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# Leadership for change: pathways to activism for African women with disability

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#### ABSTRACT

In African countries, women with disability encounter severe discrimination as their devalued status as women intersects with negative and hostile community attitudes toward disability. Women with disability who are engaged as leaders in the disability movement play a vital role in addressing this discrimination. Through in-depth interviews, this study examined barriers and pathways to leadership encountered by women with disability from Tanzania, Ghana, and Kenya who were active within the disability movement. By dismantling and reshaping stigmatising attitudes the participants had been able to form a positive sense of self and gain the self-esteem needed to succeed as leaders. Publicly, they defied traditional gender roles by leveraging their privileged status as leaders; Leadership was often linked to educational attainment, and being educated legitimised and their achievements as women. Using an intersectional lens, this study sheds further light on the discrimination specific to African women with disability and the strategies that they employ to overcome them.

#### **ARTICLE HISTORY**

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#### **KEYWORDS**

Women; gender; disability; intersectionality; Africa; leadership

#### Points of interest

- African women with disability encounter severe forms of discrimination both due to their gender and due to their disability
- Women with disabilities who are engaged as leaders in the African disability movement play an important role in fighting this discrimination
- In this study, we identified how women with disability had overcome various barriers to become disability leaders
- We found that by resisting negative attitudes the women were able to develop the confidence they needed to become leaders
- The women also had to ensure that others accepted them as leaders. Being educated was one way in which they were able to convince others that they were competent as leaders.

#### Introduction

Among the one billion people estimated to live with disability, some 80% reside in the Global South (World Health Organization and The World Bank 2011). In African nations, people with disability struggle with marginalisation, social exclusion, human rights violations, and violence (Eide et al. 2011). The treatment of African people with disability and the resulting exclusion can be traced to underlying powerful, negative beliefs regarding disability (Grischow et al. 2018). Women with disability are a particularly vulnerable group that faces a triplex of disadvantage and marginalisation due to the nexus of poverty, disability, and their gender (Kabia et al. 2018; Muthukrishna, Sokoyo, and Moodley 2009). In this context, women with disability who are engaged as leaders in the disability movement have the potential to play a vital role in addressing discrimination to improve their circumstances and to encourage and enable full citizenship for all people with disability. Disability leadership is distinct from other forms of leadership (e.g. corporate or political), in that it is often assumed by people in positions of powerlessness and exclusion. It is therefore important to investigate disability leadership separately; however, the voices of African women with disability are often culturally silenced and rarely heard, and few studies have investigated their experiences.

#### Intersectionality

Understanding the experiences of subordinate or oppressed groups of people requires a consideration of how different marginalised identities can intersect to form unique conditions of discrimination and disadvantage. Intersectionality offers a lens through which such experiences can be captured and explained. Crenshaw (1989), an African American lawyer and civil rights advocate first coined intersectionality. She originally examined the discrimination encountered by Afro-American women whose experiences could not be fully explained by either racism or sexism alone. However, intersectionality has expanded beyond the nexus of marginalised identities to further encompass the notion that social groups exist within a hierarchy where some are privileged and some oppressed (Collins and Bilge 2020). As people hold multiple social identities, it is possible for them to simultaneously experience both oppression and privilege (Goodman 2015; Purdie-Vaughns and Eibach 2008). Through this conceptualisation, intersectionality can be used to expose invisible structures of both power and oppression, and in doing so explain the complex realities of people who struggle with discrimination (Atewologun 2018). In the current study, intersectionality was used to explore leadership experiences among African women with disability from Tanzania, Ghana, and Kenya, focusing on the nexus between gender and disability.

#### Disability in the African context

To better understand how African women with disability embrace leadership, it is important to consider how disability is politically, socially, and culturally constructed. Superstitious or religious/magical views of disability have a long history in African countries (Grischow et al. 2018; Setume 2016). One striking example can be found in the myths that surround albinism. In many African countries, people with this condition are viewed as ghosts or spiritual beings with skills in both sorcery and healing (Baker et al. 2010; Ikuomola 2015). Coupled with a belief that their body parts can bring wealth or good luck, these views have led to severe forms of stigma and discrimination; and the mutilation and ritual murders of people with albinism (Cruz-Inigo, Ladizinski, and Sethi 2011). The view of other types of disabilities, including autism, epilepsy, and physical impairments, as punishment for past sins, are commonly described in African countries. The imagined wrongdoings are many and varied, including witchcraft, ancestral violations of societal norms, adultery, incest, or specific acts such as mocking or laughing at a person with disability or a father-to-be killing an animal without provocation during a wife's pregnancy (Bunning et al. 2017; Baskind and Birbeck 2005; Gona et al. 2015; Oyori and Jerop 2002; Stone-MacDonald and Butera 2014). Often, transgressions are assumed to be of the mother or from the mother's side of the family (Bunning et al. 2017; Gona et al. 2015).

