

BOOK REVIEW

CHALOTTE GLINTBORG AND MANUEL L DE LA MATA (EDS)
IDENTITY CONSTRUCTION AND ILLNESS NARRATIVES IN PERSONS
WITH DISABILITIES (2021)

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1 Introduction

The perspectives of individuals with disabilities, which include those with chronic illnesses, have continued to be amplified in the new millennium, leading to more awareness and acceptance of disability. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) states that:

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.¹

Inclusion of the term 'life-long' in the concept of disability in the CRPD is inclusive as it allows for individuals with chronic illnesses to claim the identity of disability and recognises the evolving nature of disability as a concept.

In this conceptualisation, disability is understood as an encompassing term which includes those with chronic illnesses that may not have widespread recognition as disability when viewed outside the scope of this

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1 UN General Assembly, Convention on the Rights of Persons with Disabilities: Resolution / adopted by the General Assembly, 24 January 2007, A/RES/61/106 (2007).

conception. For these individuals, diagnosis and recognition of their lived realities are often used as the parameters to determine if they can identify as persons with disabilities. Along with mantras such as ‘nothing for us without us’ that have been widely used in social justice activism spaces, disability studies literature recognises the importance of including narratives of those with disabilities in disability conversations.

Stigma and discrimination against persons with disabilities are often connected to beliefs held about certain embodiments and the stories told about them. On the African continent and beyond, negative attributes are assigned to people whose body or mind realities deviate from the normative expectations. These attributes, often based on misinformation, are grounds for exclusion, attacks and dehumanisation. This has been evident in the discrimination and attacks on persons with rare disabling conditions such as albinism, based on the beliefs that they result from curses or that they possess supernatural powers.² A story teller’s style and the language they employ, reveal a lot about the power that the storyteller holds, in relation to the communities they exist in. It matters that persons with disabilities get to narrate their own stories.

Identity construction and illness narratives in persons with disabilities (2021) edited by Chalotte Glintborg and Manuel L de la Mata explores the concepts of narrative and identity from the perspectives of individuals with chronic illnesses in several European countries. The book is part of an interdisciplinary disability studies series aimed at applying disability studies approaches in different fields. It foregrounds the narratives of persons with disabilities and chronic illnesses in its exploration of the experience of specific disabilities. It asserts the place of the first-hand narrator about their experiences. This edited volume relies on the stories of those with aphasia, acquired brain injury, dementia, severe mental illness, as well as children with speech and language disabilities.

This book is presented as a collection of research study reports that focus on narrative inquiry and identity construction. The first two chapters generously introduce the two concepts thus creating a foundation for the readers. Subsequent chapters dedicate space to the research participants in the various studies to share narrations of themselves. Narrations by people with the disabilities themselves are the focus of this book unlike popular practice where narratives about especially people with cognitive and language-impacting disabilities are told by others. Additionally, the contributions of other community members are noted as important elements in narrations.

2 UN Human Rights Council, Report of the Independent Expert on the enjoyment of human rights by persons with albinism, 10 January 2017, UN Doc A/HRC/34/59 (2017).

Glintborg and Mata, the editors of this book, begin with a vision that sees the possibility of everyone, including those with cognitive disabilities, to shape narratives about their lives by amplifying direct voices in this collection. Their objective is to hand narration powers to persons with disabilities and chronic illnesses who are often silenced and invisibilised. The editors argue that ‘narrative inquiry amplifies voices that may have otherwise remained silent’.³ Glintborg and Mata believe this to be a necessary addition to literature as it expands on the existing perceptions of stories and narratives of persons with chronic illnesses.

2 Overview of the book

The book has ten chapters with the first two serving as an introduction to the concepts of narrative inquiry and narrative identity. Its editors use the final chapter to share their conclusion and future perspectives with the reader. In the introduction, the authors outline the various definitions of the terms, narrative, narrative inquiry, narrative choices and stories. They also share their reasons for focusing on ‘health and illness research’ as the springboard for their contribution to illness narratives.⁴

In chapter one, the authors preface the book on narratives of those with disabilities that have an illness component. Glintborg and De la Mata introduce the concept of narrative inquiry as a research approach for its ability to capture direct narrations of those experiencing the disabilities. They also discuss the various power dynamics that are negotiated between those with these illnesses and the healthcare professionals who provide care. In leaning on the patients’ perspectives, the book notes the place of media platforms in ‘creating illness communities’ by those who seek to be in communities that may not be immediately available to them physically.⁵ Further, they argue that narratives allow for individuals to renegotiate their perceptions of self in the instance of chronic illness.

