

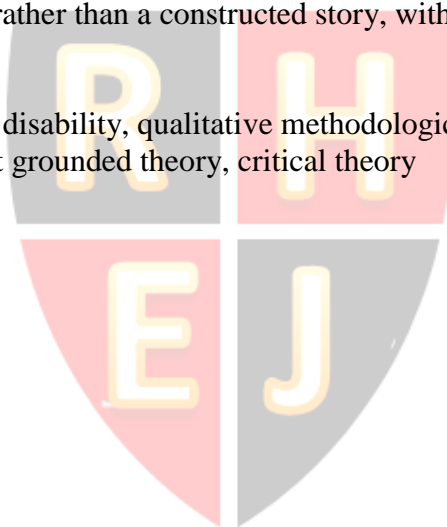
## Reflections on a pilot project: Removing the “dis” from disability

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### ABSTRACT

This paper explores preliminary results of a pilot study whose purpose was to document, through an oral history narrative, the personal and work experiences of a female artist and social entrepreneur who is legally blind. These experiences included the challenges that the research participant has experienced in the U.S. as a woman with an “invisible” disability, specifically legal blindness that was acquired in adulthood. This qualitative research project began with the initial intent of contributing to the genre of narrative inquiry with a feminist lens (Saldana, 2011). During the stage of data analysis, the researcher became more intrigued with constructivist grounded theory as a methodological paradigm, informed by both critical theory and feminist theory as broader theoretical perspectives (Kushner, 2003; Stern, 2011; Wuest, 1995). The investigative concern through the course of the project has thus evolved into giving shape to a theoretical process, rather than a constructed story, with the voice of the participant in the foreground.

Keywords: disability, invisible disability, qualitative methodological paradigms, feminist narrative inquiry, constructivist grounded theory, critical theory



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## **INTRODUCTION**

There continues to be a dearth of feminist ethnographic narratives of women with “invisible” disabilities. This pilot study is a qualitative research project that began with the initial intent of contributing to the genre of narrative inquiry with a feminist lens (Saldana, 2011). However, during the stage of data analysis, the researcher became more intrigued with constructivist grounded theory as a methodological paradigm, informed by both critical theory and feminist theory as broader theoretical perspectives (Kushner, 2003; Stern, 2011; Wuest, 1995). The investigative concern through the course of the project has thus evolved into giving shape to a theoretical process, rather than a constructed story, with the voice of the participant in the foreground.

## **PURPOSE**

The purpose of this pilot study was to document, through an oral history narrative, the personal and work experiences of a female artist and social entrepreneur who is legally blind. These experiences included the challenges that the research participant has experienced in the U.S. as a woman with an “invisible” disability, specifically legal blindness that was acquired in adulthood.

## **THEORETICAL FRAMEWORK**

The conceptual lens encompassing this study was critical disability theory with a gendered perspective. Critical disability theory posits that disability is a social construct, which may consequently vary dependent upon social context and culture, rather than an immutable attribute that inheres in an individual (Devlin & Pothier, 2006). It seeks to deconstruct the binary duality in mainstream perceptions of disability (e.g., abled vs. dis-abled). In exploring how societal norms contribute to definitions and perceptions of disability, critical disability theory aims to illuminate how these hegemonic norms may, in fact, be the predominant socially disempowering, dis-abling component in the lives of persons with disabilities.

A significant limitation of critical disability theory is that an examination of the role of gendered norms in society’s construction of disability is emergent. To remedy this existing theoretical gap in this study, the lens of feminist theory was overlaid on the lens of critical disability theory to illumine the potential role of gendered perspectives in the social construct of disability and in the social limitations of those who may be politically marginalized.

## **RESEARCH SETTING**

Institutional Review Board (IRB) approval for this pilot project was obtained from the University of San Francisco’s Institutional Review Board for the Protection of Human Subjects. Purposive sampling was utilized in the recruitment of potential participants for the study. Purposeful qualitative sampling involves the intentional selection by the researcher of individuals to enhance the understanding of the phenomenon under inquiry (Creswell, 2008; Seidman, 2006).

The research was conducted within Santa Clara County of the San Francisco Bay Area of California in early 2011. The researcher held dialogues with the research participant (hereafter

referred to by the pseudonym DC) in the privacy of the participant's living room within her home, at the discretion and choice of the participant.