In African cultures, a medical view of disability was introduced with modern medicine and Western education (Setume 2016) and now exists alongside traditional beliefs (Reynolds 2010; Bunning et al. 2017). In a literature review of cultural beliefs and attitudes surrounding disability in East Africa, Stone-MacDonald and Butera (2014) found that the cause of disability was commonly seen as a punishment for 'bad' acts, the result of witchcraft, or God's will, but conversely, medical views of disability were becoming more widely accepted. The authors noted that people at times used a combination of superstitious and medical explanations to make sense of their experiences and neutralise some of the stigma surrounding their condition. In an earlier study of a special school in Tanzania, Stone-MacDonald (2012) described how parents of children with disability accepted a medical diagnosis as the cause of disability, but attributed the reason for the diagnosis to the will of God, witchcraft, or a curse. It is likely that contemporary African countries now view disability through a pluralistic lens that sees disability as a synthesis of traditional and biomedical explanations.

#### Women's rights and leadership in Africa

Composite indices such as the Global Gender Gap Index, indicate that women have made strides toward equality in African nations (World Economic Forum 2020). In the three study countries, Tanzania, Ghana, and Kenya the gender gap in terms of educational attainment and health and survival lies around 95%, indicating that the remaining gap to close is 5%. However, in many other areas, women's experiences continue to be defined and shaped by deeply ingrained patriarchal structures and attitudes (Agot et al. 2010; Mobolaji, Fatusi, and Adedini 2020; World Health Organization (WHO) 2020). Formal political participation is limited in the three countries with only 25%, 17%, 13% of the political empowerment gender gap having been closed so far in Tanzania, Ghana, and Kenya, respectively. Women are also significantly less present in the labour market, with the three study countries having closed between 60 and 70% of the gap between women and men (World Economic Forum 2020).

The exclusion of women from political and economic spheres is mirrored by societal attitudes that favour female subordination. A survey of over 46,000 respondents from 15 countries in the southern parts of Africa reported, for example, that 75% of men and 76% of women believe a wife should obey her husband; and 46% of men and 39% of women believe that if a man has paid bride price for his wife, he owns her (Southern Africa Gender Protocol Alliance, Southern Africa Development Community (Sadc) 2016). Traditional harmful customs also remain in several places with women continuing to fight for full protection against practices such as female genital cutting/mutilation, widow inheritance, and child marriages (Agot et al. 2010; Mobolaji, Fatusi, and Adedini 2020; World Health Organization (WHO) 2020)

Structural inequities and societal attitudes have formed barriers toward women's workplace advancement and leadership attainment across African countries (Chabaya, Rembe, and Wadesango 2009; Majiet and Africa 2015; Nkomo and Ngambi 2009). Early socialisation toward domestic roles, illiteracy or lower educational attainment, stereotypes of women as weak and emotional, discriminatory organisational policies, and workplace discrimination all work to limit women's career achievements and leadership advancement (Nkomo and Ngambi 2009). Research that privileges the experiences of women with disability shows that stereotypes and prejudice can have a profoundly negative impact on the formation of identity and self-esteem (Muthukrishna, Sokoyo, and Moodley 2009), which can further hold women back from leadership roles. In a qualitative study of the experience of female leaders in organisations for persons with disability (OPDs) in Zimbabwe, participants had struggled well into adulthood to gain the confidence needed for effective leadership, which had delayed their leadership development (Majiet and Africa 2015). In addition, the women in this study spoke of having encountered the same patriarchal structures within their organisations as present in society at large. The women felt they were stereotyped as weak and unsuited for leadership; encountering direct resistance from other men with disability within their respective OPDs.

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#### The current study

This study considered cultural barriers and pathways to leadership among African women with disability. Findings from in-depth interviews with nine women from Tanzania, Ghana, and Kenya were examined in this study. All the women lived with disability (see Table 1) and had obtained leadership positions within the disability movement. The study had two broad aims. With intersectionality as the analytical lens, the first aim was to describe societal views of women and of people with disability in the three countries and to explore how these views intersected to drive experiences of stigma, shame, and exclusion. Here, a focus was placed on participants' lived experiences of this marginalisation, and how it had shaped their lives. The second aim of the study was to draw upon participants' experiences to further explore how they had forged pathways toward leadership within the disability movement. In doing so, attention was given not only to the marginalising intersection between gender and disability, but also to the exploration of other (privileged) social identities that were available to the women through which they could gain power and legitimacy for leadership.