The concept of identity-self is presented in chapter two. The chapter explores the existing definitions of this concept as it exists within narrative approaches. The authors argue that disability cannot be understood in isolation but has to be viewed beyond the embodied medical diagnosis in the self. Influences of culture and everyday interactions make up the narratives of disability that get told. Identity is not a rigid concept. Persons with and without disabilities are often forced by contextual factors to shift the ways in which they define themselves. Changes in geographical location, life stage and educational level, for example, require a shift in the stories of self. While ‘master narratives’ may be more focused on the experiences of the disease, the constructions of these narratives are urged

3 At 4.

4 At 3.

5 As above.

to not solely focus on the embodied reality.⁶ The master narratives approach can be likened to the social model of disability which requires that the identification of disability, especially in the context of discrimination be situated in the society.

Chapters 3 to 9 capture research into specific disabilities and chronic illnesses. In chapter 3, ‘Stories of self when living with aphasia in a digitised society’, by Helena Taubner, Malin Hallén and Åsa Wengelin, is divided into the following parts, the introduction, method, results, discussion and references. This chapter focuses on individuals with aphasia which is often acquired during life and impacts on the linguistic capabilities of an individual. Focusing on narratives and the stories individuals tell of themselves, it allows the authors to illustrate that the impact on narrative and identity for those with aphasia is greater on the self than those whose disabilities do not impact on their language capabilities. Nevertheless, because ‘the language we use to tell our stories of self does not only include spoken words’, this study also relied on observation of written social media accounts of the nine participants.⁷

Taubner, Hallén and Wengelin’s research took place over a period of five years. They made use of Problem-Centered-Interviews (PCIs) and ethnographic observations. These two research methods allowed them to collect information while taking into consideration the linguistic implications of aphasia on their respondents. Collecting data from social media pages was highlighted to have added layers of ethical and consent considerations to the research. This research finds that respondents create narratives of themselves while constantly deciding on disclosure or lack thereof of their aphasia. Societal expectations on communication are seen to also impact on the stories of self that the respondents create. The authors name these ‘identity dilemmas’.⁸ These are captured in the stories that respondents tell of themselves before and after experiencing a stroke. The authors assert that, by telling stories about themselves, individuals are exercising their agency as selves regardless of the amount of language they have access to, and that online spaces make this choice possible.

Chapter four, “‘We got a second chance’: Couple narratives after being affected by an acquired brain injury”, by Chalotte Glinthorg and Cecilie Thøgersen, takes a close look at how couples navigate the change of bodymind realities.⁹ In this chapter, the impact of acquired brain injuries (ABI) on spouses and family members who often become caregivers is captured and discussed alongside the stories that the individual with the ABI tell of themselves. This can be said of many acquired disabilities or

6 At 15.

7 At 21.

8 At 29.

9 ‘Bodymind’ is used as coined by Dr Sami Schalk in her description of the embodiment of disability being a conflation of both realities. S Schalk *Bodyminds reimagined: (Dis)ability, race, and gender in Black women’s speculative fiction* (2018).

disabilities with late-onsets that similarly do not receive rehabilitative therapy to adjust to their new realities. The authors capture the high likelihood for spouses to view the acquired injury as an opportunity to recreate their life-stories as well. In their discussion of the negative impact of ABI, the authors apply the concepts of benefit finding in chronic illness instead.

