essentially co-opted narrative, an essential communication mechanism of cultural importance with disabled people of color, for research purposes. A review of the importance of narratives to disabled people of color, the use of narratives in health contexts, and the benefits and limitations of narrative health interventions targeting disabled people and people of color is needed to support health equity within the

people of color with the intention of helping "vulnerable" populations experiencing negative health outcomes. In doing so, they have

Disabled people of color, people whose identities lie at the intersection of disability and race, experience negative health outcomes resulting from a combined impact of social, economic, and environmental barriers that include yet extend beyond those faced by people who belong to either group alone. Health researchers and practitioners have relied on health interventions based on the use of narratives to target both people with disabilities and people of color in an effort to reduce health disparities. While disabled people of color are rarely considered a cohesive social group in the previous research, much has been accomplished with the intention of helping to improve health inequity in these "vulnerable" populations. Yet, an analysis of these previous interventions can illuminate what is gained and lost when scholars (however well-intentioned) co-opt the use of narratives - an essential communication mechanism of cultural importance particularly within marginalized communities - for research purposes.

There is a burgeoning generation of health communication researchers who come from these communities. As one of them, I aim to help

nuance terms and highlight concerns in a way that supports my colleagues as we look to increase equity within the field of narrative-based health research. This work can serve as a strong foundation for health researchers who desire to continue using narrative health interventions in their efforts to address health disparities. First, I will redefine the term narrative through the lens of disabled people of color. Next, I will explore the hidden paradigm of health researchers who use narratives to reach marginalized groups. Finally, I will analyze previous narrative health interventions targeting disabled people and people of color including a discussion of limitations of these studies due to the lack of an intersectional lens. **Defining Narrative Through the Lens of Disabled POC** A story is an account or representation of connected events and characters in time and space on a particular topic with a message.² This simple definition has wide agreement within influential works across disciplines.^{2–8} However, certain "truisms" about narrative have been

refuted by unraveling assumptions behind what a narrative is, could be, or has been for a wide range of communities. 9,10 For example,

Stereotypes expressed in mainstream Western cultural narratives and disseminated through media narratives have supported and perpetuated the oppression of marginalized communities including disability and race. 11,12 Furthermore, the assumption underlying narrative coherence - that narratives with a beginning, middle and end are better than other ways of organizing experiences – has been shown limit other types of narratives. 9,13 For example, the insistence of narrative coherence ignores the key stage in a disabled person's identity development, particularly for those who acquire disability, where they are initially dealing with the task of repairing the broken pieces of their story in light of significant, and sometimes traumatic, change. 14,15 These "chaos" narratives are not only valid, but they are often necessary when the pain of current experiences is too overwhelmingly present for the reflection that allows for coherent narratives.¹⁶

However, even considering the limits of narrative, Black, disabled scholars and activists argue that there is power in the ability of disabled

people of color to build connections between the events and people that make up their stories of lived experience. 17,18 Furthermore, being

able to brandish the structure of traditional stories may prove important to the capacity of disabled people more generally to rectify the

Uses of Narrative in Health Contexts with Marginalized Populations Generally, narratives can change how a person feels about themselves, their identity, and their capacity to handle life challenges.²¹ Social psychologists, including Walter Fisher and those who work specifically in narrative medicine like Frank and Rita Charon, all agree that narratives can help individuals with mental health in terms of coping with everything from major trauma and emotional distress to everyday hassles. 14,22,23 However, the viewer of a narrative message is typically on the receiving end of someone else's decision-making about what aspects of the story should be emphasized in the construction of the narrative. 20,24

happens to yield a positive health impact on the receiver. At most, social science researchers and health experts have come together with professional filmmakers and other stakeholders and poured (at times, significant) capital into the intentional act of persuading the viewer, maybe unbeknownst to them, to adapt a health behavior those outside forces deem advantageous. The use of narratives in this way privileges narrative construction yet final decisions on significant story elements are made by someone other than the story receiver. Often, this kind of work is used to promote health to those most at risk for negative health outcomes, which ultimately means targeting marginalized and minoritized groups.^{20,24} Health researchers can empower disabled people of color as an intersectional identity group by investing in tools that build their narrative construction skills toward self-healing.²⁵ They can also provide opportunities for disabled people of color who participate in research to challenge outside narratives of the marginalized group, including the assumptions of health researcher and stakeholders themselves.