#### Method

#### **Participants**

Participants were recruited to the study opportunistically, resulting in participants from two East African countries (Kenya and Tanzania) and one country from West Africa (Ghana). Participants were attending a training program in late 2014 delivered by the first two authors that was conducted at the Queensland University of Technology, Brisbane, Australia. The short course focused on empowering women with disability. Table 1 gives an overview of participant demographics. Three participants each were from Tanzania, Ghana, and Kenya. One participant lived with albinism and

Identifier	Age (years)	Nationality	Disability	Interview type
Participant 1	41	Tanzania	Right arm severed in car crash	Face-to-face
Participant 2	47	Kenya	Partial paralysis in one leg	Face-to-face
Participant 3	40	Kenya	Partial paralysis on the right side of the body and amputation of the right leg	Face-to-face
Participant 4	37	Tanzania	Blind	Face-to-face
Participant 5	25	Tanzania	Albinism: UV sensitivity and vision impairment.	Face-to-face
Participant 6	51	Ghana	Partial paralysis in one leg	Face-to-face
Participant 7	33	Ghana	Vision impairment	Face-to-face
Participant 8	28	Kenya	Deaf	Written
Participant 9	30	Ghana	Deaf and unspecified learning disability	Written

Table 1.	Overview	of	participants.
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experienced UV sensitivity and low vision. Another four participants had acquired physical impairment which included amputation and/or partial paralysis. Sensory impairments were experienced by the remaining four participants, relating either to deafness or vision impairment, including one participant who described herself as blind. The sensory impairments were congenital for one participant and acquired for the remaining three. Among the four participants with sensory impairments, Participant 9 also lived with an unspecified learning disability.

#### Material and procedure

Participants were invited to engage in one in-depth interview at a time and place of their choosing. The interviews were conducted by a Research Assistant unaffiliated with the short course to safeguard confidentiality and to ensure participants could speak freely. As advocates for disability rights and through their commitment to the empowerment of women with disability, the participants were all eager to share their stories. The interviews explored participants' lived experiences of the nexus between disability and leadership in Africa. The women provided consent to participate and the study was given ethical approval from the QUT Human Research Ethics Committee. Seven interviews were conducted face-to-face. Although interpreters were available, the two participants with hearing impairment choose to provide written answers to the interview questions. It should be noted that the written responses did not generate the same depth in the data as the interviews did, as participants could not be prompted to elaborate or give examples to their answers. The seven face-to-face interviews were recorded and transcribed verbatim and then combined with the written information provided by the two participants.

During interviews, the participants were encouraged to discuss their personal background, life stories, and experience as disability leaders. They were asked to describe how women and people with disability were viewed and treated in their culture, and to identify and comment on barriers to leadership. As the research sought to identify pathways to leadership, particular attention was placed on the way in which cultural attitudes had impacted the participants' self-identity, activism, and successful leadership aspirations. Interviews considered pathways to leadership and explored cultural attitudes toward women and people with disability; and how those attitudes impacted the participants' activism and successful leadership aspirations.

#### Analysis

Thematic analysis was used to organise and interpret the data, broadly drawing on the analytical steps outlined by Boyatzis (1998) and Ulin,

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Robinson, and Tolley (2005). An inductive approach was taken, with the aim to form theoretical abstractions based on common elements identified from the data. However, the analytical process incorporated what Corbin and Strauss (1990) termed theoretical sensitivity; the guidance of the prior theoretical understanding (in this case intersectionality) in identifying what is of importance in the material and in giving meaning to the findings. To start the analysis, the transcripts were read in whole to form an initial impression and identify tentative patterns and themes. This was followed by coding of the data, and the grouping of codes into categories. From this, an inductive coding scheme evolved to guided subsequent analysis. The coding scheme continued to evolve, as new categories emerged and others were combined or subdivided. The analysis was an iterative process; as new categories emerge previously analysed transcripts were re-analysis and incorporated. Last, categories were organised into broader themes. Notes and reflections were written throughout to capture ideas and aid the interpretation of the final themes in the theoretical context of the study.

#### Results

The women in this study had rich and different life stories. Most had childhood histories of poverty, although the minority had come from economically stable backgrounds. Three of the participants had excelled in their secondary and tertiary education while others had not had the opportunity to do so. Common to all was that they were determined and passionate advocates for people with disability and they had overcome abuse, stigma, and structural inequality to claim the position they were in when interviewed.

Findings are presented as themes. The first two themes set the scene by exploring how the women experienced gender and disability through their cultural lenses. In all three countries, these views were predominately hostile, demeaning, and stigmatising. However, many participants emphasised that attitudes existed on a continuum with variations found across different cultural groups, between rural and urban areas, and within individual families. The participants also described how attitudes were slowly changing for the better, both at the individual and societal level. The third theme talks to the intersection of gender and disability that worked to devalue women with disability and trap them in marginalised and vulnerable positions. Finally, the participants' pathways to emancipation, advocacy, and leadership are described.

#### 'To be a woman is to be in the kitchen' - societal views of gender

When asked about societal views of women in general (not specific women with disability), all participants spoke of deeply patriarchal attitudes largely

dominated by hostile sexism. The participants collectively described how women in their cultures were seen as weak, intellectually inferior, and less capable than men. The role of African women was confined to the domestic world where they were positioned as servants to their husbands; '*The servant, the caretaker of everything. It's like he's employed you there'*. (Participant 3, Kenya). Women were systematically excluded from decision-making processes, in their personal lives and the social and political sphere.