While ABI is categorised as a traumatic occurrence which is bound to shift one's assumptions about life, the chapter argues that 'post-traumatic growth involves sense-making'.¹⁰ Based on the severity of the trauma, this can often be sifted through the lens of spirituality to guide the creation of the individual narratives as evident in those shared by the authors. The discussion in this chapter confirms the hierarchy of believability that is applied to narratives told by those ABI tell of themselves, their loved ones and those of a professional attending to them. The accounts of the professional are ranked highest on this scale. The chapter also introduces the concept of 'dyadic coping' as the framework through which to understand the dynamic of couples dealing with traumatic experiences such as ABI and how this plays out across generations.¹¹ Against this backdrop, the authors argue for a focus on the positive outcomes of acquired brain injury narratives as a necessary addition in the exploration of post-traumatic life experiences.

Chapter five on 'Narrative identity and dementia: The problem of living with fewer available resources' by Lars-Christer Hydén and Mattias Forsdlad delves into the reality of identity and narrative creation amongst persons with dementia. In the telling of autobiographical stories, individuals with dementia may face cognitive, linguistic or interactional limitations. The authors propose an inclusion of the memories and linguistic capabilities of those around the individual with dementia as resources that the person with dementia can make use of in their telling of the stories of self.

This chapter offers a definition of dementia and its various forms. These are directly related to the specific impact that the individual's dementia has on their ability to tell stories. Challenges range from fewer cognitive and linguistic resources, memory, attention and voicing which impact on their ability to create narratives of their identities. However, the authors maintain that, 'loss of memory (in particular episodic and autobiographical memory) does not automatically lead to a loss of identity'.¹² Due to the limited resources internally available, the chapter suggests that the reliance on narratives of others with similar experiences in online platforms should be identified as valid stories that the person can utilise.

10 At 39.

11 At 47.

12 At 59.

In chapter six, 'Recovery stories of people diagnosed with severe mental illness: Katabatic and anabatic narratives', by Francisco Javier Saavedra-Macias employs recovery narratives (RNs) along with illness narratives (INs) to analyse stories told by persons diagnosed with severe mental illness. The chapter offers definitions of the terms 'disease', 'illness' and 'sickness' in prefacing the study. Much like the preceding chapters, it reasserts that 'narrative is the basic tool that allows us to construct our identities'.¹³ These constructions have an added layer when the narrator is a patient with psychosocial disability whose reality and symptoms of the disability can be conflated. In recovery models of mental health, patients take a more active role in their management along with healthcare professionals. This is in contrast to predominant models in healthcare where the professional has a higher power status than the patient in deciding treatment or management and this extends to patients without disabilities too.

Unlike illness narratives that can incorporate caregivers' views, recovery narratives solely rely on the information offered by the people affected by the specific disability or condition. The individual gets to decide which aspects of their bodymind realities to share in their narrations of themselves. However, due to their singular focus on upward improvements, recovery narratives have been termed 'recovery porn' for their failure to take into consideration all the other possible outcomes besides recovery.¹⁴ This can be likened to 'inspiration porn'. Inspiration porn is a trope of disability which relies on the stereotypical view of persons with disabilities as objects of inspiration for non-disabled people in a non-disabled world.¹⁵

Chapter seven on '(Re)constructing identity after aphasia: A preliminary study about how people with aphasia describe their lives' by Sara Yuste, Andrés Santamaria, Mercedes Cubero and Manuel L de la Mata moves away from accounts of the impact of aphasia and illuminates 'identity construction of the patient after aphasia'.¹⁶ We are the total sum of our experiences, past, present and our hopes for the future. This chapter analyses the linguistic impact that aphasia has on an individual and how they make use of the existing language resources to communicate their identities. Information in this chapter is gathered from a study with four respondents with varying degrees of aphasia. All respondents in the study view their experience of a stroke as a turning point in their conceptions and narrations of selves. All respondents identified the therapy they received as

13 At 68.

14 At 78.

15 Stella Young 'I'm not your inspiration, thank you very much' TEDxSydney https://www.ted.com/talks/stella_young_i_m_not_your_inspiration_thank_you_very_much/transcript?language=en (accessed 5 August 2022).

16 At 84.

having been a helpful factor in their constructions of their current narratives.