## **RESEARCHER AND PARTICIPANT BACKGROUNDS**

The research participant (DC) is a U.S.-born adult female of European ancestry who has crossed the bridge from the realm of able-ism into dis-able-ism through acquired legal blindness in late mid-adulthood, secondary to cone dystrophy. The researcher is a Chinese-American adult female who has worked, as a pediatric speech-language pathologist, with children with disabilities and their families. The researcher is ostensibly "able-bodied" except for myopia with astigmatism. Although this myopia is not severe enough to be considered blindness in legal terms, the researcher's vision is severely compromised without prescription lenses or glasses.

## **METHODS**

The primary methodological tool informing the study was feminist narrative inquiry, as elucidated by Chase (2005). Contemporary narrative inquiry from a feminist perspective creates an ontological space for the life histories and personal narratives of those who have been marginalized to be heard, acknowledged, and validated. Feminist theory embraces those aspects of individual identity that may contribute to sociopolitical marginalization, such as race, ethnicity, nationality, social class, sexual orientation and disability (Lee, 2006). Women's personal narratives also function as primary documents for feminist exploration and analysis (Chase, 2005).

For this study, feminist inquiry helped to facilitate the discovery of the potentially interconnected roles of disability and gender in DC's social and work experiences in the U.S. The researcher engaged DC in answering open-ended questions that were primarily informed by feminist theory and critical disability theory. The dialogues between the researcher and the participant took place in private settings of the participant's choice to assure maximum privacy, confidentiality, and comfort. All dialogues were recorded for later transcription after obtaining the consent of the participant.

## **DATA COLLECTION**

### **Questions to Guide the Initial Dialogue**

For this pilot study, the researcher aspired to use a feminist lens to explore potentially interconnected roles of disability and gender in DC's social and work experiences in the United States (U.S.). The following were prospective questions that were used to guide the conversations with DC:

- 1) What does it mean to live and work as an adult woman with an invisible disability, such as legal blindness, in the U.S.?
- 2) How do you define your adult identity given your life experiences in two cultures: the culture of "sight" and the culture of "blindness"?
- 3) How do you define your adult identity given your life and work experiences in both the "abled" and "disabled" communities in the U.S.?

- 4) How do you define and perceive the impact of an invisible disability on your quality of life in both personal and professional contexts?
- 5) What are any social or cultural attitudes toward disability that may be impacting your life?

Three sets of dialogues were conducted with the participant on two separate days in the winter of 2011. Rest breaks were provided as needed to allow maximum comfort for DC. In addition, on any one day, the dialogue time did not exceed a total of four hours. All dialogues were conducted in the privacy of the participant's living room in her home, at the request of the participant. The first dialogue, held on the first day, was 90 minutes in duration. The second dialogue on the second day was 45 minutes in length; the third dialogue on the second day was one hour, 15 minutes in length. All dialogues were digitally recorded using two devices, specifically an iPhone and a laptop with an auxiliary microphone.

## **DATA ANALYSIS**

The recorded audio files were transcribed by a professional transcriber from the resulting MP3 audiofiles; all the files were anonymized. Three and one-half hours of recorded interviews yielded approximately 85 pages of transcription.

### **Preliminary Results**

Initial coding and review of the transcriptions have unveiled these emerging themes:

- DC identifies as a business person, entrepreneur, artist, and social entrepreneur; the disability is secondary or even tertiary to the construction of her identity
- DC expressed openness and transparency surrounding her disability: "I am not ashamed to have a disability.... Disabled is not unable"
- DC articulated upon the challenge of social isolation secondary to disability. Specifically, the challenge is not the disability itself, but the sequelae and concomitant logistics of managing the disability when there exists inadequate social infrastructure in non-urban areas (e.g., transportation for those who are blind)
- Milestones impacting DC's adult life were turning a certain age (40), getting married, and losing her mother; loss of sight was not included in these milestone
- Economic marginalization for the disabled in the U.S. is extant, even for those who were gainfully employed prior to becoming disabled
- DC expounded upon the ethical dilemma of "people-first" language (e.g., "I am not going to see any better no matter what you call me" and "I don't see any better or worse no matter what you label it so why are you spending time on that?")
- DC expressed low-grade anger secondary to frustration with obstacles in her business rather than frustration with her disability. Obstacles in her business included potential manufacturers' lack of understanding regarding her business model that licenses the art of disabled artists.

## Reflections on the Analytical Process

The most challenging part of this pilot project was the researcher's unexpected need to work through a methodological muddle following the initial collection of data. First, the researcher had not anticipated the profundity and quantity of data from the dialogues. The researcher discovered the unexpected dilemma of potentially too much data to read, code, and analyze. Secondly, the researcher had vastly under-anticipated the amount of time it would take to code and analyze all the data, as well as the composite background knowledge needed to cogently code and organize the data for further analysis.