Most participants spoke of open hostility toward women, captured in quotes such as; 'everything about a woman to be lowly viewed' (Participant 3, Kenya) and 'a woman's like a dust bin. So, all bad things, it's come from woman'. (Participant 5, Tanzania). Many women were subjected to abuse, violence, and dehumanising practices. Examples of devaluing practices included the custom of women and female children eating 'in the kitchen outside the house, and fathers stay in the table [...] with other children who are the boys' (Participant 5, Tanzania), child marriages, and the view that education is wasted on women; They viewed that education is for boys alone and isn't important tool for the mother and the girl child (Participant 9, Ghana). Participant 4 (Tanzania) described how women were their reproductive rights, which could result in; '[...] one woman can have ten, fourteen, fifteen, up to sixteen children'. Similarly, the naming of boys and girls reflected the belittling of women.

[...] the culture, the women culture in Africa, ah, like now men are called lion, elephant, eh, leopard, the powerful, powerful names. But when you come to women, a food, a fire fetching woman, ah, a water carrying, very things, you are called according to the job [...] – (Participant 2, Kenya)

The views and mistreatment of women were formidable barriers to leadership. The participants spoke of sexual harassment from other men in the workplace, of lost career opportunities, and of having to work 'ten times more than the man' (Participant 3, Kenya) and having to face twice the scrutiny to prove themselves. By highlighting the incongruence of leadership and femininity, men would draw on the discourse of female weakness to subvert leadership attempts.

[...] a woman who comes out to be so forceful and wants to voice ideas and wants to also be a leader, be in governments, many time they are called names that are demeaning, you know, lowering [...] they will tell you something like go and put on trousers, why are you wearing skirts? – (Participant 3, Kenya)

However, headway toward the recognition of women's abilities and protection of their rights was slowly being made. Women had organised nationally and pan-nationally and had had many of their constitutional rights recognised, although not always implemented, in law.

#### 'Being haunted by evil spirits' – the social construction of disability

The participants described how some progress has been made toward the promotion of disability rights and inclusion of people with disability in African countries, although compared to women's rights, fewer gains had been made. Traditional views persisted and participants described how disability was thought of as a punishment for past sins or as the result of a curse. Other misconceptions were common, such as the notion that a physical disability could be contagious and that the birth of a child with disability was caused by evil spirits. Sleeping with a woman with albinism was thought to be a cure for HIV. It was also thought that various body parts from people with albinism could bring success and fortune, which fuelled maiming and murders. Views such as these were described by all participants and align with previous literature outlining the superstitious beliefs that surround disability in many African countries (Bunning et al. 2017; Setume 2016; Stone-MacDonald and Butera 2014).

However, a minority of participants also described how superstitious views co-existed alongside medical explanations of disability. Although the medical perspective was gaining acceptance in African countries, it was nonetheless stigmatising and was intrinsically linked to dependency, vulnerability, and helplessness;

[...] but others also view it as normal thing that can happen to anybody. And ah, they see persons with disability as being vulnerable, who needs help. They don't look at them capacities of the persons with disability, but rather they look at the disability aspect, what they are not able to do. – (Participant 7, Ghana)

Attitudes were pejorative, with people with disability being seen 'as requiring pity and sympathy' (Participant 8, Kenya).

In the Global North, the social model of disability and more recently the human-rights model linked to the United Nations (2006) Convention on the Rights of Persons with Disabilities 2006, has been integral to the disability rights movement (Lawson 2001; Lawson and Beckett, 2021). The social model attributes the helplessness and exclusion many people with disability experience to the poor fit between a person's impairment and their social environment. The human rights model of disability goes further, arguing for full inclusive citizenship (Degener 2016). Whether the social model or the human rights model, systemic physical and attitudinal barriers, such as lack of accessible infrastructure (e.g. ramps or elevators), prejudice, and discrimination, are identified as significant contributors or causes of the exclusion of people with disability rather than functional impairments they live with (Hogan 2019). Below, Participant 1 (Tanzania) conceptualised her own disability in this way.

Disability is socially constructed. It is, you who think that I cannot do. While you haven't given me a good friendly environment to do. So, disability is caused by the people... [...] I had an accident, I don't have my arm. My arm is not a disability, my arm is an impairment.

However, Participant 1 (Tanzania) went on to explain that this distinction between impairment and disability is virtually unknown to people in her culture (Tanzania); So, this, this, this difference is not formed by many, many people don't know. Even you could be asking the president, the minister, even the person \*inaudible\* doesn't know the difference.