In chapter eight on 'Narratives and identity construction of children with developmental speech and language disorders' by Kristine Jensen de Lopéz and Rena Lyons, much needed literature on the identity construction and narratives of children who are often silenced, is presented. Often children with the limited linguistic resources on account of developmental speech and language disabilities are presumed to not have cognitive abilities that would allow for the experiences of stigma. De Lopéz and Lyons contest this assumption. The self-narratives of these children are heavily reliant on societal narratives about them. Equally, their identities are shaped by society. Consequently, children's agency is compromised.

This chapter illustrates that identities of disabilities are not always the dominant ones in children with disabilities. The possibility of negatively framed identities being projected from society is thus quite high. This chapter advocates for the active and wholesome involvement of children with developmental speech and language disabilities in the creation of narratives that are told about them by adults. The children involved in this study were supported through 'identity construction sessions' which provided them with safe environments to explore conceptions of their narratives. This chapter highlights that access to a space to create identity has a direct impact on a child's mental health.

Chapter nine, 'Hope in offenders' narratives of attention deficit hyperactivity disorder (ADHD)' by Nichlas Permin Berger and Lars Fynbo captures a study involving adults who are incarcerated. They all have a diagnosis of ADHD. The interviews with all the respondents reveal that they blame disability for their crimes. They all indicated a connection between their diagnosis and their crimes to claim innocence. Some of the respondents fault the social welfare systems for failing to diagnose their ADHD earlier and causing them to commit crime out of despair. Most of the respondents were grateful for their diagnosis as it granted access to language to explain their realities, something they lacked before.

In the concluding chapter, the authors spotlight once more, the interplay of diagnosis of some disabilities and chronic illnesses and the individual constructions of identity. The chapter reaffirmed the commitment to amplify voices of individuals with these identities that are often erased and invisibilised as a necessary venture.

3 Significance

Although its main focus is chronic illnesses in Europe, *Identity construction and illness narratives in persons with disabilities* offers literature that is welcome

in the African disability context. Its cardinal thesis about the ability for all individuals to narrate their stories and construct their narratives is instructive for a continent where professionals, either as healthcare professionals or humanitarian workers historically have led these conversations. The book allows for meaning-making in the never-ending cycle of reconstructing identities on the part of individuals with chronic illnesses which are progressive in nature.

Online modalities allow people with disabilities to tell their stories of self in the way they choose. Social media access with the fast-growing internet coverage across the world and the African continent allows for those with disabilities to contribute to the narratives that are told of disabilities. A recognition of this as a valid form of narrative creation also shifts significantly from the need to first have social connections or high economic capability to get mainstream media coverage. The creation of illness communities becomes that much easier especially for those with chronic illnesses who are unable to exist in physical spaces either due to inaccessibility, immune-compromised status or any other disability impacting reality.

The book captures multiple instances of interdependence in everyday life and in the creation of narratives of self and identities. Disability justice lists interdependence as one of the core principles of disability existence.¹⁷ Due to the prevalence of the capitalistic notion of independence, the concept of interdependence can be difficult for some to grasp especially in the context of disability. This book generously offers examples of how interdependence plays out while also teasing out the nuances around community living.

Most of the chapters show receiving therapy after experiencing injuries was helpful in the process of reconstructing identities. This is noteworthy especially in the instances where rehabilitation upon injury or diagnosis of disability only focuses on physical recovery to approximate non-disabled identity. Additionally, the research practice in the study in respect of children, embodies best interests of the child practices through active involvement and should be adopted.

4 Conclusion

Identity construction and illness narratives in persons with disabilities carves out clear space for narratives of those with chronic illnesses and positions them within disability discourse. The book's targeted focus on self-narrations of people with illnesses and conditions whose disability status is at times contested, is a powerful message and its greatest strength. It opens up

17 '10 principles of disability justice' Sins Invalid 17 September 2015 <https://www.sinsinvalid.org/blog/10-principles-of-disability-justice> (accessed 5 August 2022).

possibilities for advocacy for individuals with chronic illnesses through their narratives. This kind of literature has a potential to propel much needed conversations about identity, rehabilitation, disability and diagnosis while foregrounding individual narratives. The inclusion of perspectives of incarcerated individuals is an essential acknowledgment of the human rights of a neglected social group and a reaffirmation of its human experience.