disparities of people of color in comparison to White people. In the vein of the medical model of disability, the literature was centered largely on "fixing" people of color whether plagued by high blood pressure, ignorance about cervical cancer, unawareness about mammograms or the like. The treatments in these studies included video stories featuring interviews of real people and fictional stories both orally read and acted out on video. The controls featured alternative experiences like a numerical tool, videos about unrelated health topics, or didactic information using charts and bulleted facts. Half of these studies, four of the seven, were randomized controlled trials consisting of two groups with the intervention as the treatment and an alternative activity as the control. $^{27-30}$ Three of the seven narrative intervention studies regarding people of color featured a variety of other methods including observation-based case studies and an exploratory sequential study. In the latter, once again, the qualitative

methods. Twenty of the twenty-six studies included were experiments. They were able to make broader generalizations from larger samples of people. These studies had high internal validity through using conditions to assess cause and effect.³⁹ They were able to eliminate alternative explanations as each participant had the same chance of being in the treatment or control groups through randomization.³⁹ The remaining qualitative studies had smaller sample sizes which allowed for an in-depth understanding of the different experiences of participants and the observation of changes that may not have been detected through experimental methods. 40 However, there were also significant limitations with these studies. Limitations of the narrative health interventions

First, there was an "either/or" approach to the worldviews behind the study. Either a post-positive emphasis on breadth or a constructivist

goals - to promote a health message. The quality and clarity of the stories used toward that end were, ultimately, established by outsiders

experiments, researchers only "used" (pun completely intended) the thoughts, views, and experiences of the participants for their own

emphasis on depth. 41,42 Second, the relationship between the researcher and participants was constraining. For example, in the

(e.g. researchers, production teams, heavy editing, etc.). Also, for the observation-based studies, we only know the researchers' interpretations of participants' experiences. For example, while one narrative therapy researcher worked with clients of color to use "their own words to tell their own stories," readers do not learn about the lived experiences of the clients in their own words. 32 Furthermore, the intention in reporting those observations is specifically to educate and create a "tool" for therapists.³² Overall, besides one study,²⁴ there is little evidence that these researchers are interested in hearing the accounts of participants lived experiences for the sake of supporting their humanity and seeing how those storied experiences shape the participants. A lack of intersectionality in these narrative health intervention studies is to be anticipated. Disability is a category often excluded from

advocacy partners.^{53,54} They can create an advisory council of community members to work with them (and hold them accountable) throughout each study from the planning phase through the decimation of the research. 53,54 **Mixing Methods** Mixed methods also provides a unique approach to addressing many of the concerns with previous narrative health interventions like those targeting disabled people and people of color which have often relied on experimental health research, informed by a positivist/postpositivist paradigm.41 Importantly, mixed methods allows the integration of both quantitative and qualitative phases of research, employed sequentially with interactive stages or simultaneously with comparable results, for research designs that can address gaps present when relying singularly on one methodological approach or the other ⁴². Mixing methods enables the intentional linking of qualitative and quantitative research. Not only can qualitative data from participants explain findings of narrative interventions based on experimental research, but qualitative data can also highlight, and even prioritize, the lived experiences of disabled people of color, which have been exploited in narrative health intervention studies, as previously discussed. Mixed methods can facilitate researchers acknowledging potential contrasts between their own objectives and the priorities of their participants. Additionally, mixed methods can allow for a more comprehensive assessment of

Acknowledgements Thank you, Lord, for the providence involved with completing the dissertation that this review helped to support. Thank you to my dissertation advisor, Maria Leonora G. Comello, and dissertation committee members, Joseph Czabovsky, Francesca Dillman Carpentier, Maria Leonora G. Comello, Ayesha Khalid Hashim, and Jane F. Thrailkill. Thank you to my parents, Eddie and Janice, my sister, Kelsey, and my entire family for your continued love and support. **Disclosure Statement**