In societies where resources are scarce, a presumed inability to contribute to family or society can trigger negative and hostile reactions (Avoke 2002). This view was highlighted by a participant when reflecting on reactions to the birth of an African child with a disability;

When I was born, you know culturally in Tanzania, if you have a child with a disability, a child who is look different, is not normal like other children [...] they think you have a weak, dependant, you don't have any help from that child. – (Participant 5, Tanzania)

The hostile attitudes towards people with disability had several negative outcomes. Viewed as helpless and unimportant, they were socially excluded from decision-making processes. Some children with disability were isolated and hidden, sometimes out of shame and sometimes as parents feared for their safety. Two of the participants also spoke of some communities where children who were born with visible impairments were killed. However, a few participants also spoke of how attitudinal changes were happening, and practices such as infanticide were dwindling;

But I want to say there is quite some change happening, with the awareness creation, and advocacy. And I want to say that's why some of us are here today, because it's not all that bad, such that every person is killed [...] – (Participant 3, Kenya).

## 'After all, I am helping you, no-body would have married you' – the intersection of gender and disability

When reflecting on how men and women experience disability participants agreed that it was harder for women, as men with disability were '*still men*' (Participant 3, Kenya).

You are a woman. Then you have disability. At least you are a man and you have disability they will look at your disability on, but still you are a man. So, they look as a woman and they look as a person with disability, ooooh, this is much worse. – (Participant 5, Tanzania)

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Previous research, both in the Global North and South has shown that disability can interfere with traditional expectations around gender for both men and women although not in uniform ways (Abu-Habib 1997; Hanass-Hancock et al. 2015; Malhotra and Rowe 2013). While physical impairments can prevent a man from claiming the ideals of physical fitness and dominance, other traditional male attributes such as leadership roles and being a provider can still be available to him. For a woman, disability threatens femininity in a more encompassing way as it affects both her perceived physical attractiveness and her ability to care for her husband and children. These traits are particularly valued in African nations and other societies characterised by traditional gender norms (Abu-Habib 1997).

In line with this work, the current findings indicated that some aspects of the hegemonic male gender role were still accessible for men with disability. Being the breadwinner of a family was identified as one such traditional role that allowed a man to retain some of his male status and attractiveness as a mate. Participant 6 (Ghana) explained;

Men with disability also face this [devaluation], but it's not as much as the women with disability. If you are a man with disability and you have money, you get an abled person to marry.

Moreover, the stories of the women in this study indicated that the attainment of a sanctioned male identity was not the only means by which men could escape some of the stigma associated with disability. The unyielding subordination of women meant that even a shaky claim to a male identity was associated with a higher status than a successful claim to female identity. Regardless of any impairment, a man was 'still a man' and therefore more highly valued than a woman. This notion was expressed by Participant 7 (Ghana) who commented on the male gender role in the absence of physical strength.

So, these are the gender roles, because in my society, no matter how you are grown, if the boy is small, once he is a man, people still give him that respect as a man.

In addition, family structures that are shaped by a hegemonic gender order work to further buffer the impact of disability for men. The participants suggested that once married, women were expected to tend to all practical needs of their husbands which naturally extended to any care they might need due to impairments.

The women said that for them, the reality was starkly different. With few or no means to escape the stereotypical assumptions associated with disability, they suffered a further devaluation of an already devalued role. Presumed to not be able to take care of their children or husband, a man marrying a woman with disability was seen as 'doing [her] a favour' (Participant 6, Ghana). In the view of the participants, disability further skewed the power

imbalance in favour of men, leaving women with disability more vulnerable to exploitation, abuse, or abandonment. Participant 2 (Kenya) discussed the struggles women with disability encountered in their marriages.

Because you get somebody who is working, who has her own money, so you become a source of free income to this man who is marrying you. He is coming to use your money, the two of you. After all, I am helping you, nobody would have married you, so I've just come to help you.

With their attractiveness as potential spouses being reduced, some of the women spoke of how they and other women with disability were only used and exploited as sexual partners. Lacking information about or availability of family planning often resulted in women with disability *'having a whole lot of children without husbands.*' (Participant 7, Ghana). In some instances, these children were the result of rape. Participants suggested that women with impairments, dependent children, and limited family support (due to rape, never being married, or to martial abandonment) were trapped in acute poverty; described as a *'vicious tragic cycle'* (Participant 3, Kenya). Yet, for other women with disability the opposite was true; their disability meant that they were denied not only romantic love, but also their sexuality, and as a result, the role of motherhood; Participant 1 (Tanzania) described views of women with disability as *'asexual, you have no feelings for love'*.

The intersection of gender and disability had implications not only for women with disability but also for able-bodied women that gave birth to children with disability. Within the hegemonic gender order, women were held responsible for all bad things and with no more value than a 'dust bin' (Participant 5, Tanzania; see above). As such, the birth of a child with disability was often blamed on the mother.

[...] and that become a source of you divorce your husband, because they tell you no, in our family we don't have those problems, those must be problems from your family. – (Participant 2, Kenya)

The financial and emotional toll of marital abandonment added to the many disadvantages that children who are born with disability were faced with.