This growing awareness of extant lacunae in the researcher's knowledge for conducting an informed analysis of the data catalyzed the researcher's existential crisis of methodology. This crisis in turn led to some additional exploration of grounded theory in comparison to the qualitative methodologies of narrative inquiry, portraiture, and case study methodologies. The opportunity to discuss this methodological conundrum at a round-table discussion at the annual American Educational Research Association conference in 2011 provided a forum for some invaluable feedback on directions for future research (Yee, 2011).

The researcher also had not anticipated the level of emotional energy that the dialogues would demand in light of where the discussions with the research participant ultimately headed. Specifically, emergent themes of anger and grief secondary to loss began to surface in the dialogues. Both the participant and the researcher became mentally and psychologically taxed from delving into this complex emotional topography. On the other hand, both DC and the researcher were also happily surprised, in the process, by the extent to which the dialogues became both a learning and awakening process for the participant. The participant began to re-negotiate her own understanding of the journey from "a-bility" to "dis-ability." To some extent, the dialogues seemed to function for DC as spaces for the reciprocal re-construction and re-interpretation of self-identity in relation to the act of narration and the creation of a narrative identity (Ricoeur, 1992). The dialogues also seemed to function for DC as a means of heightening *conscientizacao* or critical consciousness (Freire, 2010). As Freire (2010) has written in *Pedagogy of the Oppressed*:

Dialogue is the encounter between men, mediated by the world, in order to name the world... Those who have been denied their primordial right to speak their word must first reclaim this right and prevent the continuation of this dehumanizing aggression. If it is in speaking their word that people, by naming the world, transform it, dialogue imposes itself as the way by which they achieve significance as human beings. Dialogue is thus an existential necessity. (p. 88)

At the beginning stage of data analysis, the researcher became paralyzed by a multitude of unresolved questions. These included the following: What is the method of data analysis that can most judiciously value and honor all the content, informed primarily by the participant's voice and perspective and embedded within the collected data? How can both the participant and the researcher in collaboration better understand the emergent themes evolving from our dialogues? What methodological process has this range of features: a posteriori induction rather than a priori assumptions, cyclical self-generation and iteration, and organic, arboreal non-linearity? What methodological approach is holistic enough to include potential triangulation between narrative transcripts, analytical memos, and subsequent dialogues with a single

participant? In this specific case, what is the method that will best facilitate understanding and chronicling of a process of change, loss, bereavement, and identity reconstruction secondary to health changes that result in permanent disability?

In contemplating these questions, and through further reading and reflection, the researcher gradually came to the realization that constructivist grounded theory as a methodology, with the overlaid, theoretical lenses of feminist theory and critical theory, could potentially allow for a comprehensive means of understanding – and documenting – how and why a participant constructs meaning or actions in particular situations (Charmaz, 2010; Kushner, 2003; Stern, 2011; Wuest, 1995). Constructivist grounded theory also acknowledges the delimiting influence and perspective of the researcher in this interpretive documentation:

A constructivist approach means more than looking at how individuals view their situations. It not only theorizes the interpretive work that research participants do, but also acknowledges that the resulting theory is an interpretation...

The logical extension of the constructivist approach means learning how, when, and to what extent the studied experience is embedded in larger, and often, hidden positions, networks, situations, and relationships..

Constructivist grounded theorists take a reflexive stance toward the research process and products and consider *how* their theories evolve, which involves reflecting on my earlier point that both researchers and research participants interpret meanings and actions...

Thus, constructivism fosters researchers' reflexivity about their *own* interpretations as well as those of their research participants. (Charmaz, 2010, pp. 130-131)

A primary research question that has thus emerged from a preliminary analysis of data from this pilot study is the following:

What is the process of change, loss, bereavement, and identity reconstruction secondary to health changes resulting in permanent disability?

In light of this a posteriori research question, the questions with which the researcher continues to grapple methodologically are these: a) whether or not a single participant's experience is sufficient for drawing upon grounded theory as an approach or b) if an amalgam approach of both narrative inquiry and grounded theory is necessary in this specific case or c) if a case study approach is more appropriate in terms of triangulation of data to understand this process. The viability of grounded theory, especially as informed by feminist and critical theories, as a means to explore and construct a potential theory about the process of loss and change inherent in moving from "a-ability" to "dis-ability", with the female participant's voice in the foreground, remains as terrain for future inquiry.

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