian American, Pacific Islander, Native American and multi-ethnic/racial each represented less than .5% of the aggregated sample.

Other Demographic Variables

With respect to other types of participant characteristics, more than half of studies reported education level for participants (52.8%). Marital status was reported in 38.9% of the studies. Approximately one quarter of studies reported data on sexual orientation (25.9%). Socioeconomic status was described in 18.5% of the samples. None of the 54 studies provided information on participant religion. Sixty-nine percent of studies did not describe whether their sample was compensated for their participation. Of those that did report this variable, 35% of the samples compensated their subjects in some way for their participation. Table 1 summarizes the reporting rates of the cultural variables.

Type of Disability

The most common type of disability reported in the studies was motor impairment, including disorders such as Spinal Cord Injury, loss or damage to limb, and Cerebral Palsy (50.0%). Approximately one-fifth of the participants in the studies (18.5%) were characterized as having disabilities in more than one domain. Thirteen percent of participants were described as having cognitive disabilities and 9.3% described psychiatric disabilities.

Table 1 Commonly reported cultural variables

Characteristic	% of studies reporting
Age	83.3
Gender	83.3
Education	52.8
Marital status	38.9
Ethnicity	37.7
Sexual orientation	25.9
Socio-economic status	18.5
Religion	0.0

Visual, Auditory, and Speech disabilities consisted of 7.4, 5.6, and 1.9% of the studies samples, respectively.

Discussion

The present study sought to understand the way that recently published disability and sexuality studies conceptualize and examine cultural factors. General findings revealed tremendous variation in the collection and reporting of cultural variables. Without adherence to an established set of universal guidelines, the methodology of studying cultural factors is largely left up to the discretion of the investigators. Comprehension may be limited based upon availability of presented data and the skills of the readership. Together, these factors will impact upon our ability to synthesize and compare findings across studies.

This paper sought to examine both who is being studied in disability–sexuality research and the methods that researchers used to address the culturally heterogeneity of their sample. For the former, contrasting the sample representation of the included studies with figures from the U.S. census and country of origin data provides a useful context for discussion. With respect to race and ethnicity in the U.S., ethnic and racial minorities were underrepresented in this study sample. Nearly 90% of participants in this analysis were European-American. However, U.S. Census figures for individuals with disabilities suggest that European-Americans make up 69.9% of the total population [21]. African-American's represented 6.1% of this sample yet are estimated to make up 12.8% of the population. Also striking was the under-representation of Latinos with disabilities, making up .83% of the study samples, despite comprising 13.4% of the national population of Americans with disabilities. Collectively this suggests that ethnic and racial minorities may be under-recruited and studied in the disability and sexuality literature. Research on health disparities has found that European-Americans are more likely to have access to health-care and less likely to encounter access barriers than minorities [22]. Because a significant portion of study participants were recruited through medical facilities, special recruitment efforts may be necessary to reach underserved populations.

With respect to the question of how researchers are utilizing the collected cultural data, there were also notable findings. More than half of studies which presented cultural data in their participants section did not report using any of these variables in their analyses. Arguably in some studies they may be a methodological rationale for not analyzing the impact of cultural variables. However, when this practice occurs in more studies than not, it raises the question of whether potential investigative opportunities are being missed, particularly given the findings suggesting the importance of cultural variables in the disability literature.

Both race and socio-economic status (SES) have been identified as meaningful variables for study in the disability literature [23]. However, in the present study, SES data were reported in only a minority of studies (33.3% of U.S. studies). On the other hand, ethnic and/or race data were reported in 83.3% of studies. The neglect of SES data in relation to ethnic/race data raises questions about confounding two variables that are known to interact in complex ways [24, 25]. For example, Kington and Smith found that after controlling for SES racial differences in health status were eliminated [26]. By utilizing crude methods of studying cultural factors, our understanding of the existence and disparities in disabilities and health will remain obscured [22].

In contrast to the discrepancy noted above, the sex of the participants in this study closely mirrored the U.S. breakdown (51.1% vs. 48.9%) with slightly more females than males living with disabilities [21]. This provides support for the contention that researchers are equitably including male and female samples in their research on sexuality and disability. Because the U.S. Census does not provide data on the number of individuals identifying as transgender with a disability, we could not make a comparison. However, only 2 of 54 studies even mentioned "transgender" as a category. Additionally, the vast majority of studies did not report data on the sexual orientation of their sample. This finding mirrors the results of Boehmer who examined the inclusion of LGBT participants over the last 20 years and found that LGBT issues are largely neglected in the research, represented in .1% of 3,777 Medline articles [27].

This study serves as a limited snapshot over a 5-year span that does not include prior or post-years for comparison. Despite the study limitations, the results highlight issues to be addressed sooner rather than later. Consensus and consistency for the reporting of demographics variables is needed in order to establish a literature base for comparison of key factors to the central themes of analysis.

The use of the computer in online services shows promise to increase community outreach research efforts. But along with the increased access that computer-based sampling provides, we must be cautious in assuming that online surveys are representative of total populations. Sophisticated studies that hope to employ the internet should consider also utilizing face-to-face methods to reach a wide ranging demographic.

One caveat to the call for increased attention to cultural factors exists. There may be environments where it is inappropriate or even non-applicable to ask questions of culture and sexuality, such as circumstances where is unsafe to ask these questions. Also, race and ethnic status are particularly salient variables in a country as diverse as the United States. Yet, internationally, other cultural variables may have greater importance. For example, in several of the sampled studies based in India, the variable of *living with extended family or not* was often reported.

We now are able to see beyond the two-dimensional status of *White* and *Other*. We are afforded the advantage of understanding the unique cultural blends that shape the individual and remain dynamic over the lifespan. Here the challenge of understanding acculturation and personal identity is critical for future research. What stands to reason is the need to know the individual(s) before we impart information, education, and therapeutic intervention. We look forward to future authors continuing to highlight these questions and searching for answers to the issues raised.

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