### *'I've so much confidence, like I'll never die' – pathways to emancipation and leadership*

The formation of a positive identity in the face of oppression and stigma formed a central theme in the women's life stories. Most of the participants had grown up with accepting, loving, and nurturing families which had acted as a buffer against external stigma. It was in this environment they had first been able to build a positive sense of self and a belief in their abilities. Later in life, their intellectual ability and personal achievements against difficult odds cemented this notion. Some of the participants spoke of an inner strength and drive that had been borne out of the hardships they had faced as women with disability.

Essential to their underlying belief in themselves and their capabilities was an ability to dismantle and avoid internalising the negative and belittling stereotypes that were associated with both disability and the female gender. The women also had to continuously fight to dismantle the same stereotypes in their social and organisational environments to clear a path toward leadership. Analysis showed that the women deconstructed stereotypes in different and highly personal ways. Broadly, resistance occurred in one of two ways. Some women rejected the disability role by either working to overcoming environmental barriers to perform on par with able-bodied people or by aligning themselves with norms of idealised womanhood. Other women escaped stigma and shame by attacking the disability role itself by strategically using the social model of disability They reformulated their disability as a problem stemming from sources outside of the person with the impairment.

The first strategy was based on the recognition that there is a large degree of misinformation around disability and that the taken-for-granted view of helplessness needed to be challenged.

They [society] think they cannot decide for themselves, they are decided for, they can't do anything, but they can do everything. - (Participant 1, Tanzania)

Some women rejected the idea of helplessness by showing that even in 'disabling' environments they were able to perform the same tasks as able-bodied people. This could come at a great cost, however, as described by Participant 6 (Ghana).

Yes, because um, you need to walk a distance, you get the car, you walk a distance to school, by the time you get to school you are tired. [...] I think some two years ago, I had to charter taxi in the morning to school, and back. Two very, very expensive, it takes about two thirds of my salary. [...] but I do that because I don't want to get tired to school so that I can do what is expected of me to do. Because at times I say no, I don't have to let my disability affect my job, or else people will say ah, because of her disability, that is why she is not able to do this.

Participant 6 (Ghana) further rejected the presumed helplessness associated with disability by reclaiming the normative female gender role. She described how she, as a young woman, was able to perform all the domestic duties expected, for everyone to see; '*it was good, because eh, I was able to do everything that a woman is expected to do, and it's open*'. Participant 6 had launched a powerful attack, for all to see, on the presumed helplessness of people with disability by overcoming the barriers society had created. Participant 5 (Tanzania), who lived with albinism, spoke of how fulfilling the ideal of beauty was a source of pride for her.

Why, that's why they say I'm proud of myself, and it is true, I have beautiful skin. So ok, just, just take a good look at me, I try to take good care of myself.

In this instance, Participant 5 (Tanzania) had been able to reformulate the most visible feature of her disability as a source of beauty and thus gain access to a desired female attribute.

Conforming to traditional gender roles was in this context a form of resistance as it neutralised some of the negative stereotypes associated with disability. Being seen as 'people that have all it takes to be a woman' (Participant 6, Ghana) would allow them to recapture aspects of idealised femininity, thus increasing their standing in society; 'our value could go up' (Participant 1, Tanzania). This strategy was however marked by ambivalence for some women as they contended with the notion that the ideal they were striving to emulate was a devalued one. Neither did it fit neatly with the narrative of strength and drive that characterised their life stories. When describing how she had been mistreated by men in the past Participant (Tanzania) 5 said;

You can find a many of them, ok, I want to sleep with you, I want to compare you with my girlfriend. You see? It's getting me angry, and, I just find I hate them! Ok, I say to my mum ok, me, I'm never getting married, no. No, why? Because men treat me badly. Very badly, very negatively. [...] So it's like, marriage is a Christian, and should believe in God, so many times use God just to change my, to change my mind. Just give me those phrases from the Bible, or ok, it's written a girl with live with her family and also many stuff. So, I'm trying to change my mind, but still I am thinking, is this for real or you know?

In order to validate her stance against entering a marriage that would most likely be abusive and characterised by power imbalance, Participant 5 (Tanzania) was starting to questioning the validity of cultural and religious norms around marriage.

The dismantling of cultural norms was at the heart of the second strategy, the reformulation of disability, that the women used to avoid the internalisation of stereotypes. For instance, Participant 2 (Kenya) drew from her personal religious belief to conceptualise disability. She was a devout Christian, but the church she belonged to was discriminatory toward women and people with disability, a stance they ostentatiously based on the teachings of the Bible. While religious dogma can remain unchallenged due to the assumed infallibility of the Christian Church and its leaders, Participant 2 (Kenya) did not accept this premise, instead, she pursued her own interpretation of biblical texts.

[...] so even the God they are talking about, is not a true God. Because if God himself can tell Moses he created the blind and the deaf and the damned, then who, who is the Church to say they want people without a defect?

Later she said;

Maybe a man will think of anything about you, but when God want to do anything, he will not consider you are disabled. He will not consider that you can't do what people think you can't do. To God you are able to do, because you don't do it by your own power. You do it through his power.