The exploitation of marginalized communities recruited to participate in research led to them being, subsequently, excluded from

participation as an unintended consequence of research ethics attempts to attend to these "vulnerable populations" 48. In time, the

intersectional lens within narrative health research. To adequately address the disconnect, health researchers developing narrative

interventions for disabled people of color should center a nuanced definition of narrative that accounts for the historic and present

realities of the group. Furthermore, researchers should consider using CBPR and mixed methods approaches to allow for a deeper

exclusion of people of color and disabled people from health research would mean the descendants of those same people would still be

excluded from the benefits of health research ⁴⁷. As evidenced by previous narrative health interventions, there is a significant lack of an

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Dr. Jaz Gray is a narrative researcher with expertise in entertainment and patient narratives who is interested in both how people in

new, diverse generation of professionals in the communication field. She is also excited to continue centering her work in service. Her nonprofit Jaz's Jammies has collected thousands of pajamas for sick and displaced children and organized volunteer opportunities for several thousand people.

field of narrative-based health research. This work can serve as a strong foundation for health researchers that use narratives to develop

distinction between stories created by people for themselves and stories produced in health research to influence change in others.²⁰

intersectionality. **Narrative interventions with people of color** There were seven narrative interventions regarding people of color identified which included a range of races and ethnicities including

Black/African American, Hispanic, Latino, and Indigenous. 24,27-32 The focus of the interventions was rooted in addressing health

Given that scholarship surrounding disabled people of color indicates that people who fall within this identity group endure a "double

burden" of marginalization in terms of both race and disability status, 1,26 it is unfortunate yet unsurprising that there is a lack of existing

literature on narrative interventions regarding disabled people of color as an intersectional identity. There is, however, literature regarding

narrative interventions within each group separately. Therefore, I will discuss the literature on narrative interventions regarding people of

color followed by people with disabilities. Then, I will discuss the limitations of the literature in terms of methodology and a lack of

Sixteen of the nineteen studies were experiments including single case design studies and randomized controlled trials. 33-35 A review of writing-based narrative intervention studies for students with disabilities discussed fourteen single-case studies with multiple baseline designs across participants where each participant served as a control.³⁵ The remaining three studies all used observation as the main method. 36-38 These observation-based studies indicated success through describing changes in behavior for the participants. Benefits of the narrative health interventions

Across both the narrative interventions featuring people of color and people with disabilities, there were some benefits to the use of mono-

conversations of intersectionality in general.⁴³ Furthermore, historically, certain minoritized groups, like African Americans, have been exploited by research.⁴⁴ The term minoritized is used to clarify that minority groups exist as nondominant communities that have contented with oppressive barriers that produce and perpetuate health disparities ^{45,46}. Time does not allow for the extensive exploration

ultimately, under too much red tape for many researchers to bother attempting to compassionately cut away by navigating how to include

these communities equitably. Only more recently have scholars, rightly, introduced more nuance to the idea of vulnerability to point

researchers toward a path forward for the inclusion of people who fall within minoritized groups.⁴⁸ Thus, it is not the belonging to the

identity group itself that automatically means the population is vulnerable. Rather, there is a situational nature to vulnerability ⁴⁸. Each

marginalized group is vulnerable in specific aspects depending on the combination of the individual person, the study characteristics, and

the circumstances ⁴⁸. Now, there is an opportunity to move the conversation forward through considering how justice-oriented research

Future Narrative Health Interventions Centering Disabled People of

Community-based participatory action research (CBPAR) is a compelling research orientation because it is particularly concerned with

improving health through prioritizing social action toward justice.⁴⁹ CBPAR implores researchers to do the work of examining their positionality in the context of working with communities, particularly issues of power and privilege when working in communities with a history of discrimination like people of color. 49 This paradigm provides a framework for health researchers developing narrative interventions to further prioritize the stories of disabled people of color for the sake of hearing, understanding and amplifying those voices.

approaches can facilitate health researchers developing narrative health interventions.

aspects including the effects of the intervention, how and why the specific intervention outcomes occurred as they did, and consequences of the narrative health intervention for the community. 41 Furthermore, quantitative and qualitative methodological approaches are often associated with "communities of researchers" who respectively hold positivist/post-positivist or constructivist paradigms for prioritizing research interests 42. Thus, mixing methods also allows for a combination of worldviews. For example, quantitatively oriented public health researchers who may ascribe to a positivist/postpositivist paradigm considered "dominant and relatively unquestioned" until the 21st century can better respond to the

The author(s) have no relevant financial disclosures or conflicts of interest.