By aligning herself with the will of God, she drew on what she considered was the ultimate power (higher than that of any man) to gain strength and to legitimise her strivings for equality and worth.

The women in this study were in a unique position due to their education, their disability advocacy, and their subsequent exposure to alternative discourses around disability. This allowed them to formulate a positive sense of self, consistent with the social model of disability that they actively embraced.

For instance, Participant 5 (Tanzania) also used person-first language when describing how she sees herself; 'I'm \*NAME\*. I'm a person without anything'. In the previous section, Participant 1 (Tanzania) distinguished between disability and impairment ('my arm is not a disability, my arm is an impairment'). She used this distinction to identify disabling societal practices as the actual cause of disability, stating that 'It is the society that has the disability'.

The view of impairments as something inherently negative was also challenged by a few of the women. For instance, Participant 3 (Kenya) spoke of her impairment as a part of herself that she had come to terms with.

I walk by support of a prosthetic limb and a crutch. A walking stick, I don't mind that because that's how I know myself, yeah.

Incorporating impairment as a neutral or positive aspect of oneself was an effective way to reject disability stigma and a pathway toward the development of pride (Bogart, Lund, and Rottenstein 2018). When speaking of the importance of pride, Participant 4 (Tanzania) divulged;

We blind, we are so pride [sic], so the only barrier for many people with visual impairment in our country are from the poor families.

In the absence of internalised stigma, she identified poverty as the only significant barrier to inclusion that people with visual impairments face. While the women employed different strategies, they were unified in their efforts to redefine the understanding of disability positively; through this reconceptualisation they actively and passionately resisted the denial of agency, value, and ability inherent in the broader discourse of people with disability in Africa

The women identified education as important to emancipation as it could provide women with disability with alternative, positive discourses around disability. Additionally, education was highly culturally valued, as captured in idioms such "education, the gift of life' (Participant 5, Tanzania). Educated people were seen as knowledgeable and capable, which afforded a degree of status and lends legitimacy to leadership claims; *People believe that I can be a leader because I am educated and thus well informed* (Participant 8, Kenya). This status and legitimacy were of particular importance to the participants as they felt constantly undermined by assumptions of helplessness and incompetence. They argued that leadership roles, once obtained and cemented, could be also used as leverage against gender oppression.

Say ok, you are a woman, you can't say no [to a man], you have to say yes because you are a woman; no, I am a leader, I know what I'm doing. – (Participant 5, Tanzania)

Being educated and having assumed leadership positions allowed the women to access two privileged social identities; by drawing on these identities the women could resist oppression associated with their gender and disability. In an almost circular manner, education allowed the women to overcome gender and disability discrimination to claim leadership, which in turn allowed resistance against gender discrimination.

In summary, by avoiding the stigma, shame, and degrading views associated with disability and the female gender, the women had been able to form a positive sense of self and healthy self-esteem. Majiet and Africa (2015) have noted that healthy self-esteem is essential to the leadership of women with disability, a view that was shared by the women in the current study.

I think the only solution for the women with disabilities to be accepted, to be a leader, the first one is just to have the strong self-recognition or self-confidence, that is the only solution. – (Participant 4, Tanzania)

#### Discussion

With a particular focus on the intersection of gender and disability, this study sought to identify and understand barriers and pathways to emancipation and leadership among African women with disability. In describing the experiences of women and people with disability, the participants echoed findings from previous African literature, including that of workplace discrimination (Nkomo and Ngambi 2009), sexual and physical abuse, and a range of negative and superstitious beliefs about disability (Grischow et al. 2018). This study found that disability threatened women's normative femininity in an encompassing and inescapable way. For men, the traditional role of breadwinner offered an 'escape hatch' (Fine and Ash 1981; Malhotra and Rowe 2013) through which they could avoid some of the stigma attached to disability. With no such escape being available to women, their presumed inability to fulfil gendered expectations resulted in further devaluation,

leaving them vulnerable to marital abuse and abandonment (Abu-Habib 1997; Kassah, Kassah, and Agbota 2014).

This study makes an important contribution to the limited literature in this space. Dominant hostile attitudes toward women gave rise to belief systems and social structures that offered some protection for men with disability. This simultaneously exacerbated women's vulnerability. Even those men with disability who were unable to claim the role of provider (or other valued male roles) were offered a degree of status and value as men, solely on the basis of their perceived superiority over women. Additionally, the views of women as domestic 'servants' meant that they were expected to care for their husband's needs, including those related to their disability. Thus, the intersection between devalued disability identity and hostile sexism can help explain previous literature that shows men with disability fare better and are more likely to remain in stable relationships than women with disability (e.g. Hanass-Hancock et al. 2015). Moreover, the finding that fathers were rarely presumed to be the cause of disability in a child (Bunning et al. 2017 and Gona et al. 2015), could be traced back to the antipathy toward African women more generally. As part of their broader devaluation, women were seen as the source of all bad things and men of all things good, which extended to the birth of a child with disability. The implication that mothers were the source of disability in children was justification for marital abandonment, resulting in the loss of vital support systems and exposure to poverty for many women and their children.

The women in this study had claimed leadership positions in a social context saturated with hostile sexism. The powerful intersection with disability further devalued their already lowered standing as women. To achieve leadership, it had therefore been vital for the women to dismantle the negative and belittling stereotypes associated with both disability and the female gender. On a personal level, challenging negative beliefs had made it possible for the women to avoid internalising the shame and stigma associated with disability and their womanhood in order to develop a positive sense of self and a belief in one's abilities. This process had been the key driving force behind the women's determination and success as advocates and leaders within the disability movement.

This study found that the formation of a positive identity was experienced as a very individualised process. The women showed both agency and ingenuity in reshaping their experiences as women with disability. Some of the participants had found ways to reframe and reconceptualise their disability by drawing on the social model of disability and/or on their religious beliefs. They also sought to neutralise negative and pejorative community views on disability by reclaiming their status as women. Interestingly, some of the women talked to their use of beauty or prowess in domestic duties as a tool to achieve this. Muthukrishna, Sokoyo, and Moodley (2009) discuss the 'rolelessness' that women with disability experience when denied their female identity and the threat this poses to their construction of self. Presumably unable to fulfil the ideal socially constructed role of a woman, women with disability are not seen to fit into society and are thus ignored (Majiet and Africa 2015; Muthukrishna, Sokoyo, and Moodley 2009). For the participants in this study, reclaiming their status as women was therefore purposeful in several ways; it protected their sense of self, allowed them to reject assumptions of helplessness, and enabled them to claim agency and their voice as women; While still marginalised, their voice as women allowed them to be increasingly be heard and valued.

Thus, while gender and disability intersected to create unique conditions of discrimination, the women navigated this nexus by both defying and enacting gender roles to stake out a positive identity and legitimise their existence, their strivings, and their successes. Additionally, the participants drew on their education and their leadership roles, and the relative status and power that they conferred, to further neutralise the negative expectancies associated with their gender. In summary, the intersection between multiple social identities shaped both the discrimination the participants faced and their resistance toward it. It appears in the African context that women with disability face double discrimination. However, by strategically resisting culturally the women in this study were able to protect their sense of self and to publicly legitimise their leadership.

#### Limitations

In this study, cultural barriers and pathways to leadership attainment among African women with disability were considered. The analysis drew upon the cultural milieu as experienced and understood by the participants. As the women's experiences had been marred by discrimination, hardship, and struggle, the accounts of the disability culture were largely negative. However, this research is mindful of the caution that has been raised against research on the Global South that is dominated by descriptions of negative attitudes while failing to acknowledge the continuum along which these attitudes exist (Kisanji 1995; Stone-MacDonald and Butera 2014). This study's focus on the women's lived experience was necessary to answer the research questions. However, it is acknowledged that the reported findings represent a segment of reality, and the authors do not claim to have captured the cultural context of womanhood and disability in full. It should also be noted that the researchers, who resided in Australia and who were of white European descent, may have missed some of the cultural complexities of the participants' stories. Last, the scope of this study did not allow for a deeper understanding of how Africa's colonial past has affected current cultural norms and practices. With this in mind, it should be acknowledged 1182 👄 J. KING ET AL.

that slavery, colonialism, western education and discourses, and non-indigenous religions have severely dislocated traditional social structures, perceptions, and African responses to people with disability (Bunning et al. 2017; Oyori and Jerop 2002).

#### Conclusions

Using an intersectional lens, this study sheds light on the discrimination specific to women with disability in Tanzania, Ghana, and Kenya. It identifies and explores key strategies that the women employed to overcome the triplex of gender, disadvantage, and marginalisation. Findings revealed that women with disability displayed a significant degree of agency and ingenuity in dismantling, reshaping, or avoiding the stigmatising attitudes encountered. In doing so, they had been able to form a positive sense of self and gain the self-esteem needed to succeed as leaders. The women defied traditional gender roles and they leveraged their privileged status as leaders to enact change. Leadership was often linked to educational attainment that legitimised their existence, their strivings, and their successes. Their experiences and insights may prove useful for other women with disability in the Global South.

The education of girls and women has been recognised as a strategic development goal across the globe, with demonstrated benefits across several indicators, including poverty reduction, better health outcomes, and increased equality (World Bank Group 2015). The importance of education was underscored in the current study as it was found to empower women with disability with the social leverage they need to resist discrimination. Being educated and able to situate disability as a human rights issue rather than a personal shortcoming had also helped the women to establish a positive sense of self. Taken together, these findings are a call to safeguard and prioritise the inclusion of girls and women with disability in the broader efforts toward female educational attainment in African countries. Moreover, it highlights the importance of establishing the rights-based approach to disability as the dominant public discourse around disability.

#### **Disclosure statement**

No potential conflict of interest was reported by the authors.

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