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PUBLISHER: BOSTON CONGRESS OF PUBLIC HEALTH **ABOUT SUBMIT JOURNAL**

BCPH / HPHR STORE

DOI: 10.54111/0001/

ISSN: 2643-6450

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Disability, Race, and the Usefulness of Narratives in Health Contexts

Abstract Health researchers and practitioners have relied on health interventions featuring narratives to target both people with disabilities and

interventions that target disabled people of color and other marginalized and intersectional identities. Introduction

when considering the lived experiences of Black people with disabilities, narrative becomes a culturally-based layering of stories expressed through different mechanisms that work together, impacting both individual and collective over time. Furthermore, narratives have not been a universally "good" thing when considering the stories told about marginalized groups by those outside the groups.

"often distorted representations in art, literature, film, theater, and other forms of artistic expression." 19 Narratives have the potential to be used toward the disability studies objective to "weave disabled people back into the fabric of society." 18 To address the ways that stories can be strategically shaped into the narratives that support social movements and bring attention to the issues faced by marginalized communities, the following definitions can be used. First, as previously mentioned, story can be defined as an account or representation of connected events and characters in time and space on a particular topic with a message.² However, the use of the term "narrative" encompasses all the ways a story can be told. While the term "story" highlights that there are connected events and characters, the term "narrative" highlights the presence of options regarding how those events and characters are connected to relay the underlying message.^{2,6} The term also underscores the potential for competing narratives. In fact, it is important to explore the

At the least, someone has decided on a topic or issue deemed important to articulate through a story and that conveyed message just so **Previous Narrative Health Interventions Targeting Disabled People** or People of Color

perspectives of the participants were collected to develop the intervention stimulus/story used to persuade the people of color toward changed health behavior, in this case prenatal care to decrease maternal mortality.³¹ Narrative interventions with people with disabilities There were nineteen narrative interventions regarding disabled people which included predominately different types of intellectual and learning disabilities. 33-38 There was little mention of race or ethnicity. In studies where names were changed, the names used were names like "Wendy" or "Harry." While not an indicator of race, the researchers chose not to use names that are more typically associated with Black or brown people. Studies that did mention race noted the participants where White/European American, although many left the racial and ethnic makeup of participants undisclosed.

of these and other travesties, including the brutal experimentation on Black slaves, the exploitation of Henrietta Lacks cells, Tuskegee Syphilis Studies, and ongoing bias in clinical and emergency care, etc.^{44,47} The response by ethics boards led to broad elision of already marginalized people from participating in research.⁴⁸ These individuals were subsequently blamed for their exclusion by insinuations that they simply refused to participate in research when the truth is much more complex. 44,47 Contributions of minoritized populations were,

Furthermore, there are barriers for minoritized populations like disabled people of color throughout the research process: recruitment into studies, consenting to participate, and completing an intervention. $^{48,50-52}$ The incorporation of CBPAR principles can be a particularly helpful guiding post for health researchers looking to prioritize equity amid constraints they might face when executing research (regarding time, resources, etc.). For example, in CBPAR, health researchers are encouraged to build "trusting relationships" with health

Color

needs of disabled people of color by incorporating the cultural responsiveness of constructivism. 41,42 In fact, one study can prioritize different worldviews in each phase of the research.^{41,42} Instead of a problematic positivist lens predicated upon a supposed singular truth, disabled people have advocated for alternatives that prioritize their voices over quantitative numbers and center the exploration of their lived experiences ^{53,55,56}. Mixed methods also supports two research paradigms that can be helpful to health researchers aiming to work equitably with disabled people of color - a pragmatic research paradigm and a transformative paradigm.⁴² In a pragmatist paradigm, researchers focus on addressing existing problems to figure out what works (and as we have discussed, the status quo does not).⁴¹ In a transformative paradigm, all aspects of the health

research are intended to enhance social justice.⁴²

examination of intersectionality and equity.

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Conclusion

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marginalized communities can use narrative to develop resiliency and how the media production process can be used to empower those communities. Her passion for story motivates the way she teaches and relates to students. She looks forward to continuing to support a **Subscribe to Our Newsletter